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# Living with multiple chronic conditions: How we achieve holistic care and optimize health outcomes

Multimorbidity or living with two or more chronic conditions is a growing concern and poses not just a major challenge to healthcare systems around the world but also calls into question how we approach the design and evaluation of clinical interventions and models of care. Cardiovascular disease (CVD) is a leading cause of death globally and an exemplar condition where individuals live with multimorbidity. A typical individual with CVD aged 65 years and older has multiple conditions, yet the clinical practice and research still focus on a single risk factor or disease condition in isolation (Rahimi et al., 2018). The proportion of individuals living with multimorbidity including CVD is projected to increase globally as the population ages and advances in medical care improve longevity. With increasing multimorbidity, the current healthcare system is in danger of being overwhelmed and rendered less effective as the current single disease-focused model becomes obsolete (Ong et al., 2020). Individuals living with multiple chronic conditions live with a high symptom burden and an increased vulnerability to stressors that affect their health status and overall quality of life (Corwin et al., 2021). Multimorbidity impacts beyond the individual. Living with multiple chronic conditions leads to greater caregiver burden, higher healthcare utilization and more critical care admissions, increased healthcare costs and a higher likelihood of mortality (Salive, 2013). The healthcare costs associated with multimorbidity can be extremely high due to disproportionate rates of primary and secondary care visits and unplanned hospitalizations.

There is limited research that explores significant determinants, challenges, and management strategies in patients with multimorbidity. This is potentially related to the challenges of identifying and recruiting patients with general multimorbidity for clinical research. Many clinical trials focus on single diseases and often specifically exclude individuals with comorbidities (Boyd et al., 2012). Similarly, practice guidelines and performance indicators are commonly disease specific and oftentimes fail to consider the interaction between multiple chronic conditions, medications and environmental stressors. Often for individuals living with multimorbidity, services tend to be highly specialized, often duplicative, fragmented and can be inaccessible, particularly to traditionally underserved patient populations. Healthcare systems need to radically change their approaches to combat the challenges and complexity that multimorbidity presents (Szanton et al., 2020).

## 1 | EXAMPLE: HEART FAILURE, MULTIMORBIDITY AND COVID-19 PANDEMIC

Heart failure (HF) is a manifestation of CVD and is a leading cause of hospitalization (Salah et al., 2022) and one of the most common diagnoses at discharge for people aged 65 years and older. HF also represents a group in which almost all individuals experience multimorbidity and the impact of multimorbidity on disease trajectory and outcomes of HF is increasingly acknowledged (Rahimi et al., 2018). There is a higher prevalence of hospital readmissions and other health outcomes among people living with HF and multimorbidity (Reddy & Borlaug, 2019). People diagnosed with HF have an average of six comorbid conditions, and about 65% of their hospital readmissions are for diagnoses other than HF (Caughey et al., 2019). This highlights the pervasiveness of multimorbidity among people living with HF and the effect that it has on patient outcomes, quality of life, healthcare utilization and costs. The presence of multiple chronic conditions along with HF increases the risk for poor health outcomes, which significantly affects the severity and progression of HF as well as the complexity of the management and care (Caughey et al., 2019). Treatment conflicts, for example, the use of medicine for other comorbid conditions may worsen HF, and drug-to-drug interactions are also common issues among patients with HF (Caughey et al., 2019). Furthermore, the COVID-19 pandemic has intensified the problem. There are significant links between HF, multimorbidity and the COVID-19 pandemic. First, the COVID-19 pandemic has had an impact on HF and other chronic condition management due to reductions in preventative care visits and hospitalizations during the pandemic that could possibly lead to an increased likelihood of worse health outcomes and mortality (Italia et al., 2021). Second, living with HF and other chronic diseases is one of the risk factors for the more severe clinical course of COVID-19. Lastly, HF can be a consequence of COVID-19-associated myocardial damage and may lead to poor health outcomes among patients living with multiple chronic conditions (Italia et al., 2021).

## 2 | COMPLEXITY OF CARE IN THE CURRENT SYSTEM

Individuals living with multiple chronic conditions often have multiple medical and social issues, and the consequences are exacerbated by

both the types and numbers of conditions. Although the challenges of efficiently and effectively managing care among individuals living with multimorbidity have been recognized, the complexity of the phenomenon is not well understood. There are various individual, societal and system complexities that patients and caregivers face while navigating care that can make it difficult to understand each condition, each treatment and the interactions among conditions and treatments. Individuals with multimorbidity have reported higher disease burden, symptom burden and treatment burden due to complex consultations and disease management needs (Caughey et al., 2019). In the general population, individuals living with five or more chronic diseases have an average of about 14 physician visits per year compared with only 1.5 physician visits per year for those with no chronic diseases (Page et al., 2016). Further, mental health issues compound other comorbid conditions increasing the complexity of care, healthcare utilization and cost. These factors increase the chances for patients with multiple care needs to fall through the cracks. Current evidence highlights key overarching themes among patients living with multiple chronic conditions; themes include a lack of holistic care; the higher burden for patients, caregivers and healthcare providers; insufficient guidance for treatment plans; a limited understanding of the preferences of patients and their family members and poor communication (van der Aa et al., 2017). Advancing the quality of care for individuals with multiple conditions is challenged by current approaches that silo individual diseases and specialists (Ong et al., 2020).

### 3 | FUTURE DIRECTIONS

Because most clinical guidelines or management programs for chronic conditions management focus on specific and single diseases, there is a rising concern that these guidelines and strategies may not be adequate or effective for people living with multiple chronic conditions (Ong et al., 2020). General practitioners and primary and acute care teams, including nurses, have a vital role in managing individuals with multimorbidity, using a patient-centred generalist approach (Rahimi et al., 2018). However, we recognize that patients have frequent interactions with the acute care system challenging care coordination. Patients' experiences and healthcare preferences in the context of multimorbidity need to be further explored as these can contribute to improving care models for the future (van der Aa et al., 2017). This will not only require an essential change in how healthcare systems are organized and funded to understand and successfully manage the challenges of multimorbidity but also in how we develop and test interventions and monitor outcomes.

### 4 | CONCLUSION

There are many challenges in the management of multimorbidity exacerbated by multifaceted patient, provider and system issues. Individuals living with multiple chronic conditions require a holistic approach to their care that balances often-competing priorities,

needs and treatment goals. Constituting one of the most substantial challenges for healthcare in the current century, more research is needed to explore and evaluate the several determinants, outcomes and consequences of multimorbidity.

### AUTHOR CONTRIBUTION

BK and PMD conceptualized the paper, BK drafted the paper and all the authors provided expert reviews and feedback with substantial contributions to the final version of the paper. All the authors have agreed on the final version.

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### CONFLICT OF INTEREST

The authors declared that they have no conflict of interest.

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## Sexual violence matters: Nurses must respond

Sexual violence in intimate relationships and families is an often-hidden form of violence that occurs across the lifespan and impacts all societies, communities, sexual and gender orientations and is a global human rights issue. Sexual violence impacts not only physical, mental and reproductive health, but also economic and life opportunities, particularly for girls. Reflecting on the scale of this problem, the United Nations has laid out several Sustainable Development Goals, with women's equality and empowerment and the elimination of all forms of violence against women and girls as one of these goals (United Nations, 2017).

Sexual violence is any sexual act that is committed against an individual's will (Centers for Disease Control and Prevention, 2022). It includes sexual harassment, assault, exploitation, rape, intimidation and unwanted sexually offensive communication. Unlike domestic and family violence, which has become more notable in the nursing literature, particularly since the onset of the COVID-19 pandemic, less attention has been paid to nursing research and scholarship on sexual violence. This is concerning as sexual violence doubles the risk of having an abortion, increases by 41% the risk of pre-term birth and increases the risk of sexually transmitted infections by 150% (WHO, London School of Hygiene and Tropical Medicine, & South African Medical Research Council, 2013). Sexual violence also amplifies the harmful health outcomes associated with partner violence (Jansen, 2020), often depriving women of education and employment (United Nations, 2017). Global estimates based on data from 57 countries also suggest that only half of all married or partnered women make decisions about their own sexual relations, contraceptive use or reproductive health care (UNFPA, 2020).

Intimate partner sexual violence (IPSV) can be perpetrated by current or past partners and may involve forced sexual activity, sexual assault, sexual coercion or sexual abuse (Bergen & Bukovec, 2006). The abuse and control tactics employed in IPSV typically do not occur in isolation. Victims experience a range of sexually violent, abusive and coercive strategies that erode their safety and their reproductive and sexual control (Bagwell-Gray, 2021). IPSV frequently co-occurs with intimate partner violence (IPV), even so, IPSV is typically not considered in nursing and medical research investigating IPV. Highlighting this incongruity, a recent systematic review of sexual and reproductive health service interventions addressing violence against women ( $n = 26$ ) only identified three studies examining IPSV (Lewis et al., 2022). It has also been reported that IPSV is viewed by the public as a less serious offence than sexual violence against a stranger (Lynch et al., 2019).



Many individuals who experience violence may have limited access to services or may be unaware of the services available.

Healthcare services that are available may not be equipped to provide care and referral for individual needs, placing individuals at risk of re-traumatisation mentally and physically, particularly in relation to sexual and reproductive health care and procedures. Further, sexual and reproductive health protective measures such as safer sex are not an option for many girls and women who experience sexual violence. Therefore, other protective contraceptive measures need to be explored and used to promote safety and well-being.

The hidden nature of sexual violence hinders the ability to the provision of healthcare and the need for assessment. For individuals, it can be difficult to comprehend sexual violence within the context of a romantic relationship, and for nurses, it is difficult to contend with the notion that outcomes of intimate relations such as a sexually transmitted infection can be an outcome of, for example, marital rape (Bellia et al., 2020; East et al., 2017). Both constructs juxtapose the provision of healthcare. Considering the mental health sequelae following sexual violence, trauma-informed physical and psychological care is needed (Mantler et al., 2022).

For too long, sexual violence and indeed sexual health and well-being have been largely ignored in nursing (East et al., 2021; Fourie et al., 2021) or have rather been confined to specific settings such as sexual health clinics and general practice. This is despite sexual health being a fundamental component of holistic care. Considering the heightened visibility and recognition of violence, it is a timely reminder for the nursing profession to overcome barriers to sexual well-being conversations and provide care in relation to sexual health care. Common misperceptions and stereotypes associated with sexual health, for example, the associations between sexually transmitted infections and promiscuity, that still exist today need to be overcome. The fact that sexual violence can be hidden and occurs in perceived loving relationships needs to be acknowledged.

Sexual violence is a major global healthcare issue. We encourage every nurse to reflect on the part they can play in addressing sexual violence. We urge nurses to upskill themselves in the identification and response to sexual violence, to initiate conversations in both the personal and public spheres in their local communities, to report workplace harassment, and hold friends, family and organizations to higher accountability for the safety of people everywhere.

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# Scalable and sustainable approaches to address the well-being of healthcare personnel

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The ongoing COVID-19 pandemic has exacerbated work-related stressors and elucidated pre-existing unsafe working conditions, which have negatively impacted the well-being of healthcare personnel. Internationally, clinical capacity continues to be strained as COVID-19 cases reach new highs and the cadence of turnover among healthcare personnel worsens. This is of concern given that perception of clinical capacity to adequately meet patient care needs is one of the strongest predictors of burnout among nurses and physicians (Carthon et al., 2021; Olayiwola et al., 2018). Burnout is recognized as a reduction in energy that manifests in emotional exhaustion, cynicism and frustration that in turn can lead to decreased work efficacy over time (Maslach et al., 1997; Maslach et al., 2001). The World Health Organization recognizes burnout as an occupational phenomenon impacting clinicians around the globe (World Health Organization, 2019; Wright et al., 2022). Prior to the pandemic burnout and strained clinical capacity were widespread among healthcare personnel and health systems, respectively (Lasater et al., 2021). For example, up to a third of nurses in the United States report leaving their jobs due to burnout (Shah et al., 2021). Increased turnover among nurses and physicians ultimately results in the inability to effectively provide high-quality care and increased operating costs across healthcare settings (Antwi & Bowblis, 2018; Han et al., 2019; Muir et al., 2022). Burnout and workload-related stress are pervasive in healthcare, having been observed among nursing assistants, medical assistants, social workers and other frontline staff working within inpatient clinical care settings during the pandemic (Prasad et al., 2021). Globally, scalable and sustainable interventions are urgently needed to improve the well-being of healthcare personnel

and to mitigate burnout resulting from the sustained trauma experienced by clinicians throughout the ongoing pandemic.

In the United States, the federal government's Health Resources and Services Administration has awarded over \$68 million to universities, healthcare systems and organizations to implement interventions to reduce burnout and optimize behavioural health in the healthcare workforce as part of their Health and Public Safety Workforce Resiliency Training Program. Among the 34 awardees of these funds, a common focus has been on implementing individual-level mindfulness and compassion-based interventions to address burnout and improve resiliency in healthcare settings. Broadly defined, mindfulness and compassion-based interventions refer to forms of meditative and contemplative practices that promote non-judgmental, intentional awareness and cultivate goodwill and empathy when facing tribulations and suffering, respectively (Conversano et al., 2020). Compared with control groups receiving no support, mindfulness interventions have been found to promote well-being, while improving stress and reducing symptoms of both anxiety and depression among healthcare providers (Spinelli et al., 2019). Organizational changes that foster healthy and safe working environments are needed to be implemented in tandem to providing individual-level programming aimed at reducing burnout and promoting resiliency among frontline workers (Montgomery et al., 2019). Therefore, individual-level opportunities to learn how to cultivate resiliency and address symptoms of burnout are but one key component to larger multipronged wellness programmes that healthcare systems can implement.

There is a substantial discourse on the discordant efforts by healthcare systems to emphasize personal resiliency among clinicians



without addressing organizational contributors of burnout (Vercio et al., 2021). Much of this is driven by the lack of well-designed studies that examine mindfulness and compassion-based interventions, the lack of standardized metrics to evaluate interventions, and the inconsistency when scaling interventions (West et al., 2016). A recent randomized controlled trial examining the role of mindfulness training on burnout and resiliency among clinicians noted that implementation and long-term effectiveness are limited by the availability of facilitators with content expertise to implement and optimize mindfulness interventions (Fraiman et al., 2022). The need to address this critical barrier to effective implementation is highlighted by a recent meta-analysis where sustained wellness interventions were shown to improve resilience among clinicians significantly better than one-time trainings (Angelopoulou & Panagopoulou, 2022). Collectively, these concerns underscore the need for designing sustainable approaches to training credentialed experts on mindfulness and compassion-based interventions within healthcare facilities. These experts can then adapt, implement and propagate comprehensive mindfulness and compassion interventions for all healthcare personnel, while organizational-level changes focused on improving working conditions are simultaneously occurring.

As recent recipients of a portion of these federal funds, our team recognizes the tremendous burden healthcare personnel are experiencing and the urgent need to deliver pragmatic resources to those providing and supporting the delivery of patient care. Therefore, our team is working diligently and purposefully to implement and rigorously evaluate a programme delivering evidence-based mindfulness and compassion-based interventions that are both scalable and sustainable. This programme, known as Atlanta's Resiliency Resource for Frontline Workers (ARROW), offers comprehensive resources for resiliency enrichment, mindfulness training and professional development for clinicians and staff working within healthcare systems across the metropolitan Atlanta region in the United States. The ARROW programme is systematically increasing access to evidence-based mindfulness and compassion-based interventions for healthcare personnel to enhance wellness and assessing the impact of this programme using validated outcome and process measures captured over time.

Our team seeks to implement this ARROW programme while addressing the critical concerns noted above that have limited previous approaches to conducting mindfulness programming in healthcare settings. Specifically, ARROW aims to address concerns regarding the paucity of long-term data following participation in mindfulness training, the use of heterogeneous and unscalable interventions, and restricted enrollment in training that ultimately hinder generalizability (Kunzler et al., 2020). Notably, ARROW is providing individuals within healthcare systems across the region opportunities to learn how to utilize mindfulness and compassion-based skills from the Community Resiliency Model, Cognitively-Based Compassion Training and the Compassion-Centered Spiritual Health programmes. These are evidence-based interventions that have been shown to improve well-being and impact underlying neural activity tied to improved participant-reported outcomes (Grabbe et al., 2020;

Mascaro et al., 2013; Mascaro et al., 2021). In addition to providing access to regularly occurring training opportunities across rotating days and shift schedules, we are leveraging federal funding to ensure that individuals within the healthcare systems are supported to become certified trainers in these evidence-based interventions. This train-the-trainer approach will enhance the sustainability of these interventions long after the funding period by enabling newly credentialed experts in these interventions to continue offering training opportunities to peers. Further, we are evaluating long-term outcomes by capturing comprehensive and validated measures of well-being, resiliency, burnout, satisfaction and behavioural health prior to and up to months after participating in these evidenced-based mindfulness interventions.

We encourage recipients of these federal funds, as well as other international funding agencies and stakeholders seeking to fund and deploy mindfulness and compassion-based training opportunities in their healthcare systems, to ensure that they are implementing scalable and sustainable programmes. This can be done by choosing to implement evidence-based mindfulness and compassion training opportunities, such as those our team is utilizing. These programmes were selected due to both the substantial amount of empirical research conducted on them and the ability to position experts, credentialed in delivering training opportunities, in practice settings to ensure intervention fidelity. This leads to another key component of supporting future implementation of mindfulness training in practice settings: the need for robust infrastructure that facilitates continuity in access to training opportunities for clinicians and staff. The ARROW federally funded programme is committed to cultivating a sizeable workforce credentialed in teaching evidence-based mindfulness and compassion approaches by covering the tuition or training costs for pursuing certification. Other institutions implementing mindfulness training would benefit from identifying advocates within their organizations and providing them with the time, pay, resources and support needed to become credentialed experts capable of leading training opportunities and providing resources to other clinicians and staff. Similar investments are needed to support healthcare personnel to attend and engage in training opportunities.

Additionally, it is vital that any programme implementation be accompanied by the development of a sustainable data-capturing infrastructure and offering of programming that meets the needs of healthcare personnel of diverse backgrounds. For example, our team is evaluating each interventional approach utilizing validated measures delivered digitally and automatically prior to and repeatedly after participating in the training to enable continuous programme evaluation. These longitudinal data are essential to understanding how best to enhance the delivery and timing of training opportunities. These data also make it possible for our team to discern changes in well-being over time both within and across training opportunities. It is necessary that training opportunities be offered to diverse audiences operating in the healthcare environment and be evaluated to confirm they meet the needs of trainees. Our team is engaging clinicians and staff across service lines, licensures and roles to guarantee equitable access to these programmatic offerings. We have

preidentified interim points of analyses to conduct tailored focus groups with trainees to elucidate themes to inform potential opportunities to enhance the programme to ensure that the material, trainers and content are representative and relevant to the individuals participating in these mindfulness training programmes. Collectively, adherence to these quality efforts can help to ensure the successful implementation and delivery of scalable and sustainable programming to enhance well-being among healthcare personnel.

In an era of unsustainable working conditions within healthcare systems and across care settings around the globe, it is critical to provide systemic support to improve the well-being of clinicians and staff. While the ARROW programme does not address the many systemic and structural drivers of burnout, our interdisciplinary team is actively working to shift cultural norms within healthcare systems on how burnout is assessed and addressed among peers working on the frontlines of the ongoing pandemic. By implementing a scalable and sustainable programme, ARROW aims to increase access for all clinicians and staff to evidence-based mindfulness and compassion interventions capable of enhancing overall well-being during these distressing times. Ensuring sustained access to high-quality evidence-based programmatic offerings is but one component to addressing the well-being of clinicians and staff in healthcare settings as they continue to provide high-quality patient care during the COVID-19 pandemic.

#### AUTHOR CONTRIBUTIONS

All authors contributed equally to the initial draft and revisions of this work.

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#### CONFLICT OF INTEREST

The authors report no conflicts of interest.

#### DATA AVAILABILITY STATEMENT

Due to the commentary nature of this work no supporting data are available.

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# Parental perceptions and experiences of infant crying: A systematic review and synthesis of qualitative research

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## Abstract

**Background:** Excessive infant crying is common and can have a huge impact on families and well-being. Systematically reviewing qualitative studies on infant crying can provide a greater understanding of parental perceptions and experiences.

**Aim:** This study sought to systematically review and thematically synthesize qualitative studies exploring parents/carers' views and experiences of infant crying.

**Design:** A systematic review and synthesis of qualitative research.

**Data Sources:** Electronic databases MEDLINE, EMBASE, PsycINFO and CINAHL were searched from the earliest date available to January 2022. We selected papers focusing on parents/carers' experiences, views, attitudes and beliefs about infant crying. We excluded papers focussing on health professionals' views and children older than 12 months.

**Review Methods:** Thematic synthesis was followed for the analysis of included studies and quality appraisal was conducted.

**Results:** We synthesized 22 papers, reporting data from 376 participants in eight countries. Four analytical themes were developed: (1) Experiences and impact of crying; (2) parental management strategies; (3) the role of the health professional; (4) the role of infant feeding and maternal diet. Our findings suggest that infant crying has a substantial emotional impact on parents/carers that often impacts relationships. Parents/carers reported using a range of soothing techniques and coping strategies but were desperate to find effective treatment or cure. Support was often perceived as lacking. Excessive crying and beliefs about the role of maternal diet on breastmilk were reported to undermine parents' confidence in breastfeeding by making them feel their milk is insufficient or harmful, or through pressure from others to stop breastfeeding.

**Conclusion:** Parents/carers use a range of strategies to interpret and deal with the challenges of infant crying, but there is a need for more information and support.

**Impact:** Findings can be used to inform future research and interventions to support families experiencing excessive infant crying.

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## KEYWORDS

excessive crying, infant crying, literature review, qualitative, systematic review, thematic synthesis

## 1 | INTRODUCTION

Excessive crying affects around 20% of infants in the first months of life (Wake et al., 2006; Wolke et al., 2017) and can have a substantial impact on families including parental anxiety and depression, early cessation of breastfeeding, increased risk of non-accidental injury and child behavioural difficulty (Douglas & Hill, 2011). Normal infant crying is high across the first 6 weeks of life and can reach a peak of over 2 h a day before reducing drastically between 6 and 12 weeks of age to 1 h a day (Wolke et al., 2017). There is clear evidence that caring for an excessively crying infant is harmful to relationships and health, but more research is needed to understand this complex phenomenon. Synthesizing findings from existing qualitative research can provide valuable new insights into parents' views, experiences and management of infant crying and how these may relate to feeding decisions.

## 2 | BACKGROUND

Excessive infant crying of unknown cause, also known as infantile colic, is defined as uncontrollable crying for more than 3 h a day, for more than 3 days a week, for at least 1 week, in a healthy infant up to 4 months of age (NHS, 2022). Colic is estimated to affect 17%–25% of infants in the first 6 weeks of life (Wolke et al., 2017). Despite its high prevalence, the aetiology of colic is very poorly understood, and diagnosis usually requires ruling out other possible causes such as gastrointestinal or feeding problems, or infections (Douglas & Hill, 2011). The severity of infant crying itself is thought to occur along a continuum, which depending on the definition of excessive crying can affect up to 12% of infants (Reijneveld et al., 2001). There is evidence of an association between excessive infant crying and poorer long-term outcomes including impact on the parent-child relationship, child mood disorders and possible developmental concerns (DeGangi et al., 2000; Hemmi et al., 2011). These may be mediated by parental attributions and perceptions of their crying infant (James-Roberts, 2001; Smarius et al., 2017), and early intervention to support parents affected by excessive infant crying could help mitigate these potential negative outcomes (Gilkerson et al., 2020).

Infant crying has been found to have a major impact on parents and families. It is associated with parental anxiety, maternal and paternal depression (McMahon et al., 2001; Smart & Hiscock, 2007), high levels of health service use and is the biggest risk factor for infant abuse, particularly shaken baby syndrome (Reijneveld et al., 2004). A mixed-methods literature review focussing on the impact of excessive infant crying on the family found consequences included: feelings of desperation, impaired breastfeeding, 'ruined' everyday life, isolation and loneliness, strained and broken family

relationships, physical and mental exhaustion and feelings of failure as a parent (Botha et al., 2019). The current review aims to build on these findings by exploring the qualitative literature beyond the impact of excessive crying to further understand parental behaviours.

## 3 | THE REVIEW

### 3.1 | Aim

We aimed to conduct a systematic review and thematic synthesis of the qualitative literature on parents/carers' views and experiences of infant crying. For the remainder of this paper parents and carers are collectively referred to as parents.

### 3.2 | Design

We conducted a systematic review and thematic synthesis (Thomas & Harden, 2008) of qualitative papers. Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (Tong et al., 2012) was used to facilitate reporting.

### 3.3 | Search methods

Four electronic databases were first searched on 6th October 2020 using a comprehensive search strategy (Table S1) devised using the SPIDER search strategy tool (Cooke et al., 2012): Medline (1946–2020), EMBASE (1947–2020), PsychINFO (1806–2020), CINAHL (1981–2020). Reference lists of all included papers were checked to minimize the risk of missing key papers. Two authors (J.M. and H.J.) independently screened all titles and abstracts against the inclusion criteria and any discrepancies were discussed with M.S. and I.M. The searches were updated on 28 January 2022, and all new titles and abstracts were screened independently by I.M. and S.H.

Papers were included where the primary focus was parents' views and experiences of infant crying. A recent analysis of online parenting forum discussions found that diagnostic labels are used interchangeably and not well understood (Ghio et al., 2022). All parental experiences of infant crying were therefore included in the review, and we did not limit inclusion to infants with a diagnostic label of colic or excessive crying. To be eligible, papers must have reported the use of qualitative methods for data collection and analysis, and at least half of the reported results had to relate to infant crying. Papers were excluded where the focus was not on a generalized parent population, or where the study focussed on a single

treatment modality for crying. There were no date or language restrictions. See [Table 1](#) for inclusion and exclusion criteria.

### 3.4 | Search outcome

Database searches yielded 5085 results and two were identified through reviewing reference lists. Deduplication resulted in 3759, of which 80 were assessed as potentially eligible following screening titles and abstracts. Full-text papers were obtained for these 80 to further assess eligibility, resulting in 22 papers being included in the final systematic review and synthesis (see [Figure 1](#)).

### 3.5 | Quality appraisal and data extraction

Key study characteristics were extracted from each paper. These included: first author, publication year, focus, number of participants, country, setting, data collection methodology, data analysis methodology and key themes reported by authors. Reporting quality of included papers was appraised by J.M. or S.H. using the CASP checklist (Singh, 2013) for qualitative studies. Quality appraisal and data extraction were discussed with IM and MS. No studies were excluded as a result of the quality appraisal. Reporting standards have changed since the 1980s and including older papers to explore how parental perceptions have changed over time was deemed valuable in this current review. All included studies were high quality except for Thompson 1986 (Thompson et al., 1986), which was rated as poor quality ([Table S2](#)).

### 3.6 | Data synthesis

Thematic Synthesis (Braun & Clarke, 2019) was followed for the analysis of included studies. First, data were explored and described. The texts were read and re-read before the data were inductively coded

according to content and meaning to produce an initial coding framework of descriptive themes. Key findings and quotes from each paper were listed and tabulated so that they could be explored and compared. The analysis also drew on principles from meta-ethnography (Noblit et al., 1988) by using the notion of first-, second- and third-order constructs to synthesize qualitative papers. First-order constructs refer to direct participant data, second-order constructs are the original researchers' interpretations of the data, and third-order constructs are the new interpretations arising from the synthesis of second-order constructs from multiple papers. The initial coding frame was developed by J.M. and M.S. and iteratively refined through discussions with I.M., M.S. and D.G. to offer different interpretations of the data and facilitate the generation of analytic themes that go beyond describing findings from included papers.

## 4 | RESULTS

### 4.1 | Study characteristics

Included studies were conducted between 1986 and 2020 in USA ( $n = 11$ ), UK ( $n = 3$ ), Switzerland ( $n = 2$ ), Sweden ( $n = 2$ ), South Africa ( $n = 1$ ), Canada ( $n = 1$ ), Norway ( $n = 1$ ) and Vietnam ( $n = 1$ ) and reported data from qualitative interviews with 376 parents. Participants were mostly mothers but also included fathers and grandmothers. Studies included infants who had been given diagnostic labels of colic ( $n = 10$ ), excessive, persistent or inconsolable crying ( $n = 5$ ) or no diagnostic label ( $n = 7$ ). See [Table 2](#) for characteristics of included studies.

Most interviews were conducted face-to-face, but some were by telephone and one study included email interviews. The most commonly reported method of data analysis was thematic analysis. Most studies focussed on parental experiences and the impact of infant crying, some focussed on parental understanding and responses to infant crying, and one paper focussed on parental beliefs about the role of diet on infant crying.

TABLE 1 Eligibility criteria for included articles

	Inclusion criteria	Exclusion criteria
Sample	Parents and carers of infants	Health professionals' views only Not generalized parent population (e.g. only parents with an anxiety disorder) Focus on children older than 12 months
Phenomenon of interest	Infant crying	Single treatment modality for crying (e.g. acupuncture)
Design	Qualitative (including ethnography, grounded theory, phenomenology, focus groups, interviews and participant observations)	Case studies Quantitative studies Literature reviews Experimental design
Evaluation	Reports of parental experiences, views, attitudes, beliefs	
Research type	Qualitative, Mixed methods	Studies that do not report qualitative data collection and qualitative data

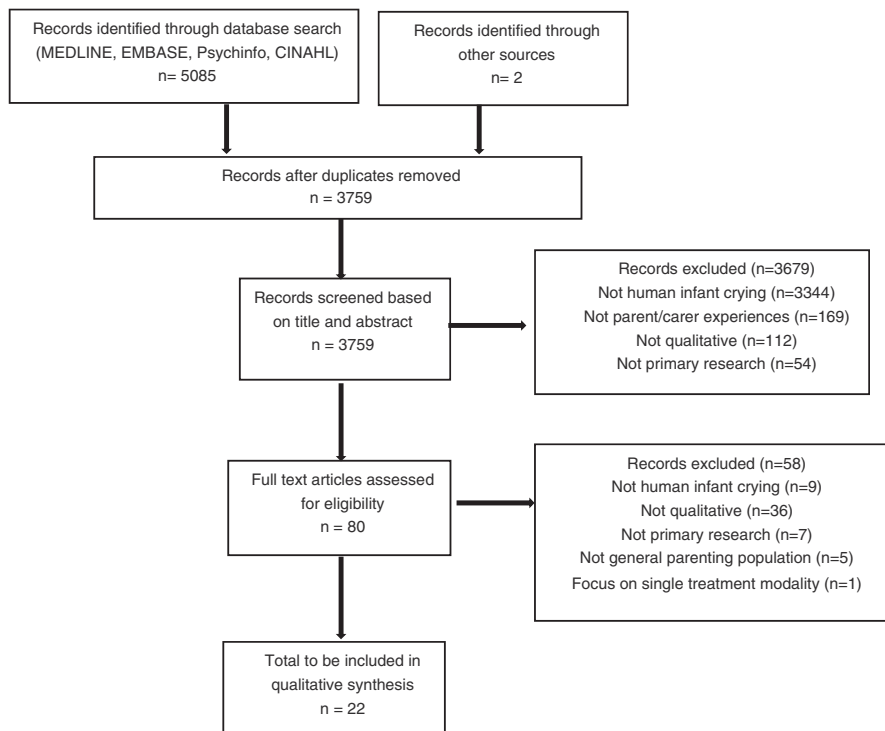


FIGURE 1 CONSORT diagram

## 4.2 | Thematic synthesis

Line-by-line coding generated descriptive themes, shown in Figure 2, which were then further developed into four overarching analytical themes: (1) Experiences and impact of crying. (2) Parental management strategies. (3) The role of health professionals. (4) The role of feeding/diet. The number of themes emerging from individual papers included in this review ranged from 2 to 9. None of the included papers covered all the themes identified in this review. Where findings emerged from largely one population, this is highlighted in the relevant section. See Table 3 for information on how the themes map to each paper.

### 4.2.1 | Experiences and impact of crying

All papers discussed parental experiences of infant crying and the impact it had on their lives. The impact of crying was described in terms of emotional impact, impact on relationships, and feeling anger towards the baby.

#### *Emotional impact of crying*

The vast majority of included studies reported accounts of parents experiencing significant emotional impact from infant crying (Cox & Roos, 2008; Ellett et al., 2009, 2005; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2014, 2010; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten & Miller, 2019; Poskey & Hersch, 2012; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005; Wiley

et al., 2020). The two included studies where this subtheme did not emerge focussed specifically on soothing techniques (Drummond et al., 1993) and dietary restrictions resulting from infant colic (Kidd et al., 2019). Parents described feeling worried, anxious, and distressed, and one study described a mother's experience of needing counselling to cope with the distress caused by her baby's colic (Ellett & Swenson, 2005). In most studies, parents also discussed exhaustion from lack of sleep (Cox & Roos, 2008; Drummond et al., 1993; Ellett & Swenson, 2005; Ellett et al., 2005, 2009; Kurth et al., 2010; Landgren & Hallstrom, 2011; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Thompson et al., 1986).

Both anger and frustration and also, partly, sadness came. So, yes, a combination of helplessness, sadness and pure rage and ... yes, madness. I am constantly furious (Landgren et al., 2012)

Tiredness. In your head. So much tiredness... When my husband came home yesterday, I sat with her in my arms, just crying. I had been crying since she stopped crying... I'm totally drained. (Landgren & Hallstrom, 2011)

All studies that described the emotional impact of crying reported parents experiencing feelings of frustration, failure, inadequacy and self-blame for being unable to soothe their baby and manage their crying (Cox & Roos, 2008; Ellett & Swenson, 2005; Ellett et al., 2005, 2009; Keefe & Froese-Fuetz, 1991; Kurth et al., 2014, 2010; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky

TABLE 2 Characteristics of included studies

No.	Authors (year)	Country	Participants (n)	Infant diagnostic label	Principle views/experiences explored	Method of data collection	Method of data analysis
1	Thompson et al. (1986)	USA	Parents and HCPs (50)	Colic—HCP diagnosed	The processes associated with infant colic in the family	Interview	Not given
2	Wiley et al. (2020)	USA	Parents (25)	None, parents of newborns	Parental perceptions of infant crying and abusive head trauma	Semi-structured interviews	Thematic analysis
3	Wade et al. (2005)	USA	Mothers (7)	None, mothers at risk of AHT	Impact of crying on mothers at high risk of abusing their child	Focus group	Phenomenological Approach
4	Landgren et al. (2012)	Sweden	Mothers (10) and fathers (7)	Colic—HCP diagnosed	Parents' experience of infant colic	Semi-structured interviews and a focus group	Content analysis
5	Cox and Roos (2008)	South Africa	Not given	Colic—HCP diagnosed	Experiences of first-time mothers with colicky infants	Semi-structured interviews	Thematic analysis
6	Drummond et al. (1993)	Canada	Mothers (19)	None, mothers of newborns	Views and understanding of infant crying and soothing	Semi-structured interviews	Thematic analysis
7	Kurth et al. (2010)	Switzerland	Mothers (15)	None, mothers of newborns	Mother's experiences and responses to infant crying	Semi-structured interviews, observation	Phenomenological Approach
8	Landgren and Hallström (2011)	Sweden	Mothers (12) and fathers (11)	Colic—HCP diagnosed	The meaning of being a parent of a colicky infant	Semi-structured interviews	Phenomenological approach
9	Megel et al. (2011)	USA	Mothers (13)	Persistent crying—parent report	Experiences of parenting an irritable infant	Semi-structured interviews	Grounded theory
10	Murray et al. (2018)	Vietnam	Mothers (21), grandmothers (3)	None, mothers of newborns	Caregivers' understanding of, and responses to, unsettled infant behaviour	Semi-structured interviews	Thematic analysis
11	Poskey and Hersch (2012)	USA	Mothers (3), fathers (3)	Inconsolable infant crying - parent report	Parental experience of infant crying	Semi-structured interviews	Thematic analysis
12	Poskey et al. (2014)	USA	Mothers (2), fathers (2)	Inconsolable infant crying—parent report	Parents' thoughts, feelings, behaviour and actions towards an inconsolable infant	Questionnaire, home observation	Ethnography
13	Ellett et al. (2009)	USA	Fathers (10)	Colic - parent report	Fathers' experiences living with colicky infant	Semi-structured interviews	Interpretive phenomenological analysis
14	Keefe and Froese-Fuetz (1991)	USA	Mothers (15)	Colic - HCP diagnosed	Experiences of mothers caring for an irritable infant	Unstructured interviews	Thematic analysis
15	Kidd et al. (2019)	Norway	Mothers (21)	Colic - parent report	Mothers' perceptions of the role of maternal diet on crying in infant	Semi-structured interviews and focus groups	Content analysis
16	Ellett et al. (2005)	USA	Parents (44)	Colic - parent report	Experiences living with colicky infant	Semi-structured interviews	Thematic analysis

(Continues)



TABLE 2 (Continued)

No.	Authors (year)	Country	Participants (n)	Infant diagnostic label	Principle views/experiences explored	Method of data collection	Method of data analysis
17	Nash et al. (2008)	UK	Mothers (22), fathers (2)	None, parents attending child health clinic	Views of the crying behaviour of infants	Semi-structured interviews	Thematic analysis
18	Kurth et al. (2014)	Switzerland	Mothers (15)	None, mothers of newborns	Views and experiences of first-time and experienced mothers of infant crying	Semi-structured interviews and observation	Phenomenological Approach
19	Long and Johnson (2001)	UK	Parents (25)	Excessive crying – parent report	Parental experience of coping with excessively crying infant	Semi-structured interviews and observation	Grounded theory
20	Ellett et al. (2005)	USA	Parents (15)	Colic – parent report	Perceptions of lasting effects of colic	Semi-structured interviews	Thematic analysis
21	Oaten et al. (2019)	UK	Mothers (6)	Excessive crying – parent report	Parental experience of coping with excessively crying infant	Semi-structured interviews	Thematic analysis
22	Levitzky and Cooper (2000)	USA	Mothers (23)	Colic – HCP diagnosed	The impact of infant colic on the emotional state of the mother	Structured interviews	Not stated

& Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten & Miller, 2019; Poskey & Hersch, 2012; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020).

Upset and angry with myself you know it's my fault I don't know it's just natural isn't it like any mother really don't know what to do. I just want to make him better – you know, stop him crying. (Nash et al., 2008)

It truly changed who I am. Life was guilt, anger, frustration, confusion, sadness, and the feeling of having been cheated. (Ellett et al., 2005)

In some studies, parents described how feelings of failure over time became feelings of hopelessness that the crying would ever improve, and helplessness that there was nothing they could do to improve it (Cox & Roos, 2008; Landgren et al., 2012; Oaten & Miller, 2019)

I felt that it would never end, the total utter helplessness to the point where you feel that you can't make this better and then losing hope that it would ever come to an end. (Cox & Roos, 2008)

#### Impact on relationships

A recurring theme across many studies was parents' descriptions of the adverse effect having a baby with excessive crying had on their relationships with their partners (Cox & Roos, 2008; Ellett et al., 2005, 2009; Kurth et al., 2014; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Murray et al., 2018; Oaten & Miller, 2019).

It's a loveless marriage with a relationship that won't exist until the crying stops, if even then, and we argue about it all the time. (Long & Johnson, 2001)

He is so angry. Every day it gets worse. It's killing us. If we had an easy baby, there would be no problem. (Levitzky & Cooper, 2000)

This was often discussed by mothers in relation to feeling alone and unsupported by their partners. A mother in one study (Cox & Roos, 2008) described how her husband's life remained largely unchanged as he was still able to socialize and go out as before whilst her life had been dominated by looking after a baby with colic.

Several papers discussed parents feeling like their parenting was being judged by others, including friends, family, and health professionals (Cox & Roos, 2008; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Oaten & Miller, 2019). This sometimes led to parents isolating themselves from unsolicited advice, negative comments, and perceived judgement. This often emerged as second-order constructs (Landgren et al., 2012; Levitzky & Cooper, 2000; Long

FIGURE 2 Overview of themes



& Johnson, 2001; Oaten & Miller, 2019), for example “Although there were examples of parents being explicitly accused of poor parenting practice, more often the feelings of guilt resulted from self-recrimination or perhaps from perceptions of external criticism” (Long & Johnson, 2001). However, feeling judged was also supported by first-order data excerpts from participants.

Then it's the comments from people, from the paediatrician to my friends. There were times when we went to visit them and looked exhausted, and they would say that you could take an antidepressant if YOU'RE not coping. You feel so frustrated because you're trying to explain that anyone in your situation wouldn't be coping (Cox & Roos, 2008).

The worst part is that everyone has something to try. And of course, it's stuff you have already tried, and you know it's not going to work. Finally, you just get tired of explaining it. (Megel et al., 2011)

In some studies, parents also discussed the negative impact infant crying had on the relationship with their child (Cox & Roos, 2008; Ellett & Swenson, 2005; Landgren & Hallström, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Megel et al., 2011; Oaten & Miller, 2019). This was usually a result of feeling like a failure and a bad parent or feeling rejected by the child.

I felt guilty and like a bad mother when I could not calm him down. I imagined that he did not love me and one day I told my husband that I was going to stop breastfeeding because the baby was just 'using me' and I wasn't going to let him do that. I immediately felt guilty and childish and, of course, did not stop breastfeeding. (Ellett & Swenson, 2005)

What are we doing wrong? My baby is telling me I'm not a good mother. (Megel et al., 2011)

#### *Anger towards baby*

Participants in nearly half of the included studies expressed feelings of anger and frustration towards their baby as a result of excessive crying (Cox & Roos, 2008; Ellett & Swenson, 2005; Kurth et al., 2010; Landgren et al., 2012; Levitzky & Cooper, 2000; Megel et al., 2011; Nash et al., 2008; Oaten & Miller, 2019; Poskey et al., 2014; Thompson et al., 1986).

There were moments when, both me and my husband ... when she was apoplectic and howling so much that I almost got this thought, 'now I'll take a pillow and put over her face just until she quiets down, until the screaming stops. (Landgren et al., 2012)

Some of the studies where parents expressed feelings of anger towards their child (Levitzky & Cooper, 2000; Nash et al., 2008; Poskey et al., 2014) specifically aimed to explore experiences and triggers to prevent abusive head trauma because of shaking the baby, which can have devastating outcomes. Some papers discussed how aggression can be induced by crying, maternal thoughts of harm and implication in the prevention of head trauma (Landgren et al., 2012; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020). The fantasies or thoughts of harm reported in these papers were all from parents of infants who have been labelled as having colic or inconsolable crying.

There were times when you want to throw him against the wall. (Cox & Roos, 2008)

In one paper, most parents said that they could not understand why someone would shake an infant (Wiley et al., 2020). However, this paper studied parents of infants that cried normally (convenience sample of parents of newborns), which could explain these differences.

She can cry for hours. I wouldn't shake her. I wouldn't be able to see myself shaking her. (Wiley et al., 2020)

TABLE 3 Themes identified in each study

Themes	Study reference																					
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
Experiences and impact of crying																						
Emotional impact on parents	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Impact on relationships	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Anger towards baby	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Parental management strategies	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Soothing techniques	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Parental coping strategies	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Need for social support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Normalizing crying	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
The role of health professionals																						
Health professional support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Seeking a cure	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
The role of infant feeding and maternal diet																						
Changes to maternal diet	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Pressure to stop breastfeeding	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

## 4.2.2 | Parental management strategies

### *Soothing techniques*

A range of consistently similar ways to manage crying was reported across the different papers. A common response was to pick the baby up when they were crying. Some papers also reported participants doing basic checks to interpret the reason for the crying or systematically working through potential soothing techniques to stop the crying (Cox & Roos, 2008; Drummond et al., 1993; Keefe & Froese-Fuetz, 1991; Kurth et al., 2014, 2010; Landgren & Hallström, 2011; Megel et al., 2011; Murray et al., 2018; Poskey & Hersch, 2012; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020).

I check to see if his diaper is wet, check to see if he is hungry, rub his back. Sometimes I give him a nice warm bath, I walk around with him ... I sing to him. (Poskey et al., 2014)

Other approaches to soothe a crying baby were feeding, auditory interventions such as singing or white noise and the use of movement (Drummond et al., 1993; Ellett et al., 2009; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Kurth et al., 2014, 2010; Landgren & Hallström, 2011; Megel et al., 2011; Murray et al., 2018; Poskey & Hersch, 2012; Poskey et al., 2014; Wade et al., 2005).

Potentially harmful strategies, such as medicating the baby with homeopathic pills or antihistamines, were reported by parents in one of the papers. (Ellett & Swenson, 2005).

### *Strategies to help parents cope*

Participants in most studies detailed a range of coping strategies they used to help them deal with the demands of their baby's crying (Drummond et al., 1993; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2010, 2014; Landgren & Hallström, 2011; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten & Miller, 2019; Poskey & Hersch, 2012; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020). Perhaps the most important was finding ways to block out the sound of crying, taking a break and safety planning. Parents in many studies described putting their baby down and physically walking away when they felt they were becoming too frustrated (Ellett et al., 2009; Kurth et al., 2010; Megel et al., 2011; Nash et al., 2008; Poskey & Hersch, 2012; Wiley et al., 2020).

For sanity's sake I'd just had to put him in his crib and walk away and kind of give myself a little time out to kind of get my breath. (Poskey & Hersch, 2012)

Other coping strategies included measures to directly calm themselves, such as driving (Poskey & Hersch, 2012), singing, smoking, taking anti-anxiety medication (Wade et al., 2005) and even boxing (Poskey & Hersch, 2012). Cognitive strategies included "keeping a stiff upper lip" and persevering (Wade et al., 2005).

Sometimes there is no one around; I just have to buck up and deal with it. (Wade et al., 2005)

One paper described how parents used self-talk, telling themselves over and over "it's only colic and it can't last forever" (Megel et al., 2011). Some parents also adapted their expectations of what being a parent would be like (Drummond et al., 1993; Kurth et al., 2010, 2014; Thompson et al., 1986). Considering the positives in the situation, such as feeling gratitude the baby was healthy, was another coping method in some papers (Drummond et al., 1993; Ellett & Swenson, 2005; Kurth et al., 2014; Thompson et al., 1986; Wade et al., 2005).

#### *Need for social support*

Participants in the majority of studies discussed the importance of social support for managing infant crying (Cox & Roos, 2008; Ellett et al., 2009; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Landgren & Hallström, 2011; Landgren et al., 2012; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten et al., 2019; Wade et al., 2005; Wiley et al., 2020).

You gotta have a support system, too, yep. I would, if something's wrong, that baby's crying, get some advice or something. Talk to someone a little more experienced than you are. (Wiley et al., 2020)

I had a great support system with friends and family, so people helped and cooked meals. (Cox & Roos, 2008)

Papers that mentioned parents who did not have social support indicated that these parents struggled (Ellett et al., 2005, 2009; Kurth et al., 2014; Poskey et al., 2014).

I basically had no help; I was on the verge of quitting everything. (Ellett et al., 2005)

Support from others was useful in multiple ways; it gave parents encouragement and advice, a chance for a break from their baby when people looked after them, and simply, a 'shoulder to cry on' (Cox & Roos, 2008; Ellett et al., 2005, 2009; Keefe & Froese-Fuetz, 1991; Landgren & Hallström, 2011; Landgren et al., 2012; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten et al., 2019; Wade et al., 2005; Wiley et al., 2020).

Whilst social support was evidently important for participants of different cultures, some communities use it in different ways. Whilst in the studies from Europe most parents lived alone with their child, the Vietnamese study (Murray et al., 2018) showed how the intergenerational household context meant grandparents were not only a key source of information about unsettled infant behaviour but were very involved in daily infant care.

Maternal and paternal grandmothers have much experience, so they can soothe him better. (Murray et al., 2018)

#### *Normalizing crying*

Several papers reported that parents discussed what is, and what is not normal in terms of infant crying. Reasons given for normal infant crying were fatigue, hunger, pain and discomfort, prematurity, reflection of environment, the need for social interaction, and understanding that sometimes babies cry for unknown reasons (Cox & Roos, 2008; Ellett et al., 2009; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Kurth et al., 2010; Murray et al., 2018; Thompson et al., 1986).

I kept saying to people that it was because he was premature, this is normal and it will be fine (Cox & Roos, 2008)

In addition, some participants from Vietnam (Murray et al., 2018) had spiritual beliefs about why their babies cried.

It was believed that (...) babies may see or be unsettled by ghosts or ancestors that have passed away. (Murray et al., 2018)

Parents described how they interpreted their baby's cries, and reasons for the crying, and responded accordingly (Cox & Roos, 2008; Ellett et al., 2009; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Kurth et al., 2010, 2014; Landgren & Hallström, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Murray et al., 2018; Nash et al., 2008; Poskey & Hersch, 2012; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020).

In many of the papers, parents' responses were described as being based on characteristics of the crying (Cox & Roos, 2008; Ellett et al., 2009; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Kurth et al., 2010; Landgren et al., 2012; Levitzky & Cooper, 2000; Murray et al., 2018; Nash et al., 2008; Wade et al., 2005; Wiley et al., 2020).

In the beginning it always sounded the same when she was crying. Then I realised she cries differently if she needs to burp or if her nappy is full. I didn't think you could distinguish this, but in fact you can. (Kurth et al., 2014)

Some parents discussed their belief that their infant's crying was not normal, and they believed there was an underlying pathology causing their excessive crying. Parents' search for a diagnosis or cure is discussed later in this paper. Many papers mentioned that parents often believed abnormal crying was caused by something they did wrong, which caused the parents' emotional distress (Ellett et al., 2005, 2009; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2010; Landgren & Hallström, 2011; Murray et al., 2018; Nash et al., 2008; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005).

It's like, what's wrong with me or my kid? Why is it this way? Why can't I quiet this baby? (Keefe & Froese-Fuetz, 1991)

This belief that crying was due to something the parents did arose from parents in almost all papers. Parental beliefs about why they were unable to soothe the baby included 'bad parenting', and parents often believed that personal factors, such as maternal stress or anxiety, caused the crying (Ellett et al., 2005, 2009; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2010; Landgren & Hallström, 2011; Murray et al., 2018; Nash et al., 2008; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005). Some papers also reported that the belief crying represented an underlying pathology was more common in inexperienced parents than those that had experience (Ellett & Swenson, 2005; Kidd et al., 2019; Kurth et al., 2014; Thompson et al., 1986): As one author described, "in contrast to first-time mothers, experienced mothers understood that all infants had 'uneasy phases' and were not always happy. Inexperienced mothers tended to interpret crying as a sign of alarm" (Kurth et al., 2014). Participants in several papers discussed the role of maternal diet and infant feeding. This is explored in theme four of the current paper.

#### 4.2.3 | The role of health professionals

##### *Health professional support*

In many studies, parents described consulting health professionals for their infant's crying, often for support and reassurance that there are no serious underlying issues and that parenting factors are not to blame (Cox & Roos, 2008; Ellett et al., 2005, 2009; Kidd et al., 2019; Kurth et al., 2010; Landgren & Hallström, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Oaten et al., 2019; Thompson et al., 1986; Wade et al., 2005). Parents in a few studies described feeling listened to, felt the health professional understood their situation and had reported having helpful experiences (Cox & Roos, 2008; Ellett et al., 2005; Landgren & Hallström, 2011; Long & Johnson, 2001; Oaten et al., 2019).

He actually listened to me and expressed concern about her colic. He gave us literature on ways to try and calm her down and reasons they believe she is this way. I left the office feeling reassured. She was going to be fine. It was just going to take some time. (Ellett et al., 2005)

Parents' descriptions of positive experiences of health professional support included health visitors (Long & Johnson, 2001; Oaten et al., 2019), midwives (Cox & Roos, 2008), nurses (Landgren & Hallstrom, 2011) and paediatricians (Ellett et al., 2005) and were described as having someone who understands what you are going through, was willing and able to listen and 'hold your hand'. Parents from the UK (Long & Johnson, 2001; Oaten et al., 2019) particularly valued health visitor support and felt they were able to provide helpful information and reassurance.

What helped was my midwife. Although I'm a logical person, when you're so sleep deprived, you can't

even think for yourself; you need somebody literally to hold your hand. (Cox & Roos, 2008)

My health visitor was brilliant. I mean, as far as they can do. They can only offer to listen to you, but that made such a change. She would listen all day if I carried on. (Long & Johnson, 2001)

However, most studies where parents went to health professionals reported that parents felt dismissed, unsupported or did not receive the information they were looking for (Ellett et al., 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2010; Landgren & Hallström, 2011; Megel et al., 2011; Thompson et al., 1986; Wade et al., 2005). As one study author describes "one mother spoke of how, after a few office visits with her colicky infant, her paediatrician started relaying information through the office staff, leaving the mother with the impression that she was an annoyance" (Levitzky & Cooper, 2000)

The nurse said it was normal for babies to cry. She said that colic cannot start as early as the fifth day. But my child did have colic that early, so that was our reality. (Landgren et al., 2012)

##### *Seeking a cure*

More than half of included papers described parents' search for a treatment or cure for their child's crying (Cox & Roos, 2008; Drummond et al., 1993; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Landgren & Hallström, 2011; Landgren et al., 2012; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Oaten et al., 2019; Poskey et al., 2014; Poskey & Hersch, 2012; Thompson et al., 1986). Papers that did not discuss seeking a cure were mostly in populations of parents with normal crying infants (Kurth et al., 2010, 2014; Nash et al., 2008; Wade et al., 2005; Wiley et al., 2020). Papers with colicky infants where a cure was not discussed were mostly from one author and specifically focussed on the impact of crying (Ellett et al., 2005, 2009; Ellett & Swenson, 2005; Levitzky & Cooper, 2000).

Parents demonstrated desperation for a treatment or cure and talked about trying various medications, feeding approaches and alternative therapies.

We started our cycle of chiropractors, reflexologists, homeopaths, medication for reflux; we changed his formula a hundred times; we have a hundred bottles, a hundred teats; it was this desperate clinging to something (Cox & Roos, 2008)

You try anything. If anybody can give you a bit of advice that you think you can use, anything at all, you do it. Problem is, of course, none of it works and you're left no better off, maybe a bit poorer, and sometimes it may even seem worse than before. It, like, knocks you back when you build up your hopes and then it doesn't work (Long & Johnson, 2001)



Participants also described their need for more information about infant crying. A few studies specifically described that parents need information about potential reasons for infant crying, and ways of managing it (Drummond et al., 1993; Ellett et al., 2009; Poskey et al., 2014). In one study of parents at risk of abusive head trauma (Wade et al., 2005), a parent disclosed having information about infant crying early on would have enabled them to prepare better and may have affected their decision to have a baby.

I think what would help people, especially who haven't had kids before, is more talk about it in the hospital (...) it's touched on in books (...) they don't really address it (...) I just don't think there's enough awareness... or warning about it. (Ellett et al., 2009)

A parent in one study (Landgren & Hallstrom, 2011) also described searching for information online and feeling like they knew more about colic than the health professionals they were consulting.

I have often felt that I know more than them, at [child health clinic]. They say the same things that they have said for years. I have found new information on the internet, new since my first child had colic six years ago. (Landgren & Hallstrom, 2011)

Seeking a cure or treatment was less likely to emerge from studies where parents did not report a diagnostic label such as colic or excessive crying.

#### 4.2.4 | The role of infant feeding and maternal diet

##### *Changes to maternal diet*

Five papers discussed the belief that maternal diet can cause excessive crying in breastfed babies due to dietary intolerances causing abdominal discomfort and pain (Kidd et al., 2019; Landgren & Hallström, 2011; Levitzky & Cooper, 2000; Megel et al., 2011; Thompson et al., 1986). Babies in all these studies were labelled as having colic or excessive crying. In two papers (Landgren & Hallström, 2011; Thompson et al., 1986), the influence of maternal diet on infant crying emerged only as recommendations from the authors rather than participants. For example, "To gain trust, nurses should give evidence-based recommendations, like recommending systematic exclusion of cow's milk protein for 5 days as this intervention relieves the symptoms in 5–25% of babies with colic. By guiding parents how to find food for the breastfeeding mother, and formulas free from cow's milk for the bottle-fed baby, the nurse can make this intervention manageable" (Landgren & Hallstrom, 2011).

In one study (Levitzky & Cooper, 2000), authors described how parents' beliefs and concerns about the impact of maternal diet on infant crying were a result of questioning and advice from health professionals. The authors state "Continuous questions by the pediatrician about the nursing mother's diet often led mothers to believe

that their food selection affected the breast milk and therefore caused their infants pain. This compounded mothers' concerns that they were 'spoiling' their milk and making their babies sick" (Levitzky & Cooper, 2000).

Data from participants discussing changes to the maternal diet in response to infant crying was only briefly mentioned in one paper (Megel et al., 2011) and extensively discussed in a paper published in 2019 (Kidd et al., 2019), suggesting this concern may be a more recent phenomenon.

The only thing I could have was meat, potatoes, and Italian bread. (Megel et al., 2011)

I have cut out dairy. I have cut out all gassy vegetables and gassy fruits (...) caffeine, and carbonated beverages. Eggs, and, of course, butter. (Kidd et al., 2019)

Parents of formula-fed infants in two papers discussed changing their baby's formulas as a strategy to reduce colic or persistent crying (Cox & Roos, 2008; Megel et al., 2011).

We changed his formula a hundred times; we have a hundred bottles, a hundred teats; it was this desperate clinging to something (Cox & Roos, 2008)

##### *Pressure to stop breastfeeding*

Parents of breastfed babies talked about feeling pressured to stop breastfeeding (Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Megel et al., 2011; Murray et al., 2018). Often this pressure came from family members suggesting that the baby was crying because breastmilk was insufficient.

Even my husband was like, "Seriously now, when are we going to have that conversation about you not breastfeeding anymore?... I am serious. When are we going to stop hearing a screaming baby? When are we going to get him on formula? (Kidd et al., 2019).

There was also a belief that feeding infants formula milk instead of breastmilk will help them sleep for longer (Kidd et al., 2019; Murray et al., 2018)

He was breastfed for two hours, but he was still crying. I didn't know how to stop his crying, meanwhile two grandmothers were convincing me that feeding him with formula milk can help him fall asleep. I did and still feel regret about that (Murray et al., 2018).

## 5 | DISCUSSION

This evidence synthesis reveals the complexity and multifaceted impact of infant crying. The review highlights the wide range of

management techniques and coping strategies parents use to deal with infant crying and the importance of social and health professional support. Findings show that parents often have difficulty interpreting why their infant is crying and suspect an abnormal cause, which may lead to overmedicalization. Included studies suggest that a lack of understanding about normal crying often led to intense emotional stress, which had adverse consequences such as social isolation (Cox & Roos, 2008; Ellett et al., 2005, 2009; Keefe & Froese-Fretz, 1991; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Oaten & Miller, 2019; Poskey, 2012), exhaustion (Cox & Roos, 2008; Ellett et al., 2005, 2009; Kurth et al., 2010; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Nash et al., 2008; Oaten & Miller, 2019; Thompson, 2009) and depression (Ellett et al., 2009; Poskey, 2012; Keefe & Froese-Fretz, 1991; Levitzky & Cooper, 2000). These findings are consistent with a previous literature review of mostly quantitative literature focussing on the consequences of excessive infant crying, which found it to be harmful to relationships and health (Botha et al., 2019). This current review synthesized the qualitative literature and identified parental experiences that go beyond the impact of excessive crying, such as management strategies, the role of health professionals and other support needs and parental help-seeking behaviours.

Participants in nearly all the papers believed that their child's crying was in some way their fault. They also discussed the importance of social support to help them through that challenging time, yet many parents described feeling judged by others and several paper authors reflected that parents isolate themselves from their social networks in response to unsolicited advice and negative comments. Arming parents with information and coping strategies to respond to perceived judgement may help build and maintain support networks.

Many families described desperately seeking a cure and often consulted health professionals repeatedly for help and support. Findings showed that many parents found their experiences with healthcare professionals to be unhelpful. Parents who reported positive experiences with health professionals valued physical examination of their baby to provide reassurance and rule out underlying causes. Parents also valued feeling understood and listened to by health professionals and being given advice on coping strategies as well as signposting to resources for further support (Cox & Roos, 2008; Ellett et al., 2009; Keefe & Froese-Fretz, 1991; Landgren & Hallstrom, 2011; Landgren et al., 2012; Long & Johnson, 2001; Megel et al., 2011; Oaten & Miller, 2019).

This review identified beliefs about the impact of maternal diet and infant feeding on excessive crying, considering parental views, and the role of health professionals and other family members. The current findings suggest beliefs that breastmilk is insufficient or harmful to their baby undermines confidence in breastfeeding for parents, families and health professionals. Similar findings were reported in a systematic review of barriers and facilitators to breastfeeding in the first 6 months of life, which found perceptions of insufficient breastmilk to be a significant barrier to exclusive

breastfeeding (Balogun et al., 2015). Interestingly, the influence of maternal diet and infant feeding on infant crying was rarely a focus in the qualitative literature and was only discussed by participants in a small minority of papers. Future research is needed to further explore parental beliefs and experiences related to diet and infant crying.

Frustration caused by crying was found to sometimes lead to feelings of anger and sometimes violent intrusive thoughts directed towards the infant (Cox & Roos, 2008; Ellett & Swenson, 2005; Kurth et al., 2010; Landgren et al., 2012; Levitzky & Cooper, 2000; Megel et al., 2011; Nash et al., 2008; Oaten & Miller, 2019; Poskey et al., 2014; Thompson et al., 1986). Current findings further our understanding of how parents experience and manage their frustration, particularly in safety planning, but it does not suggest ways to identify those parents at risk and further research is needed in that area.

Parents' views of crying and ways of managing it were similar across papers despite the different cultural and healthcare contexts of included countries, suggesting a degree of universality across cultures when responding to infant crying. Labels used to describe infant crying ranged across the studies and included 'colic', 'persistent crying', 'inconsolable crying' and 'excessive crying'. Interestingly, in papers where 'colic' was used to describe their participants' infants, this was based on health professional diagnosis by all but one author (Cox & Roos, 2008; Keefe & Froese-Fuetz, 1991; Landgren & Hallström, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Thompson et al., 1986). Studies that described infant crying as 'persistent', 'inconsolable' or 'excessive' were based on parent self-report (Long & Johnson, 2001; Megel et al., 2011; Oaten et al., 2019; Poskey et al., 2014; Poskey & Hersch, 2012). Most themes arose across all populations, irrespective of the diagnostic label, suggesting the findings are relevant to all parents/carers who consider their infant's crying problematic.

Included studies focused on different samples of participants, such as fathers, grandmothers, and low-income mothers. These were only a small proportion of the pooled sample with a total of three grandmothers included and seven mothers identified as low-income. Most included studies did not report the ethnic background of participants and it was not possible to explore how experiences may have differed specifically for fathers, grandparents, low-income families, or ethnic minority groups. Furthermore, all participants were biologically related to the infants and may not reflect the experiences of alternative family structures. This review focussed on a generalized population of parents so findings may not apply to populations such as parents with mental health conditions.

## 6 | CONCLUSION

Infant crying has a major impact on families. Parents use a range of strategies to interpret and deal with the challenges of infant crying, but there is a large unmet need for better resources and support for parents living with excessive infant crying. This review can help

health professionals understand the complexity and impact of living with infant crying. Health professionals could support families by ensuring their concerns are listened to and where possible providing reassurance or appropriate diagnoses. Greater awareness of the impact of infant crying such as emotional stress, social isolation, undermined confidence in breastfeeding and feelings of anger and intrusive thoughts could help health professionals provide better and more targeted support and advice when needed. Parents are often desperate for reliable information or a treatment/cure and this needs to be managed with evidence-based advice and acknowledgement of the impact infant crying can have.

Understanding that parents often feel to blame for their infant's crying may also help health professionals structure supportive discussions. Little is known about the potential effects infant crying may have on parent-child bonding or the impact of dietary modifications or other interventions made in response to infant crying. Further research is needed to explore these potential impacts. Further research is also needed to identify parents in need of support and to find how and when families could be best supported with infant crying.

#### AUTHOR CONTRIBUTIONS

M.S., J.M., I.M. and D.G. made substantial contributions to the conception and design of the study. All authors contributed to the acquisition, analysis and interpretation of data. All authors were involved in drafting the manuscript and revising it critically for important intellectual content. All authors also gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

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#### CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

#### PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15492>.

#### DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# Parental perceptions and experiences of infant crying: A systematic review and synthesis of qualitative research

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## Abstract

**Background:** Excessive infant crying is common and can have a huge impact on families and well-being. Systematically reviewing qualitative studies on infant crying can provide a greater understanding of parental perceptions and experiences.

**Aim:** This study sought to systematically review and thematically synthesize qualitative studies exploring parents/carers' views and experiences of infant crying.

**Design:** A systematic review and synthesis of qualitative research.

**Data Sources:** Electronic databases MEDLINE, EMBASE, PsycINFO and CINAHL were searched from the earliest date available to January 2022. We selected papers focusing on parents/carers' experiences, views, attitudes and beliefs about infant crying. We excluded papers focussing on health professionals' views and children older than 12 months.

**Review Methods:** Thematic synthesis was followed for the analysis of included studies and quality appraisal was conducted.

**Results:** We synthesized 22 papers, reporting data from 376 participants in eight countries. Four analytical themes were developed: (1) Experiences and impact of crying; (2) parental management strategies; (3) the role of the health professional; (4) the role of infant feeding and maternal diet. Our findings suggest that infant crying has a substantial emotional impact on parents/carers that often impacts relationships. Parents/carers reported using a range of soothing techniques and coping strategies but were desperate to find effective treatment or cure. Support was often perceived as lacking. Excessive crying and beliefs about the role of maternal diet on breastmilk were reported to undermine parents' confidence in breastfeeding by making them feel their milk is insufficient or harmful, or through pressure from others to stop breastfeeding.

**Conclusion:** Parents/carers use a range of strategies to interpret and deal with the challenges of infant crying, but there is a need for more information and support.

**Impact:** Findings can be used to inform future research and interventions to support families experiencing excessive infant crying.

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## KEYWORDS

excessive crying, infant crying, literature review, qualitative, systematic review, thematic synthesis

## 1 | INTRODUCTION

Excessive crying affects around 20% of infants in the first months of life (Wake et al., 2006; Wolke et al., 2017) and can have a substantial impact on families including parental anxiety and depression, early cessation of breastfeeding, increased risk of non-accidental injury and child behavioural difficulty (Douglas & Hill, 2011). Normal infant crying is high across the first 6 weeks of life and can reach a peak of over 2 h a day before reducing drastically between 6 and 12 weeks of age to 1 h a day (Wolke et al., 2017). There is clear evidence that caring for an excessively crying infant is harmful to relationships and health, but more research is needed to understand this complex phenomenon. Synthesizing findings from existing qualitative research can provide valuable new insights into parents' views, experiences and management of infant crying and how these may relate to feeding decisions.

## 2 | BACKGROUND

Excessive infant crying of unknown cause, also known as infantile colic, is defined as uncontrollable crying for more than 3 h a day, for more than 3 days a week, for at least 1 week, in a healthy infant up to 4 months of age (NHS, 2022). Colic is estimated to affect 17%–25% of infants in the first 6 weeks of life (Wolke et al., 2017). Despite its high prevalence, the aetiology of colic is very poorly understood, and diagnosis usually requires ruling out other possible causes such as gastrointestinal or feeding problems, or infections (Douglas & Hill, 2011). The severity of infant crying itself is thought to occur along a continuum, which depending on the definition of excessive crying can affect up to 12% of infants (Reijneveld et al., 2001). There is evidence of an association between excessive infant crying and poorer long-term outcomes including impact on the parent-child relationship, child mood disorders and possible developmental concerns (DeGangi et al., 2000; Hemmi et al., 2011). These may be mediated by parental attributions and perceptions of their crying infant (James-Roberts, 2001; Smarius et al., 2017), and early intervention to support parents affected by excessive infant crying could help mitigate these potential negative outcomes (Gilkerson et al., 2020).

Infant crying has been found to have a major impact on parents and families. It is associated with parental anxiety, maternal and paternal depression (McMahon et al., 2001; Smart & Hiscock, 2007), high levels of health service use and is the biggest risk factor for infant abuse, particularly shaken baby syndrome (Reijneveld et al., 2004). A mixed-methods literature review focussing on the impact of excessive infant crying on the family found consequences included: feelings of desperation, impaired breastfeeding, 'ruined' everyday life, isolation and loneliness, strained and broken family

relationships, physical and mental exhaustion and feelings of failure as a parent (Botha et al., 2019). The current review aims to build on these findings by exploring the qualitative literature beyond the impact of excessive crying to further understand parental behaviours.

## 3 | THE REVIEW

### 3.1 | Aim

We aimed to conduct a systematic review and thematic synthesis of the qualitative literature on parents/carers' views and experiences of infant crying. For the remainder of this paper parents and carers are collectively referred to as parents.

### 3.2 | Design

We conducted a systematic review and thematic synthesis (Thomas & Harden, 2008) of qualitative papers. Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (Tong et al., 2012) was used to facilitate reporting.

### 3.3 | Search methods

Four electronic databases were first searched on 6th October 2020 using a comprehensive search strategy (Table S1) devised using the SPIDER search strategy tool (Cooke et al., 2012): Medline (1946–2020), EMBASE (1947–2020), PsychINFO (1806–2020), CINAHL (1981–2020). Reference lists of all included papers were checked to minimize the risk of missing key papers. Two authors (J.M. and H.J.) independently screened all titles and abstracts against the inclusion criteria and any discrepancies were discussed with M.S. and I.M. The searches were updated on 28 January 2022, and all new titles and abstracts were screened independently by I.M. and S.H.

Papers were included where the primary focus was parents' views and experiences of infant crying. A recent analysis of online parenting forum discussions found that diagnostic labels are used interchangeably and not well understood (Ghio et al., 2022). All parental experiences of infant crying were therefore included in the review, and we did not limit inclusion to infants with a diagnostic label of colic or excessive crying. To be eligible, papers must have reported the use of qualitative methods for data collection and analysis, and at least half of the reported results had to relate to infant crying. Papers were excluded where the focus was not on a generalized parent population, or where the study focussed on a single

treatment modality for crying. There were no date or language restrictions. See [Table 1](#) for inclusion and exclusion criteria.

### 3.4 | Search outcome

Database searches yielded 5085 results and two were identified through reviewing reference lists. Deduplication resulted in 3759, of which 80 were assessed as potentially eligible following screening titles and abstracts. Full-text papers were obtained for these 80 to further assess eligibility, resulting in 22 papers being included in the final systematic review and synthesis (see [Figure 1](#)).

### 3.5 | Quality appraisal and data extraction

Key study characteristics were extracted from each paper. These included: first author, publication year, focus, number of participants, country, setting, data collection methodology, data analysis methodology and key themes reported by authors. Reporting quality of included papers was appraised by J.M. or S.H. using the CASP checklist (Singh, 2013) for qualitative studies. Quality appraisal and data extraction were discussed with IM and MS. No studies were excluded as a result of the quality appraisal. Reporting standards have changed since the 1980s and including older papers to explore how parental perceptions have changed over time was deemed valuable in this current review. All included studies were high quality except for Thompson 1986 (Thompson et al., 1986), which was rated as poor quality ([Table S2](#)).

### 3.6 | Data synthesis

Thematic Synthesis (Braun & Clarke, 2019) was followed for the analysis of included studies. First, data were explored and described. The texts were read and re-read before the data were inductively coded

according to content and meaning to produce an initial coding framework of descriptive themes. Key findings and quotes from each paper were listed and tabulated so that they could be explored and compared. The analysis also drew on principles from meta-ethnography (Noblit et al., 1988) by using the notion of first-, second- and third-order constructs to synthesize qualitative papers. First-order constructs refer to direct participant data, second-order constructs are the original researchers' interpretations of the data, and third-order constructs are the new interpretations arising from the synthesis of second-order constructs from multiple papers. The initial coding frame was developed by J.M. and M.S. and iteratively refined through discussions with I.M., M.S. and D.G. to offer different interpretations of the data and facilitate the generation of analytic themes that go beyond describing findings from included papers.

## 4 | RESULTS

### 4.1 | Study characteristics

Included studies were conducted between 1986 and 2020 in USA ( $n = 11$ ), UK ( $n = 3$ ), Switzerland ( $n = 2$ ), Sweden ( $n = 2$ ), South Africa ( $n = 1$ ), Canada ( $n = 1$ ), Norway ( $n = 1$ ) and Vietnam ( $n = 1$ ) and reported data from qualitative interviews with 376 parents. Participants were mostly mothers but also included fathers and grandmothers. Studies included infants who had been given diagnostic labels of colic ( $n = 10$ ), excessive, persistent or inconsolable crying ( $n = 5$ ) or no diagnostic label ( $n = 7$ ). See [Table 2](#) for characteristics of included studies.

Most interviews were conducted face-to-face, but some were by telephone and one study included email interviews. The most commonly reported method of data analysis was thematic analysis. Most studies focussed on parental experiences and the impact of infant crying, some focussed on parental understanding and responses to infant crying, and one paper focussed on parental beliefs about the role of diet on infant crying.

TABLE 1 Eligibility criteria for included articles

	Inclusion criteria	Exclusion criteria
Sample	Parents and carers of infants	Health professionals' views only Not generalized parent population (e.g. only parents with an anxiety disorder) Focus on children older than 12 months
Phenomenon of interest	Infant crying	Single treatment modality for crying (e.g. acupuncture)
Design	Qualitative (including ethnography, grounded theory, phenomenology, focus groups, interviews and participant observations)	Case studies Quantitative studies Literature reviews Experimental design
Evaluation	Reports of parental experiences, views, attitudes, beliefs	
Research type	Qualitative, Mixed methods	Studies that do not report qualitative data collection and qualitative data

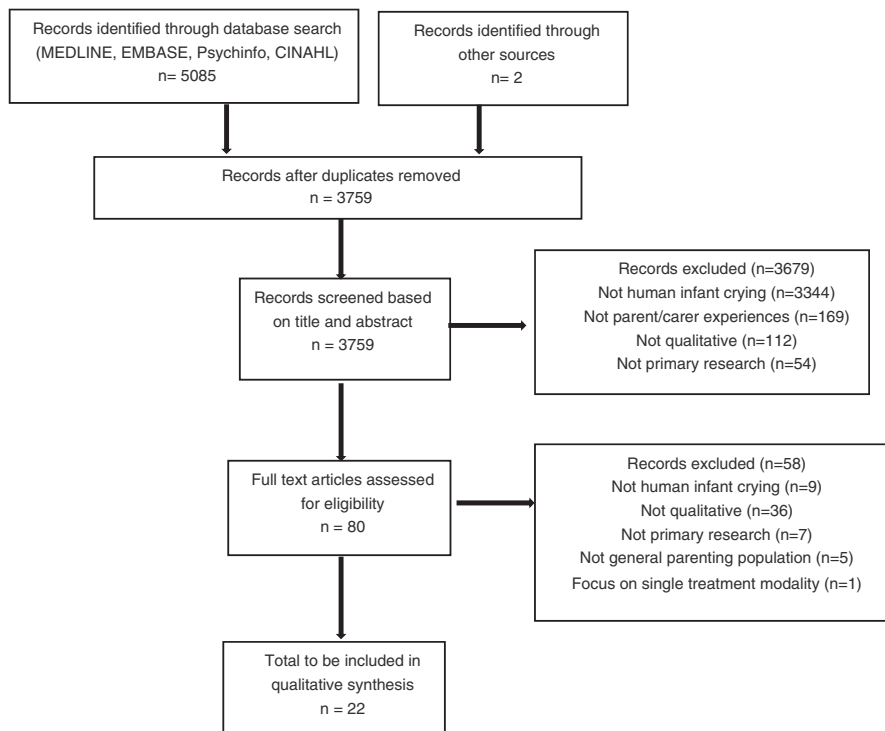


FIGURE 1 CONSORT diagram

## 4.2 | Thematic synthesis

Line-by-line coding generated descriptive themes, shown in Figure 2, which were then further developed into four overarching analytical themes: (1) Experiences and impact of crying. (2) Parental management strategies. (3) The role of health professionals. (4) The role of feeding/diet. The number of themes emerging from individual papers included in this review ranged from 2 to 9. None of the included papers covered all the themes identified in this review. Where findings emerged from largely one population, this is highlighted in the relevant section. See Table 3 for information on how the themes map to each paper.

### 4.2.1 | Experiences and impact of crying

All papers discussed parental experiences of infant crying and the impact it had on their lives. The impact of crying was described in terms of emotional impact, impact on relationships, and feeling anger towards the baby.

#### *Emotional impact of crying*

The vast majority of included studies reported accounts of parents experiencing significant emotional impact from infant crying (Cox & Roos, 2008; Ellett et al., 2009, 2005; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2014, 2010; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten & Miller, 2019; Poskey & Hersch, 2012; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005; Wiley

et al., 2020). The two included studies where this subtheme did not emerge focussed specifically on soothing techniques (Drummond et al., 1993) and dietary restrictions resulting from infant colic (Kidd et al., 2019). Parents described feeling worried, anxious, and distressed, and one study described a mother's experience of needing counselling to cope with the distress caused by her baby's colic (Ellett & Swenson, 2005). In most studies, parents also discussed exhaustion from lack of sleep (Cox & Roos, 2008; Drummond et al., 1993; Ellett & Swenson, 2005; Ellett et al., 2005, 2009; Kurth et al., 2010; Landgren & Hallstrom, 2011; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Thompson et al., 1986).

Both anger and frustration and also, partly, sadness came. So, yes, a combination of helplessness, sadness and pure rage and ... yes, madness. I am constantly furious (Landgren et al., 2012)

Tiredness. In your head. So much tiredness... When my husband came home yesterday, I sat with her in my arms, just crying. I had been crying since she stopped crying... I'm totally drained. (Landgren & Hallstrom, 2011)

All studies that described the emotional impact of crying reported parents experiencing feelings of frustration, failure, inadequacy and self-blame for being unable to soothe their baby and manage their crying (Cox & Roos, 2008; Ellett & Swenson, 2005; Ellett et al., 2005, 2009; Keefe & Froese-Fuetz, 1991; Kurth et al., 2014, 2010; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky

TABLE 2 Characteristics of included studies

No.	Authors (year)	Country	Participants (n)	Infant diagnostic label	Principle views/experiences explored	Method of data collection	Method of data analysis
1	Thompson et al. (1986)	USA	Parents and HCPs (50)	Colic—HCP diagnosed	The processes associated with infant colic in the family	Interview	Not given
2	Wiley et al. (2020)	USA	Parents (25)	None, parents of newborns	Parental perceptions of infant crying and abusive head trauma	Semi-structured interviews	Thematic analysis
3	Wade et al. (2005)	USA	Mothers (7)	None, mothers at risk of AHT	Impact of crying on mothers at high risk of abusing their child	Focus group	Phenomenological Approach
4	Landgren et al. (2012)	Sweden	Mothers (10) and fathers (7)	Colic—HCP diagnosed	Parents' experience of infant colic	Semi-structured interviews and a focus group	Content analysis
5	Cox and Roos (2008)	South Africa	Not given	Colic—HCP diagnosed	Experiences of first-time mothers with colicky infants	Semi-structured interviews	Thematic analysis
6	Drummond et al. (1993)	Canada	Mothers (19)	None, mothers of newborns	Views and understanding of infant crying and soothing	Semi-structured interviews	Thematic analysis
7	Kurth et al. (2010)	Switzerland	Mothers (15)	None, mothers of newborns	Mother's experiences and responses to infant crying	Semi-structured interviews, observation	Phenomenological Approach
8	Landgren and Hallström (2011)	Sweden	Mothers (12) and fathers (11)	Colic—HCP diagnosed	The meaning of being a parent of a colicky infant	Semi-structured interviews	Phenomenological approach
9	Megel et al. (2011)	USA	Mothers (13)	Persistent crying—parent report	Experiences of parenting an irritable infant	Semi-structured interviews	Grounded theory
10	Murray et al. (2018)	Vietnam	Mothers (21), grandmothers (3)	None, mothers of newborns	Caregivers' understanding of, and responses to, unsettled infant behaviour	Semi-structured interviews	Thematic analysis
11	Poskey and Hersch (2012)	USA	Mothers (3), fathers (3)	Inconsolable infant crying - parent report	Parental experience of infant crying	Semi-structured interviews	Thematic analysis
12	Poskey et al. (2014)	USA	Mothers (2), fathers (2)	Inconsolable infant crying—parent report	Parents' thoughts, feelings, behaviour and actions towards an inconsolable infant	Questionnaire, home observation	Ethnography
13	Ellett et al. (2009)	USA	Fathers (10)	Colic - parent report	Fathers' experiences living with colicky infant	Semi-structured interviews	Interpretive phenomenological analysis
14	Keefe and Froese-Fuetz (1991)	USA	Mothers (15)	Colic - HCP diagnosed	Experiences of mothers caring for an irritable infant	Unstructured interviews	Thematic analysis
15	Kidd et al. (2019)	Norway	Mothers (21)	Colic - parent report	Mothers' perceptions of the role of maternal diet on crying in infant	Semi-structured interviews and focus groups	Content analysis
16	Ellett et al. (2005)	USA	Parents (44)	Colic - parent report	Experiences living with colicky infant	Semi-structured interviews	Thematic analysis

(Continues)



TABLE 2 (Continued)

No.	Authors (year)	Country	Participants (n)	Infant diagnostic label	Principle views/experiences explored	Method of data collection	Method of data analysis
17	Nash et al. (2008)	UK	Mothers (22), fathers (2)	None, parents attending child health clinic	Views of the crying behaviour of infants	Semi-structured interviews	Thematic analysis
18	Kurth et al. (2014)	Switzerland	Mothers (15)	None, mothers of newborns	Views and experiences of first-time and experienced mothers of infant crying	Semi-structured interviews and observation	Phenomenological Approach
19	Long and Johnson (2001)	UK	Parents (25)	Excessive crying – parent report	Parental experience of coping with excessively crying infant	Semi-structured interviews and observation	Grounded theory
20	Ellett et al. (2005)	USA	Parents (15)	Colic – parent report	Perceptions of lasting effects of colic	Semi-structured interviews	Thematic analysis
21	Oaten et al. (2019)	UK	Mothers (6)	Excessive crying – parent report	Parental experience of coping with excessively crying infant	Semi-structured interviews	Thematic analysis
22	Levitzky and Cooper (2000)	USA	Mothers (23)	Colic – HCP diagnosed	The impact of infant colic on the emotional state of the mother	Structured interviews	Not stated

& Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten & Miller, 2019; Poskey & Hersch, 2012; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020).

Upset and angry with myself you know it's my fault I don't know it's just natural isn't it like any mother really don't know what to do. I just want to make him better – you know, stop him crying. (Nash et al., 2008)

It truly changed who I am. Life was guilt, anger, frustration, confusion, sadness, and the feeling of having been cheated. (Ellett et al., 2005)

In some studies, parents described how feelings of failure over time became feelings of hopelessness that the crying would ever improve, and helplessness that there was nothing they could do to improve it (Cox & Roos, 2008; Landgren et al., 2012; Oaten & Miller, 2019)

I felt that it would never end, the total utter helplessness to the point where you feel that you can't make this better and then losing hope that it would ever come to an end. (Cox & Roos, 2008)

#### Impact on relationships

A recurring theme across many studies was parents' descriptions of the adverse effect having a baby with excessive crying had on their relationships with their partners (Cox & Roos, 2008; Ellett et al., 2005, 2009; Kurth et al., 2014; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Murray et al., 2018; Oaten & Miller, 2019).

It's a loveless marriage with a relationship that won't exist until the crying stops, if even then, and we argue about it all the time. (Long & Johnson, 2001)

He is so angry. Every day it gets worse. It's killing us. If we had an easy baby, there would be no problem. (Levitzky & Cooper, 2000)

This was often discussed by mothers in relation to feeling alone and unsupported by their partners. A mother in one study (Cox & Roos, 2008) described how her husband's life remained largely unchanged as he was still able to socialize and go out as before whilst her life had been dominated by looking after a baby with colic.

Several papers discussed parents feeling like their parenting was being judged by others, including friends, family, and health professionals (Cox & Roos, 2008; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Oaten & Miller, 2019). This sometimes led to parents isolating themselves from unsolicited advice, negative comments, and perceived judgement. This often emerged as second-order constructs (Landgren et al., 2012; Levitzky & Cooper, 2000; Long

FIGURE 2 Overview of themes



& Johnson, 2001; Oaten & Miller, 2019), for example “Although there were examples of parents being explicitly accused of poor parenting practice, more often the feelings of guilt resulted from self-recrimination or perhaps from perceptions of external criticism” (Long & Johnson, 2001). However, feeling judged was also supported by first-order data excerpts from participants.

Then it's the comments from people, from the paediatrician to my friends. There were times when we went to visit them and looked exhausted, and they would say that you could take an antidepressant if YOU'RE not coping. You feel so frustrated because you're trying to explain that anyone in your situation wouldn't be coping (Cox & Roos, 2008).

The worst part is that everyone has something to try. And of course, it's stuff you have already tried, and you know it's not going to work. Finally, you just get tired of explaining it. (Megel et al., 2011)

In some studies, parents also discussed the negative impact infant crying had on the relationship with their child (Cox & Roos, 2008; Ellett & Swenson, 2005; Landgren & Hallström, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Megel et al., 2011; Oaten & Miller, 2019). This was usually a result of feeling like a failure and a bad parent or feeling rejected by the child.

I felt guilty and like a bad mother when I could not calm him down. I imagined that he did not love me and one day I told my husband that I was going to stop breastfeeding because the baby was just 'using me' and I wasn't going to let him do that. I immediately felt guilty and childish and, of course, did not stop breastfeeding. (Ellett & Swenson, 2005)

What are we doing wrong? My baby is telling me I'm not a good mother. (Megel et al., 2011)

#### *Anger towards baby*

Participants in nearly half of the included studies expressed feelings of anger and frustration towards their baby as a result of excessive crying (Cox & Roos, 2008; Ellett & Swenson, 2005; Kurth et al., 2010; Landgren et al., 2012; Levitzky & Cooper, 2000; Megel et al., 2011; Nash et al., 2008; Oaten & Miller, 2019; Poskey et al., 2014; Thompson et al., 1986).

There were moments when, both me and my husband ... when she was apoplectic and howling so much that I almost got this thought, 'now I'll take a pillow and put over her face just until she quiets down, until the screaming stops. (Landgren et al., 2012)

Some of the studies where parents expressed feelings of anger towards their child (Levitzky & Cooper, 2000; Nash et al., 2008; Poskey et al., 2014) specifically aimed to explore experiences and triggers to prevent abusive head trauma because of shaking the baby, which can have devastating outcomes. Some papers discussed how aggression can be induced by crying, maternal thoughts of harm and implication in the prevention of head trauma (Landgren et al., 2012; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020). The fantasies or thoughts of harm reported in these papers were all from parents of infants who have been labelled as having colic or inconsolable crying.

There were times when you want to throw him against the wall. (Cox & Roos, 2008)

In one paper, most parents said that they could not understand why someone would shake an infant (Wiley et al., 2020). However, this paper studied parents of infants that cried normally (convenience sample of parents of newborns), which could explain these differences.

She can cry for hours. I wouldn't shake her. I wouldn't be able to see myself shaking her. (Wiley et al., 2020)

TABLE 3 Themes identified in each study

Themes	Study reference																					
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
Experiences and impact of crying																						
Emotional impact on parents	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Impact on relationships	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Anger towards baby	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Parental management strategies	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Soothing techniques	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Parental coping strategies	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Need for social support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Normalizing crying	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
The role of health professionals	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Health professional support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Seeking a cure	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
The role of infant feeding and maternal diet	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Changes to maternal diet	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Pressure to stop breastfeeding	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

## 4.2.2 | Parental management strategies

### *Soothing techniques*

A range of consistently similar ways to manage crying was reported across the different papers. A common response was to pick the baby up when they were crying. Some papers also reported participants doing basic checks to interpret the reason for the crying or systematically working through potential soothing techniques to stop the crying (Cox & Roos, 2008; Drummond et al., 1993; Keefe & Froese-Fuetz, 1991; Kurth et al., 2014, 2010; Landgren & Hallström, 2011; Megel et al., 2011; Murray et al., 2018; Poskey & Hersch, 2012; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020).

I check to see if his diaper is wet, check to see if he is hungry, rub his back. Sometimes I give him a nice warm bath, I walk around with him ... I sing to him. (Poskey et al., 2014)

Other approaches to soothe a crying baby were feeding, auditory interventions such as singing or white noise and the use of movement (Drummond et al., 1993; Ellett et al., 2009; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Kurth et al., 2014, 2010; Landgren & Hallström, 2011; Megel et al., 2011; Murray et al., 2018; Poskey & Hersch, 2012; Poskey et al., 2014; Wade et al., 2005).

Potentially harmful strategies, such as medicating the baby with homeopathic pills or antihistamines, were reported by parents in one of the papers. (Ellett & Swenson, 2005).

### *Strategies to help parents cope*

Participants in most studies detailed a range of coping strategies they used to help them deal with the demands of their baby's crying (Drummond et al., 1993; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2010, 2014; Landgren & Hallström, 2011; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten & Miller, 2019; Poskey & Hersch, 2012; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020). Perhaps the most important was finding ways to block out the sound of crying, taking a break and safety planning. Parents in many studies described putting their baby down and physically walking away when they felt they were becoming too frustrated (Ellett et al., 2009; Kurth et al., 2010; Megel et al., 2011; Nash et al., 2008; Poskey & Hersch, 2012; Wiley et al., 2020).

For sanity's sake I'd just had to put him in his crib and walk away and kind of give myself a little time out to kind of get my breath. (Poskey & Hersch, 2012)

Other coping strategies included measures to directly calm themselves, such as driving (Poskey & Hersch, 2012), singing, smoking, taking anti-anxiety medication (Wade et al., 2005) and even boxing (Poskey & Hersch, 2012). Cognitive strategies included "keeping a stiff upper lip" and persevering (Wade et al., 2005).

Sometimes there is no one around; I just have to buck up and deal with it. (Wade et al., 2005)

One paper described how parents used self-talk, telling themselves over and over "it's only colic and it can't last forever" (Megel et al., 2011). Some parents also adapted their expectations of what being a parent would be like (Drummond et al., 1993; Kurth et al., 2010, 2014; Thompson et al., 1986). Considering the positives in the situation, such as feeling gratitude the baby was healthy, was another coping method in some papers (Drummond et al., 1993; Ellett & Swenson, 2005; Kurth et al., 2014; Thompson et al., 1986; Wade et al., 2005).

#### *Need for social support*

Participants in the majority of studies discussed the importance of social support for managing infant crying (Cox & Roos, 2008; Ellett et al., 2009; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Landgren & Hallström, 2011; Landgren et al., 2012; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten et al., 2019; Wade et al., 2005; Wiley et al., 2020).

You gotta have a support system, too, yep. I would, if something's wrong, that baby's crying, get some advice or something. Talk to someone a little more experienced than you are. (Wiley et al., 2020)

I had a great support system with friends and family, so people helped and cooked meals. (Cox & Roos, 2008)

Papers that mentioned parents who did not have social support indicated that these parents struggled (Ellett et al., 2005, 2009; Kurth et al., 2014; Poskey et al., 2014).

I basically had no help; I was on the verge of quitting everything. (Ellett et al., 2005)

Support from others was useful in multiple ways; it gave parents encouragement and advice, a chance for a break from their baby when people looked after them, and simply, a 'shoulder to cry on' (Cox & Roos, 2008; Ellett et al., 2005, 2009; Keefe & Froese-Fuetz, 1991; Landgren & Hallström, 2011; Landgren et al., 2012; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Nash et al., 2008; Oaten et al., 2019; Wade et al., 2005; Wiley et al., 2020).

Whilst social support was evidently important for participants of different cultures, some communities use it in different ways. Whilst in the studies from Europe most parents lived alone with their child, the Vietnamese study (Murray et al., 2018) showed how the intergenerational household context meant grandparents were not only a key source of information about unsettled infant behaviour but were very involved in daily infant care.

Maternal and paternal grandmothers have much experience, so they can soothe him better. (Murray et al., 2018)

#### *Normalizing crying*

Several papers reported that parents discussed what is, and what is not normal in terms of infant crying. Reasons given for normal infant crying were fatigue, hunger, pain and discomfort, prematurity, reflection of environment, the need for social interaction, and understanding that sometimes babies cry for unknown reasons (Cox & Roos, 2008; Ellett et al., 2009; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Kurth et al., 2010; Murray et al., 2018; Thompson et al., 1986).

I kept saying to people that it was because he was premature, this is normal and it will be fine (Cox & Roos, 2008)

In addition, some participants from Vietnam (Murray et al., 2018) had spiritual beliefs about why their babies cried.

It was believed that (...) babies may see or be unsettled by ghosts or ancestors that have passed away. (Murray et al., 2018)

Parents described how they interpreted their baby's cries, and reasons for the crying, and responded accordingly (Cox & Roos, 2008; Ellett et al., 2009; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Kurth et al., 2010, 2014; Landgren & Hallström, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Murray et al., 2018; Nash et al., 2008; Poskey & Hersch, 2012; Thompson et al., 1986; Wade et al., 2005; Wiley et al., 2020).

In many of the papers, parents' responses were described as being based on characteristics of the crying (Cox & Roos, 2008; Ellett et al., 2009; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Kurth et al., 2010; Landgren et al., 2012; Levitzky & Cooper, 2000; Murray et al., 2018; Nash et al., 2008; Wade et al., 2005; Wiley et al., 2020).

In the beginning it always sounded the same when she was crying. Then I realised she cries differently if she needs to burp or if her nappy is full. I didn't think you could distinguish this, but in fact you can. (Kurth et al., 2014)

Some parents discussed their belief that their infant's crying was not normal, and they believed there was an underlying pathology causing their excessive crying. Parents' search for a diagnosis or cure is discussed later in this paper. Many papers mentioned that parents often believed abnormal crying was caused by something they did wrong, which caused the parents' emotional distress (Ellett et al., 2005, 2009; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2010; Landgren & Hallström, 2011; Murray et al., 2018; Nash et al., 2008; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005).

It's like, what's wrong with me or my kid? Why is it this way? Why can't I quiet this baby? (Keefe & Froese-Fuetz, 1991)

This belief that crying was due to something the parents did arose from parents in almost all papers. Parental beliefs about why they were unable to soothe the baby included 'bad parenting', and parents often believed that personal factors, such as maternal stress or anxiety, caused the crying (Ellett et al., 2005, 2009; Ellett & Swenson, 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2010; Landgren & Hallström, 2011; Murray et al., 2018; Nash et al., 2008; Poskey et al., 2014; Thompson et al., 1986; Wade et al., 2005). Some papers also reported that the belief crying represented an underlying pathology was more common in inexperienced parents than those that had experience (Ellett & Swenson, 2005; Kidd et al., 2019; Kurth et al., 2014; Thompson et al., 1986): As one author described, "in contrast to first-time mothers, experienced mothers understood that all infants had 'uneasy phases' and were not always happy. Inexperienced mothers tended to interpret crying as a sign of alarm" (Kurth et al., 2014). Participants in several papers discussed the role of maternal diet and infant feeding. This is explored in theme four of the current paper.

#### 4.2.3 | The role of health professionals

##### *Health professional support*

In many studies, parents described consulting health professionals for their infant's crying, often for support and reassurance that there are no serious underlying issues and that parenting factors are not to blame (Cox & Roos, 2008; Ellett et al., 2005, 2009; Kidd et al., 2019; Kurth et al., 2010; Landgren & Hallström, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Oaten et al., 2019; Thompson et al., 1986; Wade et al., 2005). Parents in a few studies described feeling listened to, felt the health professional understood their situation and had reported having helpful experiences (Cox & Roos, 2008; Ellett et al., 2005; Landgren & Hallström, 2011; Long & Johnson, 2001; Oaten et al., 2019).

He actually listened to me and expressed concern about her colic. He gave us literature on ways to try and calm her down and reasons they believe she is this way. I left the office feeling reassured. She was going to be fine. It was just going to take some time. (Ellett et al., 2005)

Parents' descriptions of positive experiences of health professional support included health visitors (Long & Johnson, 2001; Oaten et al., 2019), midwives (Cox & Roos, 2008), nurses (Landgren & Hallstrom, 2011) and paediatricians (Ellett et al., 2005) and were described as having someone who understands what you are going through, was willing and able to listen and 'hold your hand'. Parents from the UK (Long & Johnson, 2001; Oaten et al., 2019) particularly valued health visitor support and felt they were able to provide helpful information and reassurance.

What helped was my midwife. Although I'm a logical person, when you're so sleep deprived, you can't

even think for yourself; you need somebody literally to hold your hand. (Cox & Roos, 2008)

My health visitor was brilliant. I mean, as far as they can do. They can only offer to listen to you, but that made such a change. She would listen all day if I carried on. (Long & Johnson, 2001)

However, most studies where parents went to health professionals reported that parents felt dismissed, unsupported or did not receive the information they were looking for (Ellett et al., 2005; Keefe & Froese-Fuetz, 1991; Kurth et al., 2010; Landgren & Hallström, 2011; Megel et al., 2011; Thompson et al., 1986; Wade et al., 2005). As one study author describes "one mother spoke of how, after a few office visits with her colicky infant, her paediatrician started relaying information through the office staff, leaving the mother with the impression that she was an annoyance" (Levitzky & Cooper, 2000)

The nurse said it was normal for babies to cry. She said that colic cannot start as early as the fifth day. But my child did have colic that early, so that was our reality. (Landgren et al., 2012)

##### *Seeking a cure*

More than half of included papers described parents' search for a treatment or cure for their child's crying (Cox & Roos, 2008; Drummond et al., 1993; Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Landgren & Hallström, 2011; Landgren et al., 2012; Long & Johnson, 2001; Megel et al., 2011; Murray et al., 2018; Oaten et al., 2019; Poskey et al., 2014; Poskey & Hersch, 2012; Thompson et al., 1986). Papers that did not discuss seeking a cure were mostly in populations of parents with normal crying infants (Kurth et al., 2010, 2014; Nash et al., 2008; Wade et al., 2005; Wiley et al., 2020). Papers with colicky infants where a cure was not discussed were mostly from one author and specifically focussed on the impact of crying (Ellett et al., 2005, 2009; Ellett & Swenson, 2005; Levitzky & Cooper, 2000).

Parents demonstrated desperation for a treatment or cure and talked about trying various medications, feeding approaches and alternative therapies.

We started our cycle of chiropractors, reflexologists, homeopaths, medication for reflux; we changed his formula a hundred times; we have a hundred bottles, a hundred teats; it was this desperate clinging to something (Cox & Roos, 2008)

You try anything. If anybody can give you a bit of advice that you think you can use, anything at all, you do it. Problem is, of course, none of it works and you're left no better off, maybe a bit poorer, and sometimes it may even seem worse than before. It, like, knocks you back when you build up your hopes and then it doesn't work (Long & Johnson, 2001)



Participants also described their need for more information about infant crying. A few studies specifically described that parents need information about potential reasons for infant crying, and ways of managing it (Drummond et al., 1993; Ellett et al., 2009; Poskey et al., 2014). In one study of parents at risk of abusive head trauma (Wade et al., 2005), a parent disclosed having information about infant crying early on would have enabled them to prepare better and may have affected their decision to have a baby.

I think what would help people, especially who haven't had kids before, is more talk about it in the hospital (...) it's touched on in books (...) they don't really address it (...) I just don't think there's enough awareness... or warning about it. (Ellett et al., 2009)

A parent in one study (Landgren & Hallstrom, 2011) also described searching for information online and feeling like they knew more about colic than the health professionals they were consulting.

I have often felt that I know more than them, at [child health clinic]. They say the same things that they have said for years. I have found new information on the internet, new since my first child had colic six years ago. (Landgren & Hallstrom, 2011)

Seeking a cure or treatment was less likely to emerge from studies where parents did not report a diagnostic label such as colic or excessive crying.

#### 4.2.4 | The role of infant feeding and maternal diet

##### *Changes to maternal diet*

Five papers discussed the belief that maternal diet can cause excessive crying in breastfed babies due to dietary intolerances causing abdominal discomfort and pain (Kidd et al., 2019; Landgren & Hallström, 2011; Levitzky & Cooper, 2000; Megel et al., 2011; Thompson et al., 1986). Babies in all these studies were labelled as having colic or excessive crying. In two papers (Landgren & Hallström, 2011; Thompson et al., 1986), the influence of maternal diet on infant crying emerged only as recommendations from the authors rather than participants. For example, "To gain trust, nurses should give evidence-based recommendations, like recommending systematic exclusion of cow's milk protein for 5 days as this intervention relieves the symptoms in 5–25% of babies with colic. By guiding parents how to find food for the breastfeeding mother, and formulas free from cow's milk for the bottle-fed baby, the nurse can make this intervention manageable" (Landgren & Hallstrom, 2011).

In one study (Levitzky & Cooper, 2000), authors described how parents' beliefs and concerns about the impact of maternal diet on infant crying were a result of questioning and advice from health professionals. The authors state "Continuous questions by the pediatrician about the nursing mother's diet often led mothers to believe

that their food selection affected the breast milk and therefore caused their infants pain. This compounded mothers' concerns that they were 'spoiling' their milk and making their babies sick" (Levitzky & Cooper, 2000).

Data from participants discussing changes to the maternal diet in response to infant crying was only briefly mentioned in one paper (Megel et al., 2011) and extensively discussed in a paper published in 2019 (Kidd et al., 2019), suggesting this concern may be a more recent phenomenon.

The only thing I could have was meat, potatoes, and Italian bread. (Megel et al., 2011)

I have cut out dairy. I have cut out all gassy vegetables and gassy fruits (...) caffeine, and carbonated beverages. Eggs, and, of course, butter. (Kidd et al., 2019)

Parents of formula-fed infants in two papers discussed changing their baby's formulas as a strategy to reduce colic or persistent crying (Cox & Roos, 2008; Megel et al., 2011).

We changed his formula a hundred times; we have a hundred bottles, a hundred teats; it was this desperate clinging to something (Cox & Roos, 2008)

##### *Pressure to stop breastfeeding*

Parents of breastfed babies talked about feeling pressured to stop breastfeeding (Keefe & Froese-Fuetz, 1991; Kidd et al., 2019; Megel et al., 2011; Murray et al., 2018). Often this pressure came from family members suggesting that the baby was crying because breastmilk was insufficient.

Even my husband was like, "Seriously now, when are we going to have that conversation about you not breastfeeding anymore?... I am serious. When are we going to stop hearing a screaming baby? When are we going to get him on formula? (Kidd et al., 2019).

There was also a belief that feeding infants formula milk instead of breastmilk will help them sleep for longer (Kidd et al., 2019; Murray et al., 2018)

He was breastfed for two hours, but he was still crying. I didn't know how to stop his crying, meanwhile two grandmothers were convincing me that feeding him with formula milk can help him fall asleep. I did and still feel regret about that (Murray et al., 2018).

## 5 | DISCUSSION

This evidence synthesis reveals the complexity and multifaceted impact of infant crying. The review highlights the wide range of

management techniques and coping strategies parents use to deal with infant crying and the importance of social and health professional support. Findings show that parents often have difficulty interpreting why their infant is crying and suspect an abnormal cause, which may lead to overmedicalization. Included studies suggest that a lack of understanding about normal crying often led to intense emotional stress, which had adverse consequences such as social isolation (Cox & Roos, 2008; Ellett et al., 2005, 2009; Keefe & Froese-Fretz, 1991; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Megel et al., 2011; Oaten & Miller, 2019; Poskey, 2012), exhaustion (Cox & Roos, 2008; Ellett et al., 2005, 2009; Kurth et al., 2010; Landgren & Hallstrom, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Long & Johnson, 2001; Nash et al., 2008; Oaten & Miller, 2019; Thompson, 2009) and depression (Ellett et al., 2009; Poskey, 2012; Keefe & Froese-Fretz, 1991; Levitzky & Cooper, 2000). These findings are consistent with a previous literature review of mostly quantitative literature focussing on the consequences of excessive infant crying, which found it to be harmful to relationships and health (Botha et al., 2019). This current review synthesized the qualitative literature and identified parental experiences that go beyond the impact of excessive crying, such as management strategies, the role of health professionals and other support needs and parental help-seeking behaviours.

Participants in nearly all the papers believed that their child's crying was in some way their fault. They also discussed the importance of social support to help them through that challenging time, yet many parents described feeling judged by others and several paper authors reflected that parents isolate themselves from their social networks in response to unsolicited advice and negative comments. Arming parents with information and coping strategies to respond to perceived judgement may help build and maintain support networks.

Many families described desperately seeking a cure and often consulted health professionals repeatedly for help and support. Findings showed that many parents found their experiences with healthcare professionals to be unhelpful. Parents who reported positive experiences with health professionals valued physical examination of their baby to provide reassurance and rule out underlying causes. Parents also valued feeling understood and listened to by health professionals and being given advice on coping strategies as well as signposting to resources for further support (Cox & Roos, 2008; Ellett et al., 2009; Keefe & Froese-Fretz, 1991; Landgren & Hallstrom, 2011; Landgren et al., 2012; Long & Johnson, 2001; Megel et al., 2011; Oaten & Miller, 2019).

This review identified beliefs about the impact of maternal diet and infant feeding on excessive crying, considering parental views, and the role of health professionals and other family members. The current findings suggest beliefs that breastmilk is insufficient or harmful to their baby undermines confidence in breastfeeding for parents, families and health professionals. Similar findings were reported in a systematic review of barriers and facilitators to breastfeeding in the first 6 months of life, which found perceptions of insufficient breastmilk to be a significant barrier to exclusive

breastfeeding (Balogun et al., 2015). Interestingly, the influence of maternal diet and infant feeding on infant crying was rarely a focus in the qualitative literature and was only discussed by participants in a small minority of papers. Future research is needed to further explore parental beliefs and experiences related to diet and infant crying.

Frustration caused by crying was found to sometimes lead to feelings of anger and sometimes violent intrusive thoughts directed towards the infant (Cox & Roos, 2008; Ellett & Swenson, 2005; Kurth et al., 2010; Landgren et al., 2012; Levitzky & Cooper, 2000; Megel et al., 2011; Nash et al., 2008; Oaten & Miller, 2019; Poskey et al., 2014; Thompson et al., 1986). Current findings further our understanding of how parents experience and manage their frustration, particularly in safety planning, but it does not suggest ways to identify those parents at risk and further research is needed in that area.

Parents' views of crying and ways of managing it were similar across papers despite the different cultural and healthcare contexts of included countries, suggesting a degree of universality across cultures when responding to infant crying. Labels used to describe infant crying ranged across the studies and included 'colic', 'persistent crying', 'inconsolable crying' and 'excessive crying'. Interestingly, in papers where 'colic' was used to describe their participants' infants, this was based on health professional diagnosis by all but one author (Cox & Roos, 2008; Keefe & Froese-Fuetz, 1991; Landgren & Hallström, 2011; Landgren et al., 2012; Levitzky & Cooper, 2000; Thompson et al., 1986). Studies that described infant crying as 'persistent', 'inconsolable' or 'excessive' were based on parent self-report (Long & Johnson, 2001; Megel et al., 2011; Oaten et al., 2019; Poskey et al., 2014; Poskey & Hersch, 2012). Most themes arose across all populations, irrespective of the diagnostic label, suggesting the findings are relevant to all parents/carers who consider their infant's crying problematic.

Included studies focused on different samples of participants, such as fathers, grandmothers, and low-income mothers. These were only a small proportion of the pooled sample with a total of three grandmothers included and seven mothers identified as low-income. Most included studies did not report the ethnic background of participants and it was not possible to explore how experiences may have differed specifically for fathers, grandparents, low-income families, or ethnic minority groups. Furthermore, all participants were biologically related to the infants and may not reflect the experiences of alternative family structures. This review focussed on a generalized population of parents so findings may not apply to populations such as parents with mental health conditions.

## 6 | CONCLUSION

Infant crying has a major impact on families. Parents use a range of strategies to interpret and deal with the challenges of infant crying, but there is a large unmet need for better resources and support for parents living with excessive infant crying. This review can help

health professionals understand the complexity and impact of living with infant crying. Health professionals could support families by ensuring their concerns are listened to and where possible providing reassurance or appropriate diagnoses. Greater awareness of the impact of infant crying such as emotional stress, social isolation, undermined confidence in breastfeeding and feelings of anger and intrusive thoughts could help health professionals provide better and more targeted support and advice when needed. Parents are often desperate for reliable information or a treatment/cure and this needs to be managed with evidence-based advice and acknowledgement of the impact infant crying can have.

Understanding that parents often feel to blame for their infant's crying may also help health professionals structure supportive discussions. Little is known about the potential effects infant crying may have on parent-child bonding or the impact of dietary modifications or other interventions made in response to infant crying. Further research is needed to explore these potential impacts. Further research is also needed to identify parents in need of support and to find how and when families could be best supported with infant crying.

#### AUTHOR CONTRIBUTIONS

M.S., J.M., I.M. and D.G. made substantial contributions to the conception and design of the study. All authors contributed to the acquisition, analysis and interpretation of data. All authors were involved in drafting the manuscript and revising it critically for important intellectual content. All authors also gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

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#### CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

#### PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15492>.

#### DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# Patient-mediated interventions in hospital: A systematic review

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## Abstract

**Aims:** To describe the characteristics of hospital-based, patient-mediated interventions and their impact on patient, clinician and organization outcomes.

**Design:** Systematic review.

**Data Sources:** Health literature databases (MEDLINE, CINAHL and EMBASE) were searched in August 2021. Backward and forward citation searching was conducted.

**Review Methods:** Studies investigating patient-mediated interventions, targeted at adult hospitalized patients were eligible. Data were extracted related to study and intervention characteristics. Narrative synthesis was used to understand intervention impact on patient, clinician and organization outcomes (as per a framework). Methodological quality was assessed using the Mixed Methods Assessment Tool.

**Results:** Thirty-three studies, reporting 18 interventions, were included. Twelve interventions prompted patients to report health information about their own health/needs/concerns and six interventions encouraged patients to provide feedback about clinical practice. Across all interventions, there was evidence that patients used patient-mediated interventions and that they may improve patient communication. Healthcare professional outcomes were mixed for actual/intended use, acceptability and usefulness of interventions; yet there was some evidence of healthcare professional behaviour change. Interventions that encouraged patients to report health information about their own health/needs/concerns appeared more successful than other types of interventions.

**Conclusions:** There is some evidence that hospital-based patient-mediated interventions may influence patient communication and healthcare professional behaviour. Patient-mediated interventions that encourage patients to report patient data before a clinical encounter may be more impactful than interventions that encourage patient feedback during or post-encounter.

**Impact:** To date, most patient-mediated intervention research has been conducted in primary care settings; we uncovered the types of patient-mediated interventions that have been trialled in hospitals. We found that patient communication and healthcare professional behaviour may be influenced by these patient-mediated interventions. Future researchers could explore the suitability and effectiveness of a wider range of hospital-based patient-mediated interventions.



**No patient or public contribution:** There was no funding to remunerate a patient/member of the public for this review.

#### KEYWORDS

change management, health personnel, nurses, patient education as topic, patient engagement, patient participation, patient-mediated, professional practice, quality of health care, systematic review

## 1 | INTRODUCTION

Hospitals are facing a 'serious crisis' in improving health outcomes because 40% of patients do not receive evidence-based care (Banner et al., 2019). Poor research utilization adds to the billions of dollars of health and medical research funding wasted annually (Glasziou & Chalmers, 2018) and can contribute to variability in patient care. Barriers to evidence-based practice (EBP) of nurses and allied health professionals in hospitals include lack of authority to change practice (Tuppal et al., 2019), lack of awareness around research, and lack of time (Cardin & Hudson, 2018). Finding ways to embed high-quality evidence into healthcare professionals' work is a major challenge (Grimshaw et al., 2012). Interventions to enhance healthcare professional use of EBP have largely focussed on targeting healthcare professionals to directly influence healthcare professional behaviour (Foy et al., 2015; Johnson & May, 2015).

Patient engagement is the new frontier for translating research into practice. Internationally, healthcare policies advocate patient engagement as a strategy to increase healthcare safety and quality (Longtin et al., 2010). Patient engagement can range from involvement in direct care delivery to involvement in policy-making and research (Carman et al., 2013; McCarron et al., 2021). The emerging benefits of patient engagement include enhanced care, improved service delivery and changes in staff culture (Bombard et al., 2018).

Patient-mediated interventions can promote patient engagement, while also influencing healthcare professional uptake of EBP. Straus et al. (2013) define these as interventions that are targeted at patients but aim to change healthcare professionals' behaviour, and ultimately patient outcomes, through patient-provider interaction. Patient engagement strategies and interventions for hospitalized patients are being published at an increased rate since 2008 (Tobiano et al., 2021), providing an extensive evidence base for identifying patient-mediated interventions.

## 2 | BACKGROUND

Previous literature reviews suggest that patient-mediated interventions may help improve patient outcomes and professional practice, but more research is needed to determine the impact of these interventions on patient and healthcare professional communication, adverse events and resources (Fønhus et al., 2018). There is evidence that patient-mediated interventions improve physician performance

and test ordering behaviours (French et al., 2010; Oxman et al., 1995) and may also positively influence patients, including increased patient satisfaction, knowledge, decision-making, communication and behaviour (Gagliardi et al., 2016). However more evidence of effectiveness is required, as other reviews show that outcomes of patient-mediated intervention are mixed (Ng & Gagliardi, 2018; Oxman et al., 1995) and that the evidence base is of low-moderate quality (Gagliardi et al., 2016). Reviews of patient-mediated interventions have predominantly included studies in primary, specialist, community or hospital outpatient settings, whereas reviews of hospital setting patient-mediated interventions are scarce (Fønhus et al., 2018; Gagliardi et al., 2016). In a review that focussed on patient-mediated interventions to improve prescriber behaviour in the hospital setting, only one patient-mediated intervention was found, which was bundled with other interventions, and was found to be ineffective (Brennan & Mattick, 2013). Given the imperative to enhance patient engagement in hospitals and support evidence-based practice of health professionals, the rise of patient-mediated interventions in hospitals is timely to increase uptake of EBP.

## 3 | THE REVIEW

### 3.1 | Aims

The aim of this review was to describe the characteristics of hospital-based patient-mediated interventions and their impact on patient, clinician and organization outcomes.

### 3.2 | Design

This systematic review was conducted and reported per the Preferred Reporting Items for Systematic Reviews (PRISMA) criteria. The systematic review protocol is published online through PROSPERO (registration number: CRD42020173157).

### 3.3 | Search methods

#### 3.3.1 | Information sources

Databases searched included MEDLINE, CINAHL and EMBASE. After the health literature database search occurred, reference

lists of included studies were searched to identify other eligible studies. Forward citation searching was undertaken in Scopus to identify any additional studies that had cited any of the included studies. Grey literature was not included as it is not subject to peer-review processes characterizing publication in scientific journals (Lawrence et al., 2014), and methodological descriptions that facilitate quality appraisal are usually missing in grey publications (Adams et al., 2017).

### 3.3.2 | Search

The search strategy was developed collaboratively by an expert health librarian (ST) and the author team. The author team had content expertise in the development and implementation of interventions for hospitalized patients and patient engagement; and had previously worked as healthcare professionals in hospitals. The full search strategies are provided in Appendix File 1. Subject headings and keywords were initially identified from Fønhus et al.'s (2018) review and expanded using authors' expertise. Working with a librarian experienced in developing and managing searches for systematic reviews, a search strategy was built to cover the following concepts: setting (hospitals), a range of healthcare professionals, patient-mediated intervention process (patient engagement) and patient-mediated intervention intent (changing healthcare professional behaviour). The search was conducted on 6 August 2021. One author conducted the search (GT) and exported search results to Endnote (Clarivate, 2022).

### 3.3.3 | Eligibility criteria

Inclusion criteria were studies investigating patient-mediated interventions, targeted at adult hospitalized patients (aged  $\geq 18$  years). Given intervention developers are not fully aware of what constitutes patient-mediated interventions, and the historical lack of clarity around taxonomies (Ng & Gagliardi, 2018), many published accounts of patient-mediated interventions did not explicitly use the terminology 'patient-mediated' and we did not require that this term be explicitly used. Determination of whether an intervention was patient-mediated was undertaken by the author team, based on the definition by Straus et al. (2013). No restrictions were placed on research design or study type; however, systematic reviews, editorials, descriptions of interventions (with no empirical data), methodological papers, abstracts, dissertations, case studies and protocols were excluded. Studies were excluded if they targeted patients who were pregnant and/or children. Studies were excluded if published in a language other than English or if they were published prior to 2010, as we sought contemporary literature, recognizing that approaches to patient-centred care have evolved considerably in the last decade (Castro et al., 2016). Specifically, literature from 1 January 2010 to 6 August 2021 were included.

### 3.3.4 | Study selection

Duplicate studies were removed in Endnote (Clarivate, 2022) before importing these studies into Rayyan for screening (Ouzzani et al., 2016). Pairs of authors (AM & ST, RM & SR, GT & CT) independently screened the title and abstract of studies against inclusion and exclusion criteria. Full-text papers were retrieved when the study met the inclusion criteria or where authors were unsure of inclusion and were screened by the same pairs of authors against the same criteria. Disagreements were resolved through consensus discussions and adjudicated in team meetings with all team members present, to ensure consistency across teams.

### 3.3.5 | Data extraction

A data extraction form was developed, containing two sections. In section one, study characteristics were extracted, including author, year, country, setting, design, methods, sample and participants. In section two, intervention characteristics were captured. These data points were guided by the template for intervention description and replication (TIDieR) checklist (Hoffmann et al., 2014). Additionally, interventions were categorized as per Fønhus et al.'s (2019) types of patient-mediated interventions (see Table 1). One author independently extracted data (GT, SR, RM, TJO and CT). A second author checked data extraction for accuracy (GT, SR, RM and TJO). Data extraction tables showing characteristics of studies and the patient-mediated interventions were summarized in text to provide descriptions and further understanding.

### 3.3.6 | Summary measures

A comprehensive list of outcomes of patient-mediated interventions was identified using Gagliardi et al.'s (2016) framework and Fønhus et al.'s (2018) descriptions, which included patient outcomes and healthcare professional and organizational outcomes (see Table 2). One author independently coded all outcomes against the list of outcome measures and provided valence (i.e. positive, mixed or negative) for the outcomes (GT, SR, RM, TJO and CT); a second author checked these for accuracy (GT, SR, RM and TJO).

## 3.4 | Quality appraisal

We originally planned to undertake a risk of bias assessment, however, the heterogeneity of study designs did not allow this, so we used the Mixed Methods Assessment Tool (MMAT) for quality assessment (Hong, Fàbregues, et al., 2018). This tool enables critical appraisal of diverse study designs and has demonstrated validity and reliability (Hong, Fàbregues, et al., 2018). Each study design (qualitative, quantitative randomized control trial, quantitative non-randomized, quantitative descriptive and mixed methods) has five

TABLE 1 Fønhus et al.'s (2019) types of patient-mediated interventions

Intervention type	Fønhus et al.'s (2019) definitions of different types of patient-mediated interventions	An example
1	"Patient-reported health information about own health/needs/concerns or other relevant outcomes (collecting information from patients and giving it to professionals before, or during a clinical encounter)" (Fønhus et al., 2019, pp. 476)	"The patient or carer completes a questionnaire or form in the waiting area before a consultation. The doctor is then given this information before or during the consultation" (Fønhus et al., 2019, pp. 476)
2	"Patient feedback about clinical practice (collecting information from patients after an encounter)" (Fønhus et al., 2019, pp. 476)	"After the patient has used a healthcare service, she might be asked about her experience with the service or doctor. This information is then fed back to the doctors and/or hospital" (Fønhus et al., 2019, pp. 476)
3	"Patient information where patients are informed about recommended care" (Fønhus et al., 2019, pp. 476)	"The patient is given a brochure with information about cancer screening" (Fønhus et al., 2019, pp. 476)
4	"Patient education/training/counselling to increase patients' knowledge about their condition" (Fønhus et al., 2019, pp. 476)	"The patient signs up for a group based self-management program where she is provided with information about her condition and becomes part of a patient group for sharing of experiences to increase self-efficacy and coping" (Fønhus et al., 2019, pp. 476)
5	"Patient decision aids to ensure that the choices about treatment and management reflect recommended care and the patients' values and preferences" (Fønhus et al., 2019, pp. 476)	"The patient is provided with information about treatment options including risks and benefits. The patient considers this information, either alone or with a healthcare professional, to reach a decision in accordance with her values and preferences" (Fønhus et al., 2019, pp. 476)
6	"Patients, or patient representatives, being members of a committee or board" (Fønhus et al., 2019, pp. 476)	"A patient representative from a patient organization is, on behalf of a patient group, part of a hospital board. The board may discuss patient care and make decisions about professional practice within the hospital" (Fønhus et al., 2019, pp. 476)
7	"Patient-led training or education of healthcare professionals" (Fønhus et al., 2019, pp. 476)	Patients taking part in training of doctors, e.g. to improve communication skills, how to perform physical examinations or the importance of certain clinical procedures" (Fønhus et al., 2019, pp. 476)

Note: For further details about each type of intervention, please see: Fønhus, M.S., Dalsbø, T.K., Johansen, M., et al. (2019). Patient-mediated interventions to improve professional practice: A summary of a Cochrane systematic review. *Patient Education and Counselling*, 102, 474–485. <https://doi.org/10.1016/j.pec.2018.10.022>.

different questions relevant to their design, which are scored 'yes', 'no' or 'cannot tell'. The MMAT provides a descriptive summary of which questions often perform well across studies with the same

design. The MMAT creators discourage MMAT users from creating an overall score for each individual study by totalling how many questions scored 'yes'. For example, users can state that for all qualitative

**Outcomes as defined by  
Gagliardi et al. (2016) and  
Fønhus et al. (2018)**

**Examples of outcomes**

**Patient outcomes**

- Satisfaction with information
- Decision-making
- Communication
- Acceptability
- Perceived usefulness
- Knowledge
- Lifestyle behaviour intent/compliance
- Symptom severity/control
- Health outcomes [i.e. pain control, functional ability]
- Positive relationship with healthcare professionals
- Intended/actual use of patient-mediated intervention

**Healthcare professional and  
organizational outcomes**

- Adherence to recommended clinical practice or clinical practice guidelines by healthcare professionals
- Acceptability
- Perceived usefulness
- Knowledge
- Communication
- Positive relationships with patients
- Satisfaction
- Intended/actual use of patient-mediated intervention
- Health service use
- Documentation

**TABLE 2** Patient-mediated intervention outcomes as per Gagliardi et al.'s (2016) framework and Fønhus et al.'s (2018) descriptions

studies, question #1 frequently scored 'yes', however, they could not say that a single qualitative study scored 5/5 (i.e. scored 'yes' for all questions). Studies with different designs are not compared directly as they have different questions. One author and another researcher independently conducted quality appraisal (GT, SJ), and then met and discussed discrepancies. A third author adjudicated any discrepancies that could not be resolved (AM).

### 3.5 | Synthesis

Meta-analysis was not possible due to heterogeneity in study designs, types of interventions and outcomes reported. A narrative-synthesis was undertaken using Popay et al.'s (2006) guidance. Narrative synthesis enables understanding of intervention effects (Popay et al., 2006). In step 1, we developed a 'preliminary synthesis' focussing on the direction of intervention effects reported. We used two tools for preliminary synthesis: 'grouping' and 'tabulating' (Popay et al., 2006). Similar interventions were grouped together, which made synthesis of the large number of studies more manageable. For example, all of the Tell-us cards interventions were grouped together (see Appendix S2). Next, outcomes of studies were displayed visually in tables. Results were transformed into a common rubric to allow comparison using the valence (positive, mixed or negative results) of outcome measures based on Gagliardi et al.'s (2016) framework and Fønhus et al.'s (2018) descriptions. Grouping and tabulating study results aided the process of looking for patterns across similar interventions that were grouped together. Descriptive summaries of the grouped and tabulated outcomes are provided in Appendix S2.

In step 2 of the narrative synthesis we 'explored relationships' across interventions, to find factors that might explain differences in the direction of effect across interventions (Popay et al., 2006). We used two tools for exploring relationships: 'conceptual models' and 'graphs' (Popay et al., 2006). For conceptual models, the lead author drew diagrams that linked extracted data (study and intervention characteristics) and preliminary synthesis findings for each intervention. Next, 'graphing' occurred using spider graphs to verify and present these results. The previously tabulated outcomes from Step 1 of the narrative synthesis (see the table in Appendix S2) were summed. The total positive, mixed and negative outcomes from type 1 and type 2 patient-mediated interventions were summed separately to allow comparison at a higher level. Further, patient outcomes and healthcare professional/organizational outcomes were summed separately to allow comparison. These summations were presented as spider graphs. Spider radar graphs provided comparisons of the frequency of outcomes reported and the directions of these outcomes.

## 4 | RESULTS

### 4.1 | Search outcome

A total of 6245 studies were retrieved from health literature databases, of which 31 had full-text review, and 13 were included. 701 studies were screened via backward and forward citation searching; 20 were included. Hence, a total of 33 studies were included in this review (see Figure 1). Across these 33 studies, there were 18 interventions, as some groups of authors published multiple studies about the same intervention.

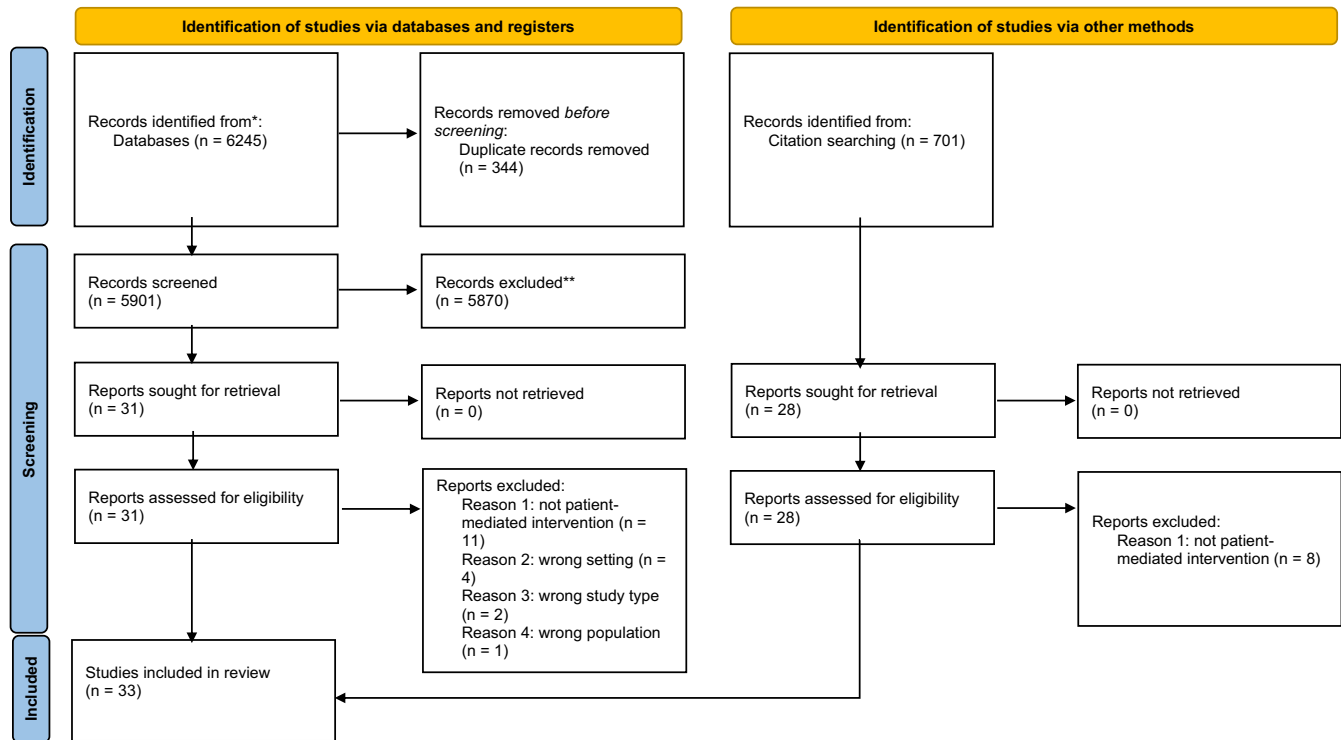


FIGURE 1 PRISMA flowchart (Page et al., 2021).

## 4.2 | Study characteristics

Most studies were conducted in Europe ( $n = 15$ ), followed by United Kingdom ( $n = 7$ ), Canada ( $n = 5$ ), United States of America (USA) ( $n = 3$ ) and Asia (China, Saudi Arabia, Singapore) ( $n = 3$ ; see Table 3). Two studies were conducted in both USA and Saudi Arabia. Studies were conducted across 1–33 hospitals (median = 1; IQR = 2.25). Most studies were conducted across a range of hospital inpatient units or the units were not explicit ( $n = 11$ ). However, some studies were more specialized, targeting medical/surgical units ( $n = 8$ ), inpatient cancer units ( $n = 8$ ), palliative care units ( $n = 4$ ), and emergency departments ( $n = 2$ ). Study designs employed included randomized control trials ( $n = 5$ ), quasi-experimental ( $n = 4$ ), multi-methods including both qualitative and quantitative design ( $n = 1$ ), qualitative ( $n = 13$ ), pre-/post-evaluation ( $n = 3$ ), mixed methods ( $n = 4$ ), cohort design ( $n = 1$ ) and cross-sectional quantitative design ( $n = 2$ ). In terms of evaluating the interventions, nine included studies had patients as participants, 14 studies had staff as participants, and 10 studies had both patient and staff participants.

## 4.3 | Intervention characteristics

Across the 18 interventions (published in 33 studies), 12 type 1 interventions (patient-reported information about own health/needs/concerns or other relevant outcomes) and 6 type 2 interventions (patient feedback about clinical practice) were included in this review (see Table 4). For type 1 interventions, different teams of researchers tested Tell-us cards, a paper-based communication tool

provided by nurses for patients to report goals, needs, questions and concerns, which nurses acted upon (Jangland et al., 2012; Jangland & Gunningberg, 2017; Theys et al., 2020; van Belle et al., 2021). Three type 1 interventions were focused on patients with cancer or patients who were palliative. These interventions elicited patients' symptoms, health problems and/or priorities using a handheld electronic device (Børøsdund et al., 2013; Heyn et al., 2011; Heyn, Finset, Eide, et al., 2013; Heyn, Finset, & Ruland, 2013; Krawczyk et al., 2019; Krawczyk & Sawatzky, 2019; Ruland et al., 2010; Sawatzky et al., 2018; Schick-Makaroff et al., 2020; Varsi et al., 2015) or a paper-based symptom diary (Coolbrandt, Bruyninckx, et al., 2017; Coolbrandt, Steffens, et al., 2017) prior to consults with healthcare professionals or morning rounds (Børøsdund et al., 2013; Coolbrandt, Bruyninckx, et al., 2017; Coolbrandt, Steffens, et al., 2017; Heyn et al., 2011; Heyn, Finset, Eide, et al., 2013; Heyn, Finset, & Ruland, 2013; Krawczyk et al., 2019; Krawczyk & Sawatzky, 2019; Ruland et al., 2010; Sawatzky et al., 2018; Schick-Makaroff et al., 2020; Varsi et al., 2015). These interventions encouraged both in-hospital and outpatient setting patient-healthcare professional communication (Børøsdund et al., 2013; Coolbrandt, Bruyninckx, et al., 2017; Coolbrandt, Steffens, et al., 2017; Heyn et al., 2011; Heyn, Finset, Eide, et al., 2013; Heyn, Finset, & Ruland, 2013; Ruland et al., 2010; Sawatzky et al., 2018; Schick-Makaroff et al., 2020; Varsi et al., 2015).

Two type 1 interventions focused on nutrition or fluid balance. The electronic MyFood intervention allowed patients to report their dietary intake daily, to prompt healthcare professionals to put in place strategies to prevent malnutrition (Paulsen et al., 2019). The other intervention was a paper-based fluid intake chart delivered

TABLE 3 Study characteristics

Author, year	Country	Setting	Design	Methods	Sample	Participant age/gender
Bobay et al. (2021)	USA and Saudi Arabia	30 Magnet hospitals; 28 in USA and 2 in Saudi Arabia (medical-surgical units)	Implementation evaluation study using qualitative design	Semi-structured focus group interviews	135 nurses	NS/NS
Børøsund et al. (2013)	Norway	2 teaching hospitals (3 inpatient and 1 outpatient cancer units)	Exploratory retrospective, qualitative study	Focus group interviews	20 nurses	34 years (mean); 23–55 years (range)/M = 2 (10%)
Cheng et al. (2017)	China	2 extended care hospitals (6 medical or surgical units)	Pilot study, pre-/post-evaluation	Interviews and observations	202 patients, 191 healthcare professionals	NS/NS
Coolbrandt, Steffens, et al. (2017)	Belgium	University hospital (6 oncology units and 2 one-day clinics)	Mixed methods	Survey, patient diaries and semi-structured interviews	143 (survey) and 17 (qualitative evaluation) patients	59–55 years (mean across methods), 13–16 years (SD across methods) M = 9 (53%)–71 (50%) (across methods)
Coolbrandt, Bruyninckx, et al. (2017)	Belgium	University hospital (6 oncology units and 2 outpatient clinics)	Mixed methods	Survey and focus group interviews	79 (survey) and 14 (focus group) nurses	39–41 years (mean across methods), 21–61 years (range)/M = 1 (7%) (focus group only)
Diedrich et al. (2020)	Germany	Tertiary care hospital (2 surgical units)	Pilot/feasibility, cross-sectional	Survey	29 unit employees (nurses, surgeons and others)	26–35 years (median)/M = 17 (77%)
Fisher et al. (2020)	USA	Large, urban community teaching hospital (all units except mother-baby and behavioural health)	Mixed methods	Interviews and detailed notes	30 (interviews) and 247 (detailed notes) key stakeholders such as bedside and managerial nurses, physicians, leaders, hospital administrators	NS/NS
Heyn et al. (2011)	Norway	University hospital (2 hospital units and 2 outpatient clinics)	Quasi-experimental	Surveys and audio-recorded consultations	196 patients (99 control and 97 intervention), 5 physicians, 19 nurses	Patients: 48.9 (mean), 15.5 years (SD), 18–80 years (range)/M = 68% HCPs: NS/M = 6 (31.5%)
Heyn, Finset, Eide, et al. (2013)	Norway	University hospital (2 hospital units and 2 outpatient clinics)	Quasi-experimental	Audio-recorded consultations	193 patients; 5 physicians, 19 nurses	Patients: 49.07 years (mean), 15.62 years, 18–80 years (range)/M = 68% HCPs: NS/M = 6 (31.5%)
Heyn, Finset and Ruland (2013)	Norway	University hospital (2 hospital units and 2 outpatient clinics)	Quasi-experimental	Audio-recorded consultations	196 patients (99 control and 97 intervention), 5 physicians, 19 nurses	Patients: 48.9 (mean), 15.5 years (SD), 18–80 years (range)/M = 68% HCPs: NS/M = 6 (31.5%)



TABLE 3 (Continued)

Author, year	Country	Setting	Design	Methods	Sample	Participant age/gender
Jangland et al. (2012)	Sweden	Large university hospital (2 surgical units)	Quasi-experimental design with control/intervention groups	Surveys	310 patients (153 control and 157 intervention)	58–58.5 years (mean across groups), 14.5–16 years (SD across groups), 21–92 (range across groups); M = 58–65 (37–42%) (across groups)
Jangland and Gunningberg (2017)	Sweden	Large university hospital (5 surgical units)	Descriptive, using quantitative and qualitative methods	Surveys (patients only) and interviews (nurses only)	198 patients, 5 nurse managers	Patients: 61.6 years (mean), 15.4 years (SD), 23–92 years (range)/M = 96 (48%) Nurse managers: 45 years (mean), 41–48 years (range); M = 0 (0%)
Kapil et al. (2016)	Canada	Mixed community and academic hospital (ED)	Pre-/post-evaluation	Chart audit and informal feedback	308 patients (239 pre-intervention and 69 post-intervention)	54–60 years (median across groups), 47–68 years (IQR across groups)/M = 31%–47% (across groups)
Keng et al. (2015)	USA	Multispecialty academic centre (ED)	Prospective cohort	Chart audit	386 patients	58–59 years (median across cohorts), 20–88 years (range across cohorts)/M = 50%–54% (across cohorts)
Krawczyk and Sawatzky (2019)	Canada	Large, urban, tertiary hospital (palliative care unit)	Pilot, 'participatory' design, using qualitative methods	Focus group interviews, individual interviews and observations	23 patients (3 interviewed and 20 observed) and 5 HCPs (physician, nurses, rotating residents) interviewed	Patients: 66 years (average)/M = 75% HCPs: NS/NS
Krawczyk et al. (2019)	Canada	Suburban acute care hospital (palliative care unit)	Qualitative methods	Focus group and individual interviews	25 staff (nurses, patient care coordinator, unit clerk, social worker, pharmacist, physicians)	43 years (median)/M = 20%
Lawton et al. (2017)	UK	5 hospitals (33 units)	Cluster randomized controlled trial	Surveys and chart audit	Average of 25 patients per unit recruited at 3 time points	Reported at unit-level tertiles: <59 years: control = 5 (31.3%); intervention = 4 (23.5%); 59–64 years: control = 4 (25.0%); intervention = 5 (29.4%); 65 years+: control = 7 (43.8%); intervention = 8 (47.1%)/ Control: M = 2 (12.5%); intervention: M = 3 (17.7%).

TABLE 3 (Continued)

Author, year	Country	Setting	Design	Methods	Sample	Participant age/gender
Liaw and Goh (2018)	Singapore	Large hospital (1 acute surgical unit)	Pre-/post-evaluation	Chart audit	90 patients (30 pre-implementation, 60 post-implementation)	NS/NS
Louch et al. (2017)	UK	2 acute NHS trust hospitals (NS wunit)	Qualitative	Focus groups and semi-structured individual interviews	15 hospital volunteers, 3 voluntary services, patient experience staff, 4 unit staff	58.8–70.67 years (mean range across focus groups), 0.58–21.38 years (SD range across groups)/M = 6 (33%)
Louch et al. (2019)	UK	3 acute NHS trust hospitals (7 units)	Qualitative	Semi-structured and focus group interviews and researcher notes	13 hospital volunteers, 5 voluntary services / patient experience staff	59.33–69.67 years (means across trusts), 3.54–9.61 years (SD range across trusts)/M = 6 (33%)
O'Hara et al. (2018)	UK	5 NHS trust hospitals (15 medical and 18 surgical units)	Cross-sectional, survey design	Surveys	2471 patients	60 (mean), 18.3 years (SD)/M = 1316 (53%)
Paulsen et al. (2019)	Norway	University hospital (2 departments)	Qualitative	Focus groups and semi-structured individual interviews	27 HCPs (nurses, physicians, dietitians, middle managers)	30–39 years (mean range across methods), 24–45 years (range across methods)/M = 2 (7.4%)
Ruland et al. (2010)	Norway	Specialized care and teaching hospital (3 inpatient and 3 outpatient cancer units)	Prospective repeated measures randomized controlled trial	Chart audit and surveys	145 patients (70 control and 75 intervention)	49–50 (mean across groups), 15–15 (SD across groups)/M = 45–45 (60 = 64.3%) (across groups)
Sawatzky et al. (2018)	Canada	2 hospitals (palliative inpatient unit and home care settings)	Qualitative	Focus group and individual interviews	18 patients, 17 family caregivers, 71 HCPs (doctors and nurses),	Patients: 61–73 years (median range across groups), 46–95 years (range across groups)/M = 13 (52%) <sup>a</sup> HCPs: 43–45 years (median range across groups); 26–63 years (range); M = 4 (9%)
Schick-Makaroff et al. (2020)	Canada	Tertiary hospital (1 inpatient palliative unit and 1 home care setting)	Secondary analysis of qualitative data	Focus group and individual interviews	66 HCPs (nurses, physicians, social workers and spiritual care coordinators)	NS/NS
Scott et al. (2019)	UK	4 teaching or general NHS Trust hospitals (16 cardiac, geriatric, orthopaedic or stroke units)	Feasibility, mixed methods	Incident reports, surveys and semi-structured individual / focus group interviews	366 patients (surveys), 28 patients (interviews) and 21 HCPs	Patients: NS/NS HCPs: NS/M = 4 (19%)

TABLE 3 (Continued)

Author, year	Country	Setting	Design	Methods	Sample	Participant age/gender
Sheard et al. (2017a)	UK	5 hospitals (17 acute units)	Qualitative process evaluation	Tapped meeting discussions, facilitator field notes and telephone interviews	63 staff (stage 1), 38 staff (stage 2), 32 staff (telephone interviews)	NS/NS
Sheard et al. (2017b)	UK	5 hospitals (17 acute units)	Qualitative process evaluation	Tapped meeting discussions, facilitator field notes and telephone interviews	Staff (n = NS)	NS/NS
Stewardson et al. (2016)	Switzerland	University, primary and tertiary care hospital (67 surgical, obstetrics/gynaecology, medical or geriatric and rehabilitation units)	Cluster randomized controlled trial	Observation and chart audit	NS patients and NS healthcare workers	NS/NS
Theys et al. (2020)	Belgium	5 regional hospitals and 1 university hospital (3 maternity, 2 surgical, 2 medical and 1 rehabilitation unit)	Qualitative	Semi-structured individual interviews	41 nurses (nurses, midwives, assistant head nurses and nurse assistants)	36.5 years (mean), 24–59 years (range)/M = 6 (14.6%)
van Belle et al. (2021)	Netherlands	1 university hospital and 1 regional hospital (2 surgical and 2 cardiology units)	Cluster randomized controlled pilot study	Surveys	265 patients, nurses working on the units (n = NS)	Patients: 54–67 years (mean range across units), 11.3–15.0 (SD range across wards), 20–90 years (range)/M = 40%–63% (range across units) HCPs: NS/NS
Varsiet al. (2015)	Norway	1 hospital (3 inpatient and 2 outpatient cancer units)	Descriptive, qualitative	Semi-structured individual interviews	9 nurse or physician managers	Nurse managers: 40 years (average)/M = 0 (0%) Physician managers: 58 years (average)/M = 3 (100%)
Weiss et al. (2019)	USA and Saudi Arabia	33 Magnet hospitals; 31 in USA and 2 in Saudi Arabia (medical-surgical units)	Cluster randomized clinical trial	Chart audit	144,868 patient discharges (70,263 control and 74,605 intervention)	59.59 years (mean), 17.54 years (SD)/M = 70,679 (48.8%)

Abbreviations: ED, emergency department; HCPs, healthcare professionals; ITPA, interactive tailored patient assessment; M, male; NHS, National Health Service; NS, not specified; SD, standard deviation.

<sup>a</sup>This percentage was reported in original paper.

TABLE 4 Intervention characteristics

Type	Author, year	Why	What procedures and materials	Who provided and how	When and how much
1	(Bobay et al., 2021; Weiss et al., 2019)	The <i>Readiness Evaluation and Discharge Interventions (READI)</i> used structured assessment of discharge readiness as a mechanism to improve discharge preparation (i.e. assisting the healthcare team in tailoring risk-mitigating actions to patient needs prior to discharge)	Three variations of the protocol were sequentially implemented progressing from nurse assessment of readiness for hospital discharge only (Protocol 1), to patient and nurse assessments of readiness for hospital discharge (Protocol 2) where patient self-assessment forms were given to the patient and reviewed by the discharging nurse immediately before completing the nurse-form, so that the patient's perspective would inform the nurse's assessment and action, to the addition of a requisite to act on low scores, requiring nurses to document an action to improve readiness and reduce readmission if the patient or nurse provided an assessment of low readiness for hospital discharge (Protocol 3). All protocols contained a structured assessment of discharge readiness, capturing four dimensions (personal status, knowledge, perceived coping ability and expected support) plus an instruction for nurse action	Who: patient assessment of readiness for hospital discharge: given to patient by the discharging nurse How: patient assessment of readiness for hospital discharge: paper-based	Patient assessment of readiness for hospital discharge: administered once (taking 2–5 min), in the 4 hours prior to discharge
	(Bjørnsund et al., 2013; Heyn et al., 2011; Heyn, Finset, Eide, & Ruland, 2013; Heyn, Finset, & Ruland, 2013; Ruland et al., 2010; Varsi et al., 2015)	<i>CHOICE</i> , an Interactive Tailored Patient Assessment and communication (ITPA) tool helped prepare patients to actively report their symptoms, problems, and priorities for care, and supported HCPs to provide person-centred communication/care, as HCPs better elicit patient perspectives to provide individually tailored symptom management support and help address patients' individual symptoms and problems that matter most	Patients used computerized assessment system/ touch pad computer to independently complete assessment of their symptoms and health problems along physical, functional, and psychosocial dimensions, noted their degree of distress or affliction, and prioritize their need for care for their symptoms. The assessment displayed tailored questions to each patient individually, based on his or her initial response. The summary is transferred to the hospital electronic system and HCPs used results to deliver face-to-face person-centred care	Who: assessment: nurse/researcher invited and explained assessment to patients How: assessment: electronic	Assessment: completed at own pace prior to seeing HCP

TABLE 4 (Continued)

Type	Author, year	Why	What procedures and materials	Who provided and how	When and how much
	(Jangland et al., 2012; Jangland & Gunningberg, 2017)	Tell-us cards where patients recorded goals, specific questions and concerns for the day/before discharge, which were used as a tool for communication with healthcare professionals	Patients given a two-sided card and were responsible for completing it: one side of the card had instructions and information about patient participation e.g. tell us what is important for you today; and opposite side had space to write down questions/concerns and fill in goals for the day. The patient used the tool to communicate with HCPs during ward rounds, nurse rounds, and meetings. Flyers including the same information as the card were set-up in bedrooms and on department website	Who: card: Registered nurse placed card in patient room; flyers: NS How: card: paper-based; flyers: paper-based and electronic	Card: given daily during inpatient stay; flyers: NS
	(Kapil et al., 2016)	Fever advisory cards were used as a communication tool to enable better identification of potential patients with febrile neutropenia and decrease time to antibiotics	Paper-based or digital photograph of the card carried by patients in pocket or smartphone. Patients presented cards to HCPs when they present to ED to improve the time to antibiotics for patients treated with chemotherapy	Who: cards: given by nurses How: paper-based and digital.	Card: given to patient when starting chemotherapy and nurses updated cards at each chemotherapy infusion
	(Keng et al., 2015)	The febrile neutropenia pathway (FNP) utilized febrile neutropenia alert cards to reduce antibiotic administration delays for febrile patients with cancer presenting to the ED, providing improved quality of care for patients with febrile neutropenia	Patients were given wallet-sized cards with instructions for febrile patients. Patients presented the card at ED triage desk to alert personnel to the seriousness of febrile neutropenia and prompt the initiation of the FNP	Who: cards: NS How: cards: paper-based.	Cards: febrile neutropenia alert cards shown on presentation to the ED
	(Coolbrandt, Bruyninckx, et al., 2017; Coolbrandt, Steffens, et al., 2017)	Symptom diary encouraged patients to monitor chemotherapy side effects to ultimately assist and supplement discussions with HCPs about symptoms experienced during visits	The symptom diary encouraged patients to monitor their symptom burden at home on a daily basis. During visits, nurses summarized the diary information in patients' electronic files. Doctors can consult the paper diary or electronic summary	Who: symptom diary: treating nurses were responsible for offering symptom diary and discussing its contents with patients How: symptom diary: paper-pencil based	Symptom diary: repeatedly offered at each new treatment cycle and patients encouraged to use diary daily

TABLE 4 (Continued)

Type	Author, year	Why	What procedures and materials	Who provided and how	When and how much
	(Liaw & Goh, 2018)	Intervention to improve the accuracy of fluid intake charting in adults who require fluid balance monitoring, through patient involvement. <i>Intake chart</i> completed by patients and nurses review, confirm and transcribe information	Patients given intake chart and provided with training and rationale for chart and instructed how to record their own intake chart with pictorial guide. Within 24-hour period nurses review/confirm information with patient, then transcribe information onto official fluid balance charts used by hospital	Who: intake chart: nurses (implied); training and pictorial guide: nurses How: intake chart: paper-based; training and pictorial guide: face-to-face and paper-based	Intake chart, training and pictorial guide: upon admission when fluid balance chart is required
	(Krawczyk et al., 2019; Krawczyk & Sawatzky, 2019; Sawatzky et al., 2018; Schick-Makaroff et al., 2020)	The <i>quality of life assessment and practice support system</i> (QPSS) is a person-centred health care information system that provided a means for patients and their family caregivers to respond to questionnaires (PROMs and PREMs), which are summarized and presented back to HCPs who can use this information to monitor and address any revealed healthcare needs or concerns, and provides a basis for enhanced person-centred care and shared decision making	Patients/caregivers reported against PROMs and PREMs within the handheld tablet-based QPSS about their symptoms, their physical, psychosocial, social, and essential/spiritual well-being and their experiences of healthcare. Patients completed the questionnaires independently or with nurse assistance. Their responses are immediately summarized and presented back to HCPs who can use this information to monitor and address any revealed health care needs or concerns. The system produced instantaneously scored information and reports in both customisable tabular and graphical formats	Who: QPSS: delivered by outreach consult team nurses How: QPSS: electronic	QPSS: the Edmonton symptom assessment system [revised] was intended to be completed prior to AM rounds; not mandated in home care. However in one study utilization data for each questionnaire is provided: the Edmonton symptom assessment system-revised version: 12 patients used it 20 times, the McGill quality of life questionnaire-revised version: 17 patients used it 23 times, and the Canadian health care evaluation project life questionnaire: 5 patients used it 5 times



TABLE 4 (Continued)

Type	Author, year	Why	What procedures and materials	Who provided and how	When and how much
	(Paulsen et al., 2019)	The MyFood decision support system provided a system where patients record their dietary intake and staff performed and followed recommendations to prevent / treat disease-related malnutrition	The app and website on handheld tablet consisted of four modules: (1) collection of information about the patient; (2) dietary assessment function; (3) evaluation of recorded dietary intake compared with individual needs and (4) report function for nurses and HCPs, including recommendations for nutrition-related actions tailored to the patient and template for nutrition care plan. The report was intended for monitor and follow up on a patient's nutritional status and treatment. Patients were expected to enter intake information, but if unable to, nurses were expected to perform	Who: app and website: NS How: app and website: electronic	App and website: patients expected to record intake daily
	(Theys et al., 2020)	Tell-us cards wer communication tool for patients/relatives to use to indicate what is important for them during their admission and before discharge, for nurses to read	The card includes: instructions on how to use the card; information for patients/relatives on how HCPs work with the tell-us card; specific prompts to write down concerns e.g. 'what is important for you today?'. The card was left on night table for nurses to read	Who: card: nurse/midwife How: card: paper-based	Card: during admission and/or before discharge, daily or as required
	(van Belle et al., 2021)	Tell-us cards a communication tool for inviting patients to talk about their preferences and needs, and to increase patient participation in daily care. The card facilitates communication between patients and nurses by means of patient preferences and needs being elicited and acted upon by nurses	Patients are invited to write down what is important to them for that day or before discharge on the card. Double-sided pocket-sized card: Side A includes instructions on how to use the card and information for patients/relatives on how HCPs work with the tell-us card, and specific prompts; side B has space for patients to write down what is important to them. The nurse goes back to the patient after an agreed amount of time to discuss the card and talk about what is important. They establish with the patient what follow-up actions are needed and by whom, which is reported in patient file	Who: Card: Nurses How: Card: Paper-based.	Card: Daily and at a mutually agreed time
2	(Cheng et al., 2017)	An education and empowerment in hand hygiene program to encourage patients to remind HCPs to perform hand hygiene	Formal education given to patients about importance of hand hygiene during hospitalization and promoting patients to remind HCPs to perform hand hygiene before direct contact with them, by politely asking "Have you cleaned your hands?". Visual aids given to patients for them to show HCPs to remind them to perform hand hygiene politely e.g. 'Did you clean your hands'	Who: formal education: infection control nurses provided patient education; visual aids: NS who provided to patients. How: formal education: face-to-face; visual aids: paper-based	Formal education: weekdays, 1 x 10-15 min session (patient education); visual aids: NS

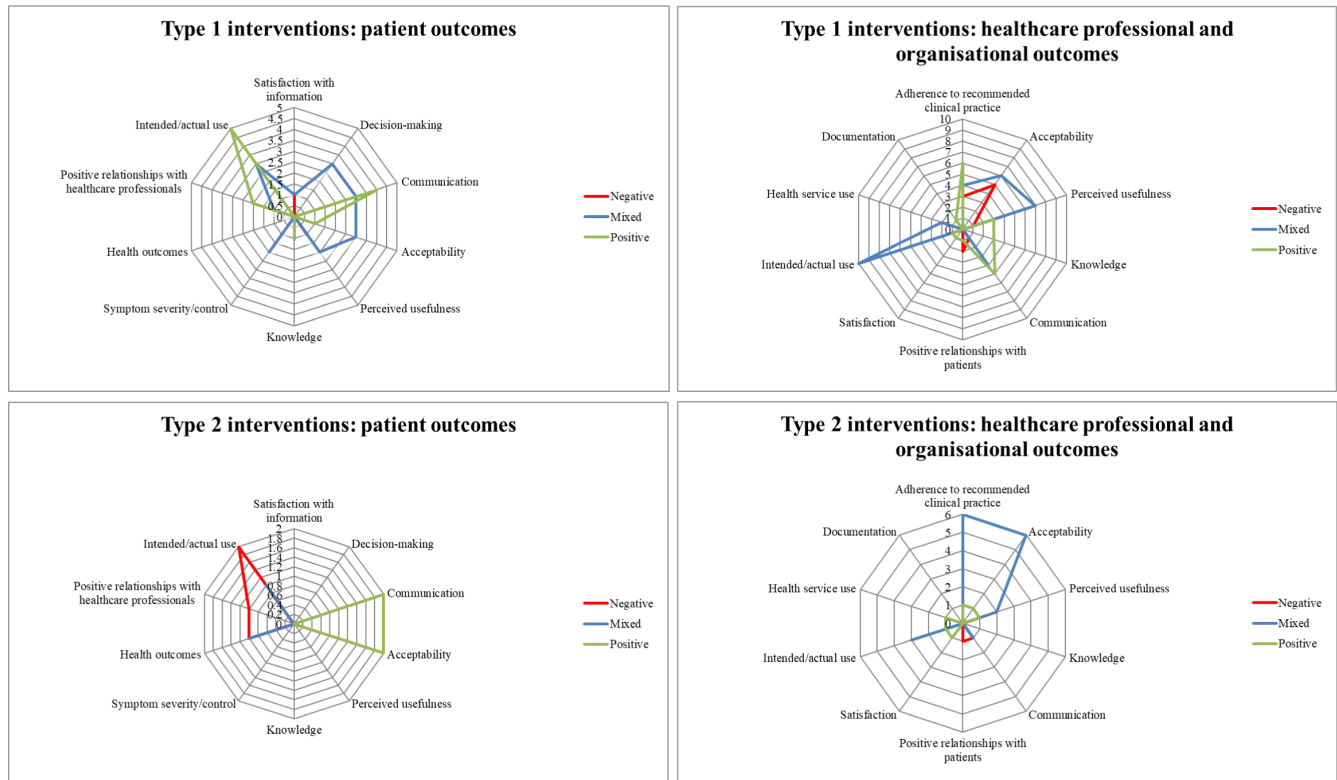
TABLE 4 (Continued)

Type	Author, year	Why	What procedures and materials	Who provided and how	When and how much
	(Diedrich et al., 2020)	<i>The Activation, Help, Open communication and Infection prevention (AHOI) intervention</i> involves patients and visitors in hand hygiene and infection control and prevention. The intervention involved adherence (patients/visitors know hygiene standards), empowerment (patients/visitors consciously observe/ address HCP hygienic behaviour) and acceptance (HCPs convey to patients/visitors that they are on equal footing in terms of infection control and prevention and patient safety).	Patients given AHOI instruments such as: (1) Visual reminders, including posters and 2 videos for patients ("Mention It!" and "Stay clean - disinfect your hands!"); and (2) AHOI-welcome box, including information about infection risks, hygiene rules and support incentives	<i>Who:</i> visual reminders: posters/visual reminders presented in entrance hall, ward corridors, patient rooms and sanitary facilities; videos presented on screens in the entrance hall and on patient's bedside. AHOI-welcome box: NS.  <i>How:</i> visual reminders: paper-based and electronic. AHOI-welcome box: paper-based	Visual reminders: videos presented on a continuous loop. AHOI-welcome box: given once-off upon admission.
	(Fisher et al., 2020)	<i>The We Want To Know (WWTK) campaign</i> was designed to make it easy for hospitalized patients to speak up about breakdowns in care (something that went wrong during the hospitalization according to the patient) and receive a response in real-time	Campaign materials were used to increase patient awareness e.g. pocket cards, tent cards, posters, screen ads. There were multiple channels for patient reporting of care breakdowns e.g. website, email address, phone or in-person, as well as an outreach service with inpatients where WWTK specialist approached patients one-by-one using open-ended questions to probe if any concerns were identified. WWTK specialist monitored the multiple channels for patient reporting and based on responses to outreach service facilitated resolution of breakdowns in real time	<i>Who:</i> campaign materials: WWTK specialists delivered pocket cards and some campaign materials. Campaign materials played on plasma screens or placed in patient rooms and public areas of the hospital; multiple channels for patient reporting monitored by WWTK specialists; outreach service provided by WWTK specialist.  <i>How:</i> campaign materials: paperbased and electronic; multiple channels for patient reporting: electronic and face-to-face; outreach service: face-to-face	Campaign materials: NS; multiple channels for patient reporting: available as needed; outreach service: patients approached once sequentially

TABLE 4 (Continued)

Type	Author, year	Why	What procedures and materials	Who provided and how	When and how much
	(Lawton et al., 2017; Louch et al., 2017; Louch et al., 2019; O'Hara et al., 2018; Sheard et al., 2017a, 2017b)	The <i>Patient Reporting and Action for a Safe Environment (PRASE)</i> intervention was intended to provide routine and systematic feedback from patients about safety of their care environment (measurement) then presented to HCPs to interpret (feedback) and act on to inform local and organizational changes, and achieve patient-centred service improvement (action planning)	Anonymous feedback collected via tablet-based validated surveys 'Patient Measure of Safety' and 'Patient Incident Reporting Tool' (theory and evidence-based measures), which enables patients to report detailed safety concerns/lagging indicators of safety and/or positive experiences. Feedback presented to HCPs in the form of a 'feedback report', which assists staff to interpret patient feedback and aid service improvements. HCPs considered this information in an action planning meeting and were facilitated to make target improvements based on the patient feedback	Who: surveys: research nurses/hospital volunteers (varied across phases of testing). How: surveys: electronic	Surveys: during hospital stay, once per patient (implied)
	(Scott et al., 2019)	<i>Safety survey</i> to capture patient/carers reports of safety experiences across three stages of care transfer (discharge, journey and arrival or admission), to provide feedback to staff	The survey has 6 domains which measure patient experience of their own safety relating to care transition (communication, responsiveness, waiting times, falls, medication and hygiene) and patients asked to indicate level of safety (safe = green, neutral = yellow or unsafe = red). Patients provided with letter of invitation, survey and pre-paid return envelope	Who: survey: HCP or an administrator responsible for compiling discharge information, e.g. discharge coordinator or ward clerk How: survey: paper-based.	Survey: provided at point of discharge.
	(Stewardson et al., 2016)	Enhanced performance feedback and <i>patient participation</i> designed to improve hand hygiene compliance	Patient participation materials: welcome pack consisting of a hand hygiene brochure and an individual pocket-sized bottle of alcohol-based hand rub; ward staff educated patients about hand hygiene; patients invited to ask healthcare professionals who did not visibly perform hand hygiene to do so before touching them. Additionally enhanced performance feedback occurred (largely targeted at staff)	Who: welcome pack: ward staff; education: ward staff How: welcome pack: paper-based and materials; education: face-to-face.	Welcome pack: provided on admission; education: NS

Note: Type of patient-mediated intervention: 1: Patient-reported health information about own health/needs/concerns or other relevant outcomes; 2: Patient feedback about clinical practice.



**FIGURE 2** Relationships between type of patient-mediated intervention and outcomes. Note: Patient-mediated intervention outcomes defined by Gagliardi et al. (2016) and Fønhus et al. (2018) represented each axis of the spider graph. Type 1 and type 2 interventions are presented separately, and patient outcomes, and healthcare professional and organizational outcomes are presented separately. The spider graphs represent the frequency and direction of outcomes reported. For example, in the graph titled “type 1: patient outcomes” communication outcomes were reported in four studies, and these outcomes were positive.

by nurses on hospital admission when required, to ensure nurses accurately reported patients' fluid intake (Liaw & Goh, 2018). Two type 1 interventions encouraged patients to show febrile neutropenia alert cards on presentation to the emergency department, to decrease time to antibiotics (Kapil et al., 2016; Keng et al., 2015). The alert cards were paper-based, and in one study some patients took a photo of the paper-based card on their phones (Kapil et al., 2016; Keng et al., 2015). The final type 1 intervention was READI, where patients used a paper-based assessment to report their discharge readiness 4 h prior to discharge; and nurses were provided with instructions on how to respond to patient scores (Bobay et al., 2021; Weiss et al., 2019).

Six type 2 interventions were identified. Three type 2 interventions prompted patients to verbally remind their healthcare professionals to wash their hands (Diedrich et al., 2020; Stewardson et al., 2016); one of these also gave patients a visual aid they could use in place of verbal communication (Cheng et al., 2017). Patients were provided with face-to-face education from a nurse (Cheng et al., 2017) or ward staff (Stewardson et al., 2016) and/or paper-based welcome boxes with instructions to enable them to prompt hand hygiene (Diedrich et al., 2020; Stewardson et al., 2016). The remaining three interventions prompted patients to provide feedback on safety issues they experienced in hospital, such as communication

issues and staff workload issues, to enhance healthcare professional performance (Fisher et al., 2020; Lawton et al., 2017; Louch et al., 2017, 2019; O'Hara et al., 2018; Scott et al., 2019; Sheard et al., 2017a, 2017b). Feedback was collected using paper-based surveys with prepaid return envelopes provided on discharge (Scott et al., 2019), electronic tablet-based surveys completed once during the hospital stay (Lawton et al., 2017; Louch et al., 2017, 2019; O'Hara et al., 2018; Sheard et al., 2017a, 2017b) and multiple methods for patients to report including website, email address, phone and in-person (Fisher et al., 2020).

#### 4.4 | Quality appraisal of individual studies

MMAT scores for individual studies are provided in Appendix S3. Common issues for RCTs were incomplete outcome data (3/5 studies, 60%) and lack of intervention adherence (4/5 studies, 80%). In three studies (60%), it was unclear if outcome assessors were blinded to the intervention. For 3/8 (38%) non-randomized studies, reviewers were often unable to tell if complete outcome data were collected. A common issue for non-randomized RCTs was determining if the intervention had been administered as intended (cannot tell = 4/8 studies, 50%; no = 2/8 studies, 25%). In quantitative descriptive

studies the risk of nonresponse bias was not well reported (2/3 studies, 67%) or high (1/3 studies, 33%). For qualitative studies, 12/14 (86%) scored yes for all five items. For mixed methods, two studies scored yes for most items (4/5 items), while the other two studies scored 'cannot tell' for most (4/5 items). All mixed methods studies had varying results for qualitative and quantitative components.

## 4.5 | Synthesis of results

### 4.5.1 | Preliminary synthesis

See Appendix S2 for the step 1 preliminary synthesis. Looking across the tabulated data (Appendix S2), overall, we found some evidence that patient-mediated interventions influence outcomes like patient communication and healthcare professional behaviours. However, process outcomes like intervention use and acceptability are mixed. Gaps exist in our understanding of the influence of patient-mediated interventions on patient knowledge and health outcomes, healthcare professionals' satisfaction and relationships with patients, and health service level changes, as these outcomes were rarely measured.

#### *Summary of type 1 interventions*

The tabulated data (Appendix S2) showed that interventions grouped together had similarities. Type 1 symptom reporting interventions appeared responsible for improving healthcare professional adherence to recommended clinical practice. This was despite healthcare professionals' mixed views for acceptability, perceived usefulness and intended/actual use. Although patient acceptability was mixed for symptom reporting interventions, patients did use these interventions, especially when they were in an electronic format. Healthcare professionals also preferred electronic interventions, as long as they were integrated with pre-existing electronic records. Symptom reporting interventions improved patient and healthcare professional communication; however, their success may be attributed to sample and setting. For example, patients on chemotherapy and who were undergoing palliative used these interventions, and sometimes continued using them in the community; these patients may have a more specialized pathway that facilitated patient-mediated interventions.

Other type 1 interventions including fever advisory cards and fluid/nutrition balance interventions made some positive changes to healthcare professional adherence to recommended clinical practice. There was some evidence that patients and healthcare professionals were using/intending to use these interventions; this was regardless of paper-based or electronic modes of delivery.

Some type 1 interventions had fewer positive findings. Although patients used Tell-us cards, outcomes were mixed and they were unacceptable to healthcare professionals. The discharge readiness assessment interventions had mixed outcomes for patients and healthcare professionals. Both of these were paper-based interventions for general patient populations (medical/surgical patients) at

the point of care. They relied on nurses to deliver materials to patients on admission, daily and/or at discharge.

#### *Summary of type 2 interventions*

For type 2 hand hygiene interventions, although patients reported they were acceptable, using/intending to use the intervention was viewed as mixed or negative by patients. There were mixed results for these interventions changing healthcare professional adherence to recommended clinical practice and healthcare professionals' perceptions of acceptability and usefulness were mixed and negative. Healthcare professionals found type 2 hand hygiene interventions to increase their own satisfaction but had a negative impact on their communication.

Type 2 safety feedback interventions positively influenced patient communication and were viewed as acceptable by patients. However, patients did not use or intend to use the intervention and reported negative health outcomes and negative relationships with healthcare professionals because of the intervention. Healthcare professionals had mixed views for intervention acceptability, perceived usefulness, communication outcomes, intended/actual use and healthcare professional adherence to recommended clinical practice. Like patients, healthcare professionals also reported negative effects on relationships with patients, but positive health service outcomes. For both type 2 interventions (hand hygiene interventions and safety feedback interventions) it did not appear that the format of the intervention (i.e. verbal patient feedback, paper-based, use cards, electronic) influenced their use.

### 4.5.2 | Exploring relationships

When 'exploring relationships', it became evident that the differences in outcomes lay in the types of interventions (type 1 and type 2). Type 1 interventions may be more promising than type 2 interventions (see Figure 2). Patients intended to or were using type 1 interventions, and they improved patient communication. Further, they enhanced healthcare professional adherence to recommended clinical practice (especially among nurses) and healthcare professional communication outcomes. Type 2 interventions showed less influence on changing healthcare professional behaviour. Although patients stated these were acceptable and they improved patient communication, usage or intended usage by patients was low. Further, healthcare professionals' acceptance and intended/actual use were mixed, and in turn adherence to recommended clinical practice were all mixed outcomes.

## 5 | DISCUSSION

In this review we found 33 studies, which were interventions that: (1) encouraged patient-reported information about own health/needs/concerns or other relevant outcomes; and (2) interventions that encouraged patient feedback about clinical practice. Most

studies were from Europe and the UK and used qualitative evaluation methods suggesting the body of evidence included in this review has been conducted early in the intervention design phase. We found evidence that patient-mediated interventions influenced patient communication and healthcare professional behaviour change, while many process outcomes measures were variable (e.g. acceptability). A key finding was that type 1 interventions had more positive outcomes than type 2 interventions, including the ability to change healthcare professional behaviour; we discuss reasons for this finding in more depth below.

In our review, type 1 interventions that encouraged patients to share health information were somewhat successful in changing healthcare professional behaviour. Previous research shows that patients view themselves as experts in sharing information about themselves that healthcare professionals might not know (Jerofke-Owen & Dahlman, 2019). Thus, type 1 interventions may activate a behaviour that is comfortable for patients. However, healthcare professionals were more negative than patients about the acceptability of these interventions. There is overwhelming evidence that healthcare professionals' unwillingness towards patient engagement, owing to workload issues and ambivalence, is a key barrier to patient engagement (Chegini et al., 2021). Thus, ensuring healthcare professionals are responsive to patient engagement could influence the success of future patient-mediated interventions.

In comparison, type 2 interventions did not appear to change healthcare professional behaviour, which might be explained by their potentially confrontational nature. Like other integrative review findings, we found that patients viewed hand hygiene interventions positively but failed to engage in these interventions (Alzyood et al., 2018). Patients' behaviour is obstructed by their feelings of embarrassment, awkwardness and fears of reprisal or causing annoyance (Alzyood et al., 2018). Healthcare professionals have also indicated they would feel irritated or there would be tension if patients asked them to wash their hands (Alzyood et al., 2018). While researchers suggest that safety feedback interventions are less confrontational for patients due to anonymity of feedback, healthcare professionals find these confrontational when complaints and concerns are raised (Maxwell, 2020). However, patient safety feedback interventions may also be challenging due to their multi-stepped nature, including: (1) making sense of patient data; (2) communicating data; and (3) making plans for improvement (Kumah et al., 2017). Completing these steps requires time, resources and working relationships at many organizational levels (Kumah et al., 2017); and may be why healthcare professionals in our review avoided these interventions. Ultimately, type 2 interventions appear to be confronting for healthcare professionals and may require changes to routine practice, highlighting the need to focus on context and factors affecting implementation.

All interventions included in our review met Straus et al.'s (2013) definition of patient-mediated interventions, yet 72% relied on healthcare professional initiation. In many cases, this was described as healthcare professionals giving patients the intervention materials, sometimes with education about the intervention provided by

the healthcare professional. Given that explicitly inviting patients or expressively giving patients authority to engage is a facilitator to engagement (Tobiano et al., 2015), introducing the intervention to patients may be a critical point in the success of hospital-based patient-mediated interventions. Future researchers should provide in-depth descriptions of this process, emphasizing whether the intervention materials were simply handed to patients, or whether healthcare professionals engaged with patients and provided education to encourage uptake and adherence. This will contribute to building the quality of reporting of implementation strategies, which are poorly reported (Powell et al., 2019).

## 5.1 | Limitations

Designing a search strategy for this review was challenging due to poor use of patient-mediated taxonomies. More articles were found using forward and backward citation searching than computerized database searching. We designed the most robust search strategy possible, based on previous reviews in the field; however, we acknowledge that some studies may have been missed. Given the diffuse terminology used in this field, we suggest that other approaches such as 'pearl growing', which uses gold standard papers to facilitate an iterative process of searching (Papaioannou et al., 2010), could be trialled in future research.

We have provided a broad range of patient-mediated interventions, which reduced our ability to pool results. Although five RCTs were included, their outcomes differed, hindering further analysis. In the future, targeted reviews may reveal more specific insights about interventions and their impact on specific clinical problems. For example, investigating 'fever advisory card' interventions and pooling the results of these may provide more specific information on their effectiveness. We also found that many interventions were in early development phases, and many qualitative evaluations occurred. Repeating this systematic review in the future may yield more RCTs and more evidence of outcomes.

Appraising the quality of studies with different methodologies is challenging. The MMAT, a widely used tool with demonstrated validity and reliability (Hong, Gonzalez-Reyes, et al., 2018; Souto et al., 2015), was selected to facilitate concurrent appraisal of the methodological quality of qualitative, quantitative and mixed methods studies. The MMAT has predefined questions, which ensured that key methodological aspects were reviewed in a systematic manner across all the included studies by the various study team members. More comprehensive quality appraisal may have been achieved using methodology-specific appraisal tools with additional criteria.

Our outcome data was mapped to a pre-existing framework by Gagliardi et al. (2016) and Fønhus et al. (2018). The framework treated all outcomes equally and did not acknowledge the time-dependent nature of outcomes, for example, impact of knowledge could be immediate, while health outcomes could take months or years to show impact. As the nature of our review was to describe impact, this framework has given a sense of what outcomes are



currently measured and reported in this field. Also, we note that the healthcare professional outcomes and organizational outcomes were grouped together; and there was only one organizational outcome present in the framework. In future work, an inductive approach may be beneficial to ensure this framework is all encompassing, and if any other organizational outcomes require consideration for the hospital setting.

## 6 | CONCLUSION

In conclusion, while patient-mediated interventions hold promise for improving patient communication and changing healthcare professional behaviour, uncertainties remain due to the infancy of this research. Many hospital-based patient-mediated interventions are in early development phases. These have been evaluated qualitatively, and critical questions remain about the influence of patient-mediated intervention on patient health outcomes and health service use. The most abundant evidence is for patient-mediated interventions that prompt patients to share health information such as symptoms, food intake and nutrition. While progress has been made in recognizing the value of patients in improving outcomes through mediated interventions, there is still much to do to address the challenges outlined.

In light of the review findings, recommendations for clinical practice, education and research are provided. Given that the evidence base for type 1 interventions, such as symptom reporting interventions, is more robust, these could be more regularly integrated into clinical practice. However, the mismatch between patients' and healthcare professionals' views of acceptability of patient-mediated interventions suggests that educating health professionals about the benefits of, and patients' receptiveness to, these interventions may improve their uptake and effectiveness in clinical practice.

There are many recommendations for research. First, type 2 interventions require further investigation to find ways to make patients feel less afraid to act. Perhaps more confidential feedback mechanisms with assurances of no repercussions could be investigated. For healthcare professionals, it will be important to shift their viewpoints that type 2 interventions are intended to improve patient outcomes and non-confrontational ways of providing feedback such as grouped feedback could be trialled. Second, evaluating effectiveness and process outcomes also requires greater attention in patient-mediated interventions, which are complex interventions (Moore et al., 2015). In our review, relatively few researchers defined or described the components of intervention acceptability for both patients and healthcare professionals, which has potential implications for uptake and overall effectiveness of the intervention. A theoretical framework of acceptability with empirical indicators has been developed (Sekhon et al., 2017), which might serve to guide future research and improve reporting. Third, our review highlighted that patient knowledge and health outcomes, healthcare professional documentation, satisfaction and relationships with patients, and health service use were infrequently measured. Researchers

should consider measuring a wider range of outcomes to further the evidence base for patient-mediated interventions. Finally, Fønhus et al.'s (2019) list of types of patient-mediated interventions includes more than two types; it may be that other types of patient-mediated interventions not included in this review are less common in hospitals, or were not identified in our search. Exploring and evaluating a broader range of types of patient-mediated interventions would extend our knowledge base in this area.

## AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE\*):

1. substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
2. drafting the article or revising it critically for important intellectual content.

\*<http://www.icmje.org/recommendations/>

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Not applicable this is a review.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# Nurse and pharmacist systemic anti-cancer therapy review clinics and their impact on patient experience and care: A systematic review

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## Abstract

**Aim:** To review the evidence of how nurse and pharmacist roles have been incorporated into the management of patients undergoing systemic anti-cancer therapy (SACT) services and their impact on patient experience and care provision.

**Design:** Systematic Review.

**Data Sources:** Seven databases were searched on 10 April 2022.

**Review Methods:** Research studies that met defined inclusion criteria were included. Quantitative findings were converted into textual descriptions and combined with qualitative results for thematic analysis. Data were categorized and aggregated into themes. Heterogeneity of studies meant meta-analysis was not possible.

**Results:** Fifteen papers were included. Three main themes were identified: advanced clinical practice (ACP) SACT service development; ACP skills and qualifications; and the impact of ACP SACT services on patient care and outcomes. There is a variation in tasks undertaken by nurses and pharmacists and role integration is restricted by limited physician engagement. Role titles used and skills and qualifications acquired differ and professional autonomy is variable. Qualitative studies were limited.

**Conclusion:** Evidence of how nursing and pharmacist ACP roles are implemented, what skills are essential and how roles are impacting patient experience and outcomes is limited. More research is required to explore patient and physician experience of, and satisfaction with multi-professional care, alongside further evaluation of clinical delivery models.

## KEYWORDS

advanced clinical practitioner, literature review, nurses, pharmacists, systemic anti-cancer therapy

## 1 | INTRODUCTION

Systemic anti-cancer therapy (SACT) is the umbrella term for curative and palliative systemic treatments for malignancy. Although

cancer incidence is increasing, survival rates have doubled over the last 40 years in the United Kingdom (UK) through early detection and enhanced management ([cancerresearchuk.org](http://cancerresearchuk.org)) including incurable cancers (Department of Health, 2019). However, SACT can lead

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to significant and complex toxicities which can be life-threatening (Farrell & Lennan, 2013).

Fundamental to delivering effective, patient-centred SACT services are access to skilled professionals and responsive patient-focused services. Significant shortfalls in these were identified in the UK (NCEPOD, 2008) leading to recommendations for improved patient pathways, including nurse-led clinics (National Chemotherapy Advisory Group, 2009). Internationally, ACP nurse and pharmacist roles have developed to support new multi-professional models of care (Farrell et al., 2010).

## 2 | BACKGROUND

A key driver for the development of advanced clinical practice (ACP) roles is recognition that multi-professional services positively impact patient care (Fothergill et al., 2022). However, an ageing population, increasing healthcare costs and medical workforce shortfalls are also driving change (Fothergill et al., 2022; rcr.ac.uk 2021).

ACP involves experienced professionals from various healthcare backgrounds, including nursing and pharmacy, working autonomously and utilizing advanced knowledge, decision making, leadership skills and research to improve patient care (Ryley & Middleton, 2016). It usually incorporates tasks associated with medicine, including physical assessment, differential diagnosis and prescribing (Ryley & Middleton, 2016). ACP roles have been linked to patients' reduced lengths of stay (Imison et al., 2016) reductions in morbidity and mortality and improved continuity of care when compared to medical care models (Imison et al., 2016). Nurse and pharmacist non-medical prescribers are as clinically effective as medical prescribers in their practice (Weeks et al., 2016). To standardize practice in England, a multi-professional framework for ACP was published, providing a definition of ACP and its underpinning standards (Health Education England, 2017).

ACP roles have developed haphazardly leading to a plethora of titles, variable role parameters, inconsistencies in education and confusion about what advanced practice entails and what constitutes competence (Ryley & Middleton, 2016). A lack of medical support and organizational infrastructure can leave nurses in ACP roles feeling frustrated and disillusioned, reducing their overall impact (Farrell et al., 2010). Concerns have been raised by nurses that ACP is task oriented not patient-focused, detracting from holistic approaches to care, which should include psychosocial support as well as disease management (Gray, 2016). For ACP pharmacists, concerns have been raised regarding their skills to fully assess patients (Forsyth & Rushworth, 2021) and lack of organizational and financial support (Jebara et al., 2018).

The incorporation of nurse and/or pharmacist ACP roles into SACT services is crucial to improving patient care and to address increasing demand and oncology workforce shortfalls (Ignoffo et al., 2016). However, it is unclear how roles have been introduced or what their impact has been. With challenges to ACP role development and implementation across healthcare organizations identified

### Impact

- This review shows nurse and pharmacist ACP roles are identifiable in SACT services and positively impact patient care. However, transferability of findings is restricted by limited research.
- This review shows significant variation in job titles, role development requirements and expectations of scope, making further service development problematic.
- This review shows nurse and pharmacist ACP roles can positively impact patient experience and outcomes; however, this is based on limited evidence.

(Gagliardi et al., 2011), and potential disparities in how nurses and pharmacists may approach holistic care, a review of the published evidence is required to inform future service expansion.

## 3 | THE REVIEW

### 3.1 | Aim

This study aims to review the evidence of how ACP nurse and/or pharmacist roles have been incorporated into the management of patients undergoing SACT treatment. The objectives are to explore:

- the skills, knowledge and experience of nurses and pharmacists in ACP SACT-specific roles and their level of autonomy,
- ACP role involvement in SACT prescribing, dose adjustments, treatment change or cessation, assessment of response to treatment and toxicity management and the impact of this on patient care and outcomes, and
- how nurse and pharmacist ACP roles in SACT management are perceived by patients and other members of the multi-professional team.

### 3.2 | Design

A systematic search was undertaken including qualitative, quantitative and mixed-methods research. Quantitative findings were converted into textual descriptions and combined with the qualitative results for thematic analysis by one reviewer (LB). The data were categorized based on similarity of meanings and then aggregated into themes for presentation as integrated findings (Pearson et al., 2015).

### 3.3 | Search methods

The review was registered on PROSPERO, ID CRD42020165191. The PEO (Population, Exposure(s), Outcome) structure was utilized to manage

the search strategy. Each key term from the research aims and objectives were entered into the Medical Subject Headings (MeSH) thesaurus ([www.nlm.nih.gov](http://www.nlm.nih.gov)) and an online thesaurus was also utilized to ensure no terms were missed. Free text search terms were used to maximize citation retrieval. These, along with terminology used in papers already located, were then collated under the relevant PEO heading (Table 1).

Several searches were undertaken using the following databases: CINAHL, MEDLINE, PUBMED, EMBASE, PsycINFO, AMED, British Nursing Index. These were chosen as they include the most comprehensive range of journals for the subject matter and are the key databases for nursing and pharmacist-related research. The final search was undertaken on 10 April 2022. Search terms were combined using the Boolean operators 'AND' and 'OR', and the truncation symbol '\*' (STable S1). No timescales were set to ensure early evidence of ACP development and progression in SACT clinics was captured.

### 3.4 | Search outcomes

The database searches yielded 5281 references; after duplicates were removed, 3974 records were screened and 3955 excluded when the titles and abstracts were reviewed using the inclusion and exclusion criteria (Table 2). Of the remaining 19 records, a further 12 references were excluded after a full-text review. Eight papers were identified

through hand searching of the reference lists of the included papers, meaning a total of 15 papers were identified for inclusion.

The authors of five conference abstracts were contacted for further information to confirm if the studies were suitable for inclusion. All five responded and confirmed their research had not yet been published and they were unable to share the data; the abstracts were therefore excluded. Full details of the searches are included in the PRISMA diagram (Figure 1).

### 3.5 | Quality appraisal

Each paper was assessed by two authors (LB, WCD, TW, and VT) independently, who then met to discuss their findings; differences in opinion were minor and resolved through discussion. All included papers were critically appraised using either the cohort study or qualitative Critical Appraisals Skills Programme (CASP) checklist, depending on the paper's methodological design (Public Health Research Unit, 2006).

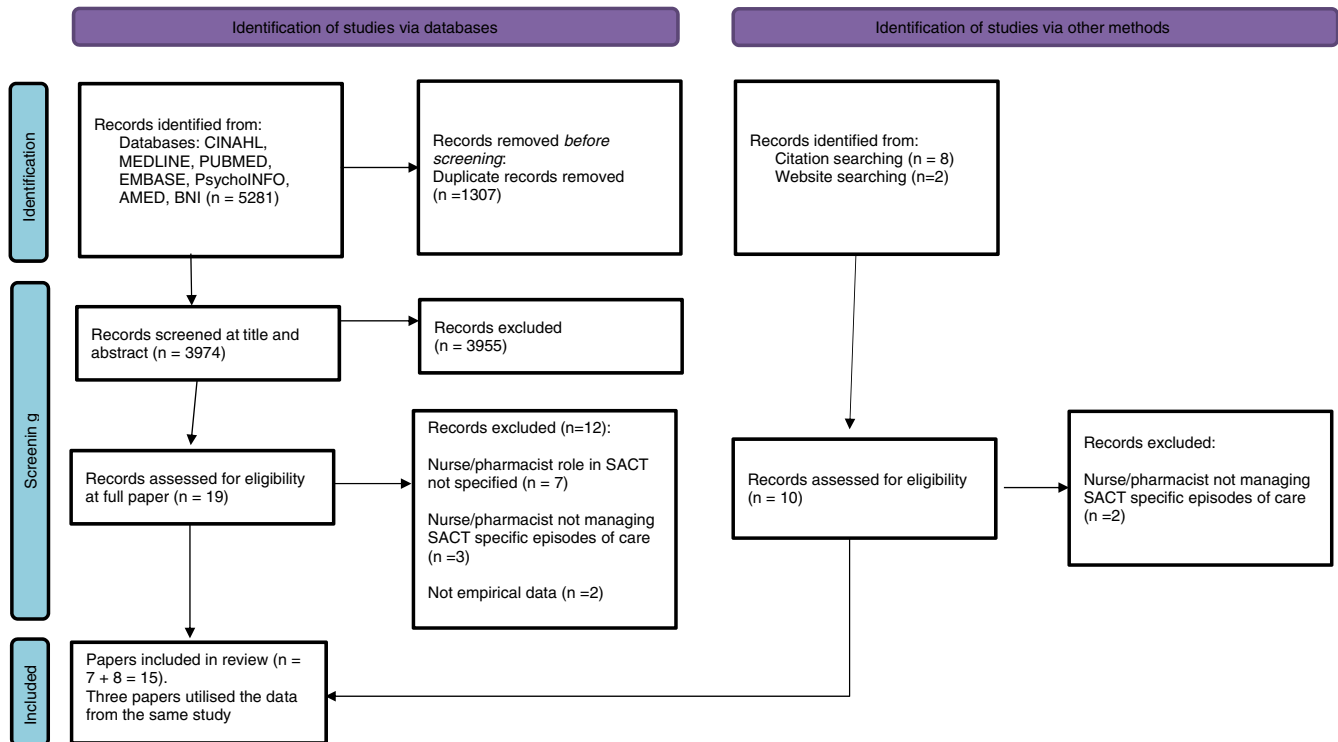
All papers were quality assessed using a numbered scoring system and ranked as high (25–35 points), medium (13–24) or low quality (1–12) (Table S2). Points were deducted according to how well each paper met the required criteria of each section. No papers were excluded based on their quality.

TABLE 1 PEO framework

POPULATION-patients receiving SACT:	EXPOSURE(S) multi-professional clinics	OUTCOME safe, effective, patient-centred care
<ul style="list-style-type: none"> <li>• SACT</li> <li>• Systemic anti-cancer therap*</li> <li>• Systemic anticancer therap*</li> <li>• Systemic anticancer treatment*</li> <li>• Systemic anti-cancer treatment*</li> <li>• Chemotherap*</li> <li>• Immunotherap*</li> <li>• Biological therap*</li> <li>• Targeted therap*</li> <li>• Checkpoint inhibitor*</li> <li>• Anti-cancer therap*</li> <li>• Anticancer therap*</li> </ul>	<ul style="list-style-type: none"> <li>• Nurs*</li> <li>• Pharmacist*</li> <li>• Advance* practitioner*</li> <li>• Advance* nurse practitioner*</li> <li>• Advance* clinical practi*</li> <li>• Multi-professional</li> <li>• Non-medical prescrib*</li> </ul>	<ul style="list-style-type: none"> <li>• Patient experience*</li> <li>• Patient satisfaction</li> <li>• Symptom management</li> <li>• Toxicities</li> <li>• Patient Outcome*</li> <li>• Patient reported outcome*</li> <li>• Patient-reported outcome*</li> <li>• Patient care</li> <li>• Effective*</li> </ul>

TABLE 2 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• Empirical research of qualitative, quantitative, or mixed methods design</li> <li>• Study participants aged 18 years and over</li> <li>• Written in English</li> <li>• Patients receiving SACT for a cancer diagnosis</li> <li>• Patients being reviewed by nurses or pharmacists independent of medical team for review and confirmation of treatment</li> <li>• Patients seen by nurses or pharmacists for treatment review and confirmation in combination with medical team</li> </ul>	<ul style="list-style-type: none"> <li>• Non-empirical papers e.g., commentary or an opinion paper</li> <li>• Conference abstracts/unpublished research</li> <li>• Systematic reviews</li> <li>• Participants under 18 years of age</li> <li>• Non-English language as no translation available</li> <li>• Participants without a cancer diagnosis</li> <li>• Patient not receiving SACT</li> <li>• Patients with no independent nurse or pharmacist reviews for treatment</li> <li>• Papers covering medical practitioners only</li> <li>• Patients being reviewed for symptom control or supportive needs only</li> </ul>



**FIGURE 1** Prisma flowchart. Adapted from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. the PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. Doi: [10.1136/bmj.n71](https://doi.org/10.1136/bmj.n71). For more information, visit: <http://www.prisma-statement.org/>

### 3.6 | Data abstraction

A data extraction tool was developed to review the included papers. Only data relevant to the research aim were included in this review (Table S3).

### 3.7 | Synthesis

Heterogeneity of the studies' focus, study population, sample size and data collection methods, as well as differences in reported outcomes meant meta-analysis was not possible. Quantitative findings were converted into textual descriptions to allow synthesis with qualitative themes. As several studies included data not related to multi-professional SACT clinics, narrative syntheses of the relevant findings only were performed (Braun & Clarke, 2006). The process was inductive; all papers were read several times, and themes were recorded in tabular format and then grouped under headings relevant to each theme. Three main themes were identified with sub-themes for each (Table 3).

## 4 | RESULTS

Fifteen papers met the inclusion criteria and were included in the review. Of these, 10 were scored as high quality and five as medium quality; none were scored as low quality. Four papers are qualitative (Farrell

et al., 2017; Hobson et al., 2009; Lennan, 2014; Siouta et al., 2019), two of which use ethnography (Farrell et al., 2017; Siouta et al., 2019), one grounded theory approach (Hobson et al., 2009) and one participatory evaluation (Lennan, 2014). Two papers used mixed methods (Farrell et al., 2020; Ignoffo et al., 2021); eight are observational studies (Bruinooge et al., 2018; Dennison et al., 2021; Farrell et al., 2010; Lam & Cheung, 2016; Maier et al., 2018; Patel et al., 2016; Simons et al., 2010; Towle et al., 2011); and one used a Delphi design (Ignoffo et al., 2016). Two papers (Farrell et al., 2020; Siouta et al., 2019) undertook secondary analysis on primary data collected in an ethnographic study (Farrell et al., 2017) and all three are therefore included in this review.

Eleven papers are hospital based (Dennison et al., 2021; Farrell et al., 2010; Farrell et al., 2017; Farrell et al., 2020; Ignoffo et al., 2016; Lam & Cheung, 2016; Lennan, 2014; Maier et al., 2018; Patel et al., 2016; Simons et al., 2010; Siouta et al., 2019) and four are hospital and community based (Bruinooge et al., 2018; Hobson et al., 2009; Ignoffo et al., 2021; Towle et al., 2011).

Seven studies were undertaken in the USA (Bruinooge et al., 2018; Dennison et al., 2021; Ignoffo et al., 2016; Ignoffo et al., 2021; Lam & Cheung, 2016; Patel et al., 2016; Towle et al., 2011); four in the UK (Farrell et al., 2010; Farrell et al., 2017; Hobson et al., 2009; Lennan, 2014); one in Germany (Simons et al., 2010) and one across nine European countries (Maier et al., 2018).

Six papers included pharmacists only (Dennison et al., 2021; Ignoffo et al., 2016; Ignoffo et al., 2021; Lam & Cheung, 2016; Patel et al., 2016; Simons et al., 2010); four included oncology nurses

TABLE 3 Themes and sub-themes development

Papers	Theme 1: ACP SACT service development		Theme 2: ACP skills and qualifications		Theme 3: Impact of ACP SACT services on patient care and outcomes		
	1.1 optimal SACT clinic model for ACP roles	1.2 challenges to ACP SACT service development	2.1 attainment of skill and qualifications	2.2 utilization of skills in ACP practice	3.1 the pharmacist role in patient adherence to SACT	3.2 provision of holistic care	3.3 patient satisfaction with ACP roles in SACT clinics
Dennison et al (2021)				X			X
Ignoffo et al (2021)				X			
Farrell et al (2020)	X		X			X	
Siouta et al (2019)			X			X	
Bruinooge et al (2018)	X		X	X			
Maier et al (2018)			X	X			
Farrell et al (2017)		X	X	X		X	
Patel et al (2016)			X	X	X		
Lam & Cheung, 2016)				X	X		
Ignoffo et al (2016)			X	X			
Lennan (2014)	X		X				
Simons et al (2010)				X	X		
Towle et al (2011)		X		X			X
Farrell et al (2011)	X		X	X			
Hobson et al (2009)				X			X

(Farrell et al., 2010; Farrell et al., 2017; Farrell et al., 2020; Siouta et al., 2019), two included oncology nurses and physician associates (Bruinooge et al., 2018; Towle et al., 2011); one included nurses, physicians, pharmacists and managers (Lennan, 2014); one included nurses and physicians (Maier et al., 2018), and one included nurses and pharmacists (Hobson et al., 2009). Three studies included data on the patient experience of ACP SACT clinics (Dennison et al., 2021; Hobson et al., 2009; Towle et al., 2011).

## 4.1 | Themes

Following analysis, several themes and subthemes were created (Table 3).

### 4.1.1 | ACP SACT service development

#### *Optimal SACT clinic model for ACP roles*

Two papers explore the optimal multi-professional team (MDT) model for SACT clinics, both highlighting the importance of close working relationships between professions (Bruinooge et al., 2018; Lennan, 2014). An evaluation of stakeholders' views and experiences of SACT Non-Medical Prescriber (NMP) clinics in one UK Trust, found a shared-care model, with patients seen alternately by the NMP and physician, is optimal. NMP nurses, not pharmacists, are preferred, but an open-formulary approach is contentious and attendance at the weekly MDT meetings is disputed (Lennan, 2014).

Advanced practitioners working in oncology clinics in the USA identified fully independent patient reviews as the most satisfying practice model and provided access to an oncologist to discuss care decisions (Bruinooge et al., 2018). The authors acknowledge that sampling of eligible professionals was constrained by a lack of an advanced practitioner national database, and that respondents were overwhelmingly white (90%) and female (97%), higher than the national average. Also, nurse practitioners and physician associates were surveyed, and findings were presented under the term 'Advanced Practice Providers' only.

#### *Challenges to ACP SACT service development*

Challenges to ACP SACT service development are explored in six papers. Poor understanding of specialist nursing roles at organizational, nursing and medical colleague levels impacts service development, with 40.6% identifying organizational barriers, 13.9% nursing barriers and 21.8% physician barriers (Farrell et al., 2010), but data are general oncology. Consultant-specific preferences control clinic development, referrals and implementation, potentially leading to an ad hoc approach, nurse frustration and clinic under utilization (Bruinooge et al., 2018; Farrell et al., 2017; Lennan, 2014). Physicians may restrict drug formulary use due to concerns about ACP prescribing competency (Lennan, 2014). All these studies identify a medical leadership model dictating clinic provision (Bruinooge et al., 2018; Farrell et al., 2017; Lennan, 2014).

The only study to survey physicians' experience of working with ACPs found 79.8% are satisfied with MDT working (Towle et al., 2011). No information is provided, however, on what contributed to this satisfaction. Profession-specific information is not provided, and data was not based solely on SACT clinics.

Billing regulations and the need for income optimisation, not patient care requirements, dictate a shared care, rather than an independent ACP clinic model approach in a USA study (Towle et al., 2011). This study reviewed nurse, pharmacist and physician associate roles under the umbrella term 'non-physician practitioners'. In the UK, nurse-led clinics with longer slots templated to support holistic assessments lead to organizational concerns about financial viability and restriction of further implementation (Farrell et al., 2017). Where clinic slot times are reduced due to capacity issues, a task-orientated rather than a holistic approach to patient care is observed (Farrell et al., 2020).

### 4.1.2 | ACP skills and qualifications

#### *Attainment of skill and qualifications*

Nine papers explore the skills and academic qualifications of advanced practitioners and demonstrate wide variation. No studies specify whether there is a minimum mandatory requirement to undertake ACP-led services at organizational or national level, although one study argues NMP should be a pre-requisite for any ACP-managed SACT clinic to ensure autonomous practice (Lennan, 2014).

Qualifications range from no academic course post-initial professional qualification (Farrell et al., 2010; Maier et al., 2018), 'on the job' training (Farrell et al., 2011), to post-graduate qualifications at masters level (Bruinooge et al., 2018; Farrell et al., 2010; Hobson et al., 2009; Ignoffo et al., 2016; Maier et al., 2018; Patel et al., 2016) and doctorate level (Bruinooge et al., 2018; Farrell et al., 2010). Five papers name qualifications undertaken but not their academic level, including NMP (Farrell et al., 2010; Farrell et al., 2017; Farrell et al., 2020; Hobson et al., 2009; Siouta et al., 2019), physical examination and advanced communication skills (Farrell et al., 2017; Farrell et al., 2020; Siouta et al., 2019). Three studies identify post-registration training without providing course details or academic levels (Bruinooge et al., 2018; Ignoffo et al., 2021; Maier et al., 2018). One study identifies eight skills as core to the role of board-certified oncology pharmacists in the USA, including SACT adjustment and management (Ignoffo et al., 2016).

Seven studies identify NMP as part of ACP roles, of which four identify nurse prescribing (Bruinooge et al., 2018; Farrell et al., 2010; Farrell et al., 2017; Maier et al., 2018), one pharmacist prescribing (Hobson et al., 2009) and two non-specific professional roles (Lennan, 2014; Towle et al., 2011). Skills may have been acquired, specifically physical assessment and NMP, but are not always utilized in practice (Farrell et al., 2010; Farrell et al., 2017).

Several role titles are identifiable in the papers, including nurse consultant, advanced nurse practitioner, chemotherapy nurse (Farrell et al., 2017; Farrell et al., 2020; Siouta et al., 2019), nurse

practitioner (Bruinooge et al., 2018), oncology clinical pharmacist (Dennison et al., 2021), oncology pharmacist (Ignoffo et al., 2016; Ignoffo et al., 2021; Lam & Cheung, 2016) and nonphysician practitioner (Towle et al., 2011), however, no link is made between role title and qualifications. One small survey study ( $n = 103$ ) identifies 19 job titles among respondents (Farrell et al., 2010).

#### *Utilization of skills in ACP practice*

Skills utilization is discussed in 12 papers that show a variation in practice. Autonomy is only explored in one paper; four levels of SACT nurse practice are identified, ranging from highly protocolled, checklist-led pre-treatment toxicity reviews to complete nurse-led clinical management for a SACT regimen (Farrell et al., 2017). Practice level is not linked to skills attainment, however, as all have NMP and physical assessment qualifications; it is instead linked to role title and seniority and relationships with medical consultant colleagues.

Ordering of chemotherapy is undertaken by 53.9% of nurses surveyed ( $n = 381$ ) in one study (Bruinooge et al., 2018). Another found 76.7% ( $n = 103$ ) run nurse-led clinics of which 25% are chemotherapy clinics; however, only 50% of nurses with an NMP qualification are prescribing chemotherapy, with physician imposition of prescribing restrictions identified as a factor (Farrell et al., 2010). Breast advanced nurse practitioners working in countries where national policy has driven ACP roles (Netherlands, England, Scotland), denoted 'innovator' countries, are more likely to prescribe SACT treatments than nurses working in 'traditional' countries with no such national policy. This includes endocrine/hormonal therapies and biological therapies, although the latter is not at statistically significant levels. For endocrine/hormonal treatments, the overall number of nurses prescribing these are relatively small at 19.5% in innovator countries versus 0% in traditional countries.

One study identifies pharmacists prescribing SACT, but only via a patient-specific clinical management plan agreed with the patient's physician (Hobson et al., 2009). In a survey of 27 oncology practices in the USA, 45%–50% of non-physician practitioners order routine chemotherapy, but individual professions are not specified (Towle et al., 2011).

In 'innovator' countries, dose adjustment by nurses is significantly higher than in 'traditional' countries for biological therapies ( $p < .01$ ), endocrine and hormonal treatments ( $p < .001$ ) and chemotherapy ( $p < .01$ ) (Maier et al., 2018). Only one study identifies ACP nurses discontinuing or deferring SACT treatments (Farrell et al., 2017). Four studies identify pharmacists undertaking SACT dose adjustments, but two provide no data on the frequency or type of adjustments made (Ignoffo et al., 2016; Ignoffo et al., 2021). One study found 14.5% of oncology pharmacist interventions are dose adjustment specific in the intervention study arm, but no comparative data is provided for the control arm (Lam & Cheung, 2016). Another study found that SACT dose adjustment is not significantly higher in the service change arm when compared to usual pharmacist care ( $p = .32$ ) (Patel et al., 2016).

SACT-specific toxicities management was presented in six studies. Two found 90% of oncology pharmacists frequently manage SACT-related toxicities (Ignoffo et al., 2016; Ignoffo et al., 2021) and another that this accounts for 16.8% of interventions in a pharmacist-led oral SACT treatment clinic (Lam & Cheung, 2016). A further two studies report this as frequently undertaken by pharmacists, but no data is provided (Dennison et al., 2021; Simons et al., 2010). Only one study identifies nurse involvement in SACT-specific toxicities but does not provide data; it is also not clear if the nurses are assessing and treating toxicities, or assessing toxicities only (Farrell et al., 2017). Two studies report nurses managing treatment-related toxicities, but neither identify if this is in SACT only or includes other treatment modalities (Farrell et al., 2010; Maier et al., 2018).

Pharmacist management of adverse events increased in a pharmacist-led chemotherapy-monitoring programme when compared to usual care but is not statistically significant ( $p = .851$ ) and no adverse event details are provided (Patel et al., 2016). Advanced practitioners support treatment side effect management in a further study, but no data or details of the treatments are provided (Bruinooge et al., 2018).

Two studies found oncology pharmacists identify response to chemotherapy as commonly undertaken (Ignoffo et al., 2016; Ignoffo et al., 2021). There is significant variation in the frequency reported at 60% (Ignoffo et al., 2021) and 92% (Ignoffo et al., 2016) of activity, but the latter study grouped toxicity and response assessment into one activity. A third study found 51% of oncology nurses assess response to treatment, but this is not SACT-specific alone (Farrell et al., 2010).

#### 4.1.3 | Impact of ACP SACT services on patient care and outcomes

##### *The pharmacist role in patient adherence to SACT*

Three studies identified pharmacists as addressing challenges to patient adherence to SACT, but the frequency, impact and types of interventions undertaken are variable (Lam & Cheung, 2016; Patel et al., 2016; Simons et al., 2010). Significantly higher levels of adherence-specific interventions are identified when compared to usual care ( $p = .004$ ), with an overall improvement in patient adherence to laboratory monitoring ( $p = .04$ ) (Patel et al., 2016). Adherence is significantly improved by a pharmacist intervention programme in another study ( $p < .0046$ ) (Lam & Cheung, 2016). A third study reports improved daily adherence to oral SACT, in the intervention group, although this is not statistically significant ( $p = .069$ ) (Simons et al., 2010). The same study shows a significantly increased likelihood of remaining on treatment by the end of the study ( $p = .019$ ) for those in the treatment arm. The impact of improved adherence on treatment response is only assessed in one study, but no significant improvement is found ( $p = .46$ ); the researchers acknowledge, however, that the sample size is small (Lam & Cheung, 2016).



## 4.2 | Provision of holistic care

Three papers explore nurse–patient interactions in nurse-led SACT clinics in four UK organizations (Farrell et al., 2017; Farrell et al., 2020; Siouta et al., 2019); all, however, utilize data from the same study (Farrell et al., 2017). In semi-structured interviews following observed clinics, the nurses perceived themselves to be taking a holistic approach to their clinical reviews (Farrell et al., 2017). However, a task-orientated approach is instead observed by researchers (Farrell et al., 2017), with higher responsiveness to treatment or disease-specific side effect concerns than to psychological or socio-cultural cues (Farrell et al., 2020). Similarly, most nurses adopt a non-personalized discourse, failing to make the interaction patient-focused (Siouta et al., 2019).

## 4.3 | Patient satisfaction with ACP roles in SACT clinics

Three papers include evidence of patient satisfaction with MDT SACT clinics, but the findings are conflicted. One study found high levels of satisfaction with a pharmacist-led oral SACT programme ( $p = .047$ ) (Dennison et al., 2021). Another qualitative study found patients prefer nurse-led to pharmacist-led services, expressing concerns about pharmacists' training to undertake clinical reviews (Hobson et al., 2009). The former study, however, did not reach power in its patient recruitment ( $n = 40$ ), and the latter is not oncology-specific alone. The third study reports 92.5% of patients surveyed are extremely satisfied with non-physician practitioners, but the clinics were generic oncology, not SACT specific and professional groups are not identified (Towle et al., 2011).

## 5 | DISCUSSION

The study aim and objectives have only been partially met due to the limited research available. There is variation in tasks undertaken by nurses and pharmacists in SACT-specific ACP roles in the USA, UK and several European countries, including Germany and the Netherlands. Evidence of role integration is limited, and a lack of physician engagement is identified. Job titles, skills and qualifications acquired differ, while professional autonomy is variable and often dictated by a medical leadership model. None of the studies identify minimum skills or qualifications required at an organizational or national level. Evolution in service models and ACP roles over time is not evidenced.

The findings align with research into ACP roles in primary care and other specialist medical and surgical services. ACP development internationally has occurred haphazardly (Anderson et al., 2020) and regulatory requirements and scopes of practice vary (Bader et al., 2020), making the transferability of studies' findings problematic. Several countries, including the USA, Australia, Canada and the Netherlands, have regulatory and legislative frameworks,

including protected titles and minimum academic requirements, within which ACP roles must operate (Anderson et al., 2020; Heale & Rieck Buckley, 2015). However, while all professionals in ACP roles in the USA must be educated to Masters or Doctoral level (Heale & Rieck Buckley, 2015), state-level regulation can restrict ACPs activity (Bader et al., 2020; Heale & Rieck Buckley, 2015), particularly in pharmacists' prescribing practice (Kislan et al., 2016).

Of the European countries included in the papers reviewed, only two have protected titles; the Netherlands require education at Masters' level to use the title 'Nurse Practitioner' (Heale & Rieck Buckley, 2015), while UK pharmacists can only use the title 'Consultant' after completion of a specific post-graduate pathway (Bader et al., 2020). No such requirements are applicable to UK nurse roles, leading to a plethora of job titles and role misunderstandings (Fothergill et al., 2022; Lawler et al., 2020), also evident in this review.

Health Education England, a government body in England that provides leadership and coordination of education for healthcare professionals, has attempted to standardize practice and qualification requirements across ACP roles by publishing an Advanced Clinical Practice Framework in 2017; this is not mandated, however, and is yet to improve standardization (Fothergill et al., 2022). Also, despite the level of regulation in some countries and acknowledgement that advanced practice roles can support the management of future demand, role ambiguity persists (Jones et al., 2015).

In this review, role autonomy and optimal MDT SACT services are linked to NMP qualifications and an associated reduction in reliance on medical colleagues (Lennan, 2014). Access to physician advice is, however, acknowledged to support safe and sustainable practice (Bruinooge et al., 2018; Lennan, 2014), as in other specialities (Andregård & Jangland, 2015). However, ACP autonomy can be infringed by physicians, who invariably dictate working practices (Bruinooge et al., 2018; Farrell et al., 2017; Lennan, 2014) and can be reluctant to engage with service development (Bruinooge et al., 2018; Farrell et al., 2017). This can negatively impact optimal service provision and can create professional friction (Bruinooge et al., 2018; Farrell et al., 2010).

There is little exploration of why physicians can be disengaged with ACP roles, beyond an identification of limited understanding of ACP (Farrell et al., 2010), and concerns regarding training (Lennan, 2014). The only study to seek physician feedback found overall satisfaction with ACP roles but does not clarify why (Towle et al., 2011).

Inter-professional collaboration has been found to improve efficiency, decrease costs, provide a more holistic approach to care and decrease physician workloads (Andregård & Jangland, 2015). A holistic approach to patient care is not, however, observed in the SACT nurse-led clinics discussed in three papers (Farrell et al., 2017; Farrell et al., 2020; Siouta et al., 2019), and evidence of improved efficiency or decreased costs is limited. Task-shifting between physicians and advanced practitioners can be increased by national policy changes (Maier et al., 2018), but is often unofficial, negotiated and a context-specific process (Jones et al., 2015), requiring physician cooperation (Lawler et al., 2020).

Despite increasing pressures on health services (Jones et al., 2015) and oncologist shortages (Ignoffo et al., 2016; Towle et al., 2011), there is ongoing under-utilization of ACP roles (Fothergill et al., 2022;

Lawler et al., 2020). Lack of ACP role clarity, the plethora of job titles and variation in training quality, can lead to physician reluctance to support role implementation (Brooten et al., 2012; Fothergill et al., 2022). Nurses highlight physician-related barriers detrimentally impacting SACT service development (Farrell et al., 2010) and advanced practitioners in other specialities report similar issues, particularly when roles are first introduced (Jones et al., 2015).

Prescribing regulations vary by profession and country. In the USA, most states only allow pharmacists to prescribe via limited 'collaborative practice agreements' with physicians (Holle & Boehnke Michaud, 2014), although some allow full prescribing rights (Sessions et al., 2010). In the UK, however, pharmacists have been able to train as independent prescribers since 2006 (Hobson et al., 2009), leading to greater inclusion in ACP roles (Health Education England, 2017) and a demonstrable impact on clinical and economic outcomes (Segal et al., 2019).

Nurse prescribing is well-established in many countries, albeit with varying levels of autonomy and integration (Fox et al., 2022). While it is accredited in the UK, USA, the Netherlands, Norway and Poland (Fox et al., 2022), it is not in Germany, Czech Republic, Italy and Turkey. This precludes nurses in these countries from prescribing SACT or supportive medications for toxicity management. There is no evidence that ACP service provision improves patient adherence to SACT or patient outcomes despite an increase in reviews (Lam & Cheung, 2016; Patel et al., 2016; Simons et al., 2010). This contrasts with study findings in specialities such as primary care (Laurant et al., 2018; Simon et al., 2021).

Improved holistic care is often linked to ACP roles through the establishment of therapeutic and collaborative relationships (Jakimowicz et al., 2015), and patients report high levels of satisfaction with ACP interactions (Bergman et al., 2013; Eriksson et al., 2018; Simon et al., 2021). Only one study in this review, reported in three papers, explores holistic care in ACP SACT clinics and found no evidence of it, despite nurses' perceptions of taking a holistic approach to patient reviews (Farrell et al., 2017; Farrell et al., 2020; Siouta et al., 2019). Three further studies provide feedback on patient experience of ACP roles, but for pharmacists findings are limited and conflicted (Dennison et al., 2021; Hobson et al., 2009; Towle et al., 2011).

This review has shown that nurse and pharmacist ACP roles in SACT clinics can improve patient management and care, but the evidence is limited. Service and role development are ad hoc and reliant on physician support, but physician experiences have not been explored. Patient experience, often a key driver for change in healthcare delivery, has also been poorly addressed. For ACP roles to develop further and gain the support of the multi-professional team, it is incumbent on nurse and pharmacist leaders to support further qualitative research into patient and physician experiences of existing services.

## 5.1 | Limitations

A limitation of this review is the small number of studies specifically addressing nurse and pharmacist role implementation in SACT

services. Two papers undertook secondary analysis on primary data collected in a third study (Farrell et al., 2017), and several other studies use generic role titles as an umbrella term. The search strategy identified only seven of the included papers, a further eight were identified through reference searching, indicating potential limitations in the search terms used. Generalizability and transferability of findings are also limited due to variation in ACP role development and regulation internationally, with access to some skills, such as NMP, often limited at a national level.

## 6 | CONCLUSION

This review has identified that while ACP roles are seen as essential to SACT service delivery in the UK and USA, there is limited evidence of how roles are being implemented, what skills and academic qualifications are essential and are utilized, and the extent to which ACP roles are impacting patient experience and outcomes. The development of the ACP role is often perceived as reliant on physician support, however, there is limited exploration of physicians' perspectives. Further research is required to explore the interaction between nurses, pharmacists, physicians and patients in MDT SACT clinics, their experience of MDT service models and what represents the key components of successful service delivery.

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## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

## AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE\*):

1. Substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
2. Drafting the article or revising it critically for important intellectual content.

## PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15512>.

## DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# Change fatigue in nursing: An integrative review

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## Abstract

**Aims:** To synthesize the empirical and theoretical literature on change fatigue in nursing, including how change fatigue affects nurses, the nursing profession and strategies to prevent and overcome it.

**Background:** Change fatigue refers to the overwhelming feelings of stress, exhaustion and burnout associated with rapid and continuous change across healthcare organizations. Change fatigue can affect nurses' wellbeing, yet there is a distinct lack of literature which synthesizes the relationship between cumulative organizational change and nurses' wellbeing.

**Design:** Integrative review following Toronto and Remington and Whittemore and Knafl methodology.

**Data Sources:** Searches were conducted in CINAHL, Embase, Medline, APA PsycInfo, Scopus, Business Source Complete and ProQuest Dissertations & Theses Global in January 2022.

**Review Methods:** A comprehensive search was conducted to identify literature on change fatigue in nursing. Included literature were critically appraised for methodological quality. Data from each article were abstracted and thematically analysed.

**Results:** Twenty-six articles were included in this review, including 14 empirical studies, 10 theoretical papers and two literature reviews. Five main themes described in the literature included: definitions, preceding factors, associated behaviours, consequences and mitigation strategies for change fatigue.

**Conclusion:** This review highlights the impact of rapid and continuous change on nurses and nursing practice. Further research is needed to explore the relationship between change fatigue and burnout, understand how and why nurses withdraw or avoid change, and to develop a metric to measure change fatigue when considering new change initiatives.

**Impact:** Findings from this review generated an improved understanding of how change fatigue affects nurses, the nursing profession and strategies to prevent and overcome it. This paper provides practical recommendations for future research, direction for nursing educators and leaders, and encourages nurses to practice political agency with change management.

**Patient or Public Contribution:** This project was an integrative review of the literature therefore no patient or public contribution was necessary.

## KEYWORDS

burnout, change fatigue, healthcare, nurses, nursing, organizational change, political agency, rapid and continuous change, resiliency, workplace change



## 1 | INTRODUCTION

Healthcare's changing landscape is driven by the need for continuous improvement in the provision of care (MacPhee, 2007; McMillan & Perron, 2020a). Amidst competing priorities, healthcare organizations face challenges implementing and sustaining multiple changes to facilitate best practices and ensure healthcare providers deliver safe, competent care (MacPhee, 2007). Numerous co-occurring changes often create an overwhelming volume of initiatives and expectations in practice (Bernerth et al., 2011; MacPhee, 2007; Torppa & Smith, 2011). When changes are implemented, healthcare providers are expected to adjust their practice and balance numerous competing priorities. The continued pressure for change contributes to a phenomenon experienced by many healthcare providers, termed change fatigue (Bernerth et al., 2011; McMillan & Perron, 2020a).

## 2 | BACKGROUND

Organizational change research has primarily focused on change resistance, and historically, change failure has thought to be due to change resistance; behaviours that threaten the success of change initiatives (Bernerth et al., 2011; de Vries & de Vries, 2021; Orlando, 2014; Ouedraogo & Ouakouak, 2021; Torppa & Smith, 2011). However, in recent years, authors have identified another phenomenon, change fatigue, which threatens the success of change implementation and has detrimental effects on individuals (Bernerth et al., 2011; de Vries & de Vries, 2021; MacPhee, 2007; Orlando, 2014; Ouedraogo & Ouakouak, 2021; Torppa & Smith, 2011; Wynen et al., 2019).

The changing landscape in healthcare is fuelled by reforms in innovation, technology, quality improvement, fiscal restraint, restructuring and optimization efforts in response to increased demand for access to services and, in recent years, the global pandemic (Bruce & English, 2020; de Vries & de Vries, 2021; MacPhee, 2007; Ouedraogo & Ouakouak, 2021; Wynen et al., 2019). Among healthcare providers, nurses have experienced high levels of stress, burnout and exhaustion due to increasing workplace demands and rapid and continuous organizational change (McMillan & Perron, 2020a). The result has created change fatigue, a complex, multifaceted phenomenon exacerbated by the need for continuous improvement in healthcare (Bernerth et al., 2011; Jantzen et al., 2017). Continuous improvement causes numerous co-occurring change agendas, resulting in an incessant and overwhelming inundation of initiatives (Bernerth et al., 2011; Ouedraogo & Ouakouak, 2021). Leaders who promote organizational change acknowledge that nurses are often expected to carry out new initiatives, continually acclimatize to changes and balance numerous competing change agendas among their already challenging workload (McMillan & Perron, 2020a). Thus, in an environment with rapid and continuous change, nurses may struggle to maintain stability and control, leading to disengagement, burnout, apathy and change fatigue (Brown & Cregan, 2008; Wynen et al., 2019). Exploring and understanding the phenomenon of change fatigue has implications for patient care, nurses' wellbeing and the nursing profession.

McMillan and Perron (2020b) argued that administrators' decisions significantly impact nurses' experience of change fatigue. Specifically, they articulated that in a neoliberal healthcare landscape, there is an immense push to implement rapid changes, often without proper evaluation of readiness for change and engagement of frontline staff in the planning and preparation, which may inadvertently foster change fatigue (McMillan, 2018). A broad exploration of change fatigue in nursing is needed to examine the relationship between repeated organizational change and the impact on nurses' wellbeing.

## 3 | THE REVIEW

### 3.1 | Aim

The aim of this integrative review was to answer the following question: What is known about how nurses experience change fatigue?

### 3.2 | Design

The aim of an integrative review is to summarize what is known about a topic and communicate a synthesis of literature to a targeted community (Toronto & Remington, 2020). Integrative reviews provide a broad understanding of a specific phenomenon by encompassing diverse literature sources, assessing the quality of evidence, identifying gaps in the literature and recognizing future steps for research and practice (Russell, 2005). This integrative review was conducted following the six-step methods described by Toronto and Remington (2020) and Whittemore and Knafel (2005): (1) formulation of a broad review question, (2) systematic search of the literature, (3) critical appraisal of selected literature, (4) analysis and synthesis of the literature, (5) discussion of new knowledge and (6) dissemination of findings.

Experts suggest using a theoretical framework to guide the review process (Toronto & Remington, 2020). To critically understand the complex phenomenon of change fatigue and its impact on nurses, critical social theory (CST) provides a new perspective that is underrepresented in the current literature (McMillan & Perron, 2020a). Exploring change fatigue from a CST lens elucidates the inequality in change management; the power and authority in leaders' decision-making juxtaposed with the powerlessness and passive acceptance nurses experience with relentless change (Sumner, 2007; Weaver & Olson, 2006). Using CST, we can examine the underlying effects of powerlessness, subordination and oppression experienced by nurses undergoing rapid and continuous change. We integrated CST throughout the review process and in the interpretation of the review findings.

### 3.3 | Search methods

The following databases were searched in June 2021 and re-run in January 2022: CINAHL Plus with Full Text (Ebsco), MEDLINE(R)

and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily (OVID), APA PsycInfo (OVID), Business Source Complete (Ebsco), Scopus (Elsevier) and ProQuest Dissertations and Theses Global (ProQuest). No limits were placed on location or publication date. Search terms included: “change fatigue” OR (“organization or workplace change” OR “fatigue or stress or burnout or exhaustion or hardiness or powerless\* or apathy”) AND “nurs\*.” As change fatigue is not well defined and is under-researched, other commonly used terms noted in the literature were included among the search words. Keywords and search terms were consistent across all databases, and appropriate subject headings were used with the appropriate database. An example strategy from CINAHL has been supplied in [Table S1](#). We conducted forward and backward citation chasing of included articles to identify additional literature. Commonly known change management organization websites, such as Prosci Inc. (Prosci Inc, 2022) and Google, were also searched using search terms “change fatigue” AND “nursing.”

Investigators exported all database records to Covidence to enable citation management, duplication removal and screening decisions. Two reviewers independently screened literature at title and abstract, and then full-text levels following strict inclusion and

exclusion criteria ([Table 1](#)). All disagreements were discussed, and consensus was achieved without requiring a third reviewer.

### 3.4 | Quality appraisal

Two reviewers conducted quality appraisal of each article independently, using Joanna Briggs Institute (JBI) checklists for each type of study design ([Table 2](#)). All disagreements were discussed to arrive at consensus on the appraisal scoring. All eligible articles were included in the review regardless of the appraisal outcome.

### 3.5 | Data abstraction

We created a data abstraction matrix table to extract pertinent information from each selected article (Toronto & Remington, 2020). Guided by the theoretical underpinnings of CST, the matrix table was created with different columns to abstract descriptive data from each article that would aid in answering the review question. Column titles included study methods, methodology, theories or frameworks, research aim or objective, authors' definition of change

TABLE 1 Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Literature type	Literature in published journals <ul style="list-style-type: none"> <li>• Experimental:               <ol style="list-style-type: none"> <li>(i) Qualitative</li> <li>(ii) Quantitative</li> <li>(iii) Mixed method</li> </ol> </li> <li>• Non-experimental:               <ol style="list-style-type: none"> <li>(i) Case reports</li> <li>(ii) Review</li> <li>(iii) Text, opinion, letters to the editor, editorials</li> </ol> </li> </ul> Grey literature (unpublished reports): <ul style="list-style-type: none"> <li>• Thesis and dissertation</li> <li>• White papers</li> </ul>	<ul style="list-style-type: none"> <li>• Social media</li> <li>• Blog posts</li> <li>• Media or newspaper</li> <li>• Magazine articles</li> <li>• Conference proceedings or abstracts</li> </ul>
Concept or phenomenon	Change fatigue	<ul style="list-style-type: none"> <li>• Change resistance</li> <li>• Change management</li> <li>• Change cynicism</li> <li>• Psychological uncertainty</li> <li>• Temporal ambiguity</li> </ul>
Area of practice	<ul style="list-style-type: none"> <li>• Nursing discipline               <ol style="list-style-type: none"> <li>(i) Any practice area</li> <li>(ii) Any level of nursing education background (i.e. student nurses, diploma or degree holder)</li> <li>(iii) Any nurse practice role (licensed practical nurse, graduate nurse, registered nurse, nurse clinician, nursing instructor, nurse practitioner, nurse manager, clinical nurse specialist)</li> <li>(iv) Educational institutions or clinical practice areas</li> </ol> </li> </ul>	<ul style="list-style-type: none"> <li>• Not in the nursing discipline</li> <li>• Unable to delineate nursing information in multidisciplinary studies</li> </ul>
Language	English language	Not in English language
Date range	No limit on date range	N/A
Geographical area	No limit on geographical setting	N/A

TABLE 2 Critical appraisal tools used

Research type	Checklist Title	Reference
Text and opinion	• JBI: Checklist for Text and Opinion	McArthur et al., 2015
Qualitative	• JBI: Checklist for Qualitative Research	Lockwood et al., 2015
Quantitative	• JBI: Checklist for Prevalence Studies	Munn et al., 2015
Mixed methods	• JBI: Checklist for Qualitative Research • JBI: Checklist for Prevalence Studies	Lockwood et al., 2015; Munn et al., 2015
Review	• JBI: Checklist for Systematic Reviews and Research Synthesis	Aromataris et al., 2015

fatigue, background, antecedents, outcomes, strategies and key results or findings. One reviewer completed the data abstraction and a second reviewer verified the accuracy.

### 3.6 | Synthesis

We used thematic analysis to identify and organize recurrent themes across multiple literature sources (Braun & Clarke, 2006). We synthesized data into five themes and 13 subthemes (Table 3). The team vetted all themes and subthemes, and disagreements were resolved through discussion.

## 4 | RESULTS

Our electronic and hand searches generated 2531 records which were screened for inclusion, and 84 underwent secondary full-text screening. Of these, 26 articles were included in the final synthesis. Figure 1 displays the flow of literature throughout our review. The 26 articles included 10 text or opinion, six quantitative, four qualitative, four mixed methods and two review-based articles (Table 4). A summary of all included studies is provided in Tables 5, 6. Two records were published as dissertations and as journal articles (Brown, 2016; Brown et al., 2018; McMillan, 2018; McMillan & Perron, 2020b, 2021). All studies were published between 2002 and 2021. Research was conducted in Australia ( $n = 2$ ), Canada ( $n = 7$ ), Europe ( $n = 3$ ) and the United States ( $n = 14$ ) in a variety of settings, some spanning multiple settings, including acute care, ambulatory care, community care, and in academic settings.

The results of the quality appraisal are presented in (Tables S2 to S5). The qualitative studies had congruency between research methodology, data collection, data analysis and results. However, in half of the qualitative studies (including mixed methods studies with qualitative arms) the authors failed to make clear statements about their philosophical worldview, cultural or theoretical location or the researcher influence on the study. The quantitative studies and mixed methods studies which included a quantitative arm were critically appraised to be of high quality. Only two of the mixed methods studies failed to provide depth in details about the participants and settings (Lind et al., 2018; Wozniak et al., 2020). In the text and opinion articles the authors clearly identified their opinions which were based on expertise and interest. However, in half of the text and opinion articles the authors failed to reference extant literature on change fatigue and were not clear if their opinions were a

result of analytical process. Only one author identified and logically defended any incongruence with literature (McMillan & Perron, 2013). Two reviews were included, and while one was appraised to be high quality (Gee et al., 2017), the other lacked details about the appraisal criteria, and process of data extraction and synthesis (Brown & Abuatiq, 2020).

Our thematic analysis of 26 articles yielded five themes and 13 subthemes, as presented in Table 3. Our theme development was informed by the theoretical tenets of CST, guided by the theoretical framework of critical management studies (CMS), which view the dominant discourses in change management practices that foster power inequities in nursing practice and illuminate the oppression, subordination and powerlessness nurses experience with rapid and continuous change (McMillan, 2018; Sumner, 2007; Weaver & Olson, 2006). Using CMS helped to recognize nurses experience of change fatigue remains significantly underrepresented in current literature (McMillan, 2018; McMillan & Perron, 2013, 2020b). In addition, using CST informed the development of mitigation strategies as the theory focuses on resolution of oppression, importance of autonomy and empowerment (Sumner, 2007; Weaver & Olson, 2006).

### 4.1 | Definitions of change fatigue

#### 4.1.1 | Homogenous definitions of change fatigue

Change fatigue was defined as an overwhelming feeling of stress, exhaustion and burnout associated with rapid and continuous change in the workplace, affecting nurses' overall health and wellbeing (Brown, 2016; Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; McMillan, 2018; McMillan & Perron, 2013, 2020b). Developing over time, change fatigue and relentless organizational change produces compounding adverse effects for nurses (Camilleri et al., 2019; Gee et al., 2017; Reineck, 2007; Szumilas, 2015). Change fatigue was also noted to be commonly mistaken for change resistance (Mayer & Hammelef, 2013; McMillan & Perron, 2013).

#### 4.1.2 | Divergent definitions of change fatigue

Although many authors reported homogeneity among their definitions of change fatigue, some had divergent definitions. For example, some authors recognized change fatigue manifests as a resistance to change or cynicism about change (Davis, 2002;

TABLE 3 Themes and sub-themes identified from the findings of the records

Themes	Sub-themes	Sources
Definitions of change fatigue	Homogenous definitions of change fatigue	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Summer Bryant, 2020; Camilleri et al., 2019; Gee et al., 2017; Kapping, 2021; Lind et al., 2018; Mayer & Hammelef, 2013; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir & Keim-Malpas, 2020; Muir et al., 2021; Reineck, 2007; Szumilas, 2015; Valusek, 2007.
	Divergent definitions of change fatigue	Davis, 2002; Huynh et al., 2018; Kapping, 2021; Mayer & Hammelef, 2013; Metusela et al., 2021; Reineck, 2007; Vestal, 2013.
	No definition provided	Davis, 2002; Ead, 2015; Gee et al., 2017; Muir & Keim-Malpas, 2020; Wozniak et al., 2020.
Factors preceding change fatigue	Rapid and continuous change	Brown et al., 2018; Camilleri et al., 2019; Davis, 2002; Ead, 2015; Havaei et al., 2021; Lind et al., 2018; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021; Szumilas, 2015; Tracy, 2006; Vestal, 2013.
	Lack of control	Brown & Abuatiq, 2020; Davis, 2002; Ead, 2015; Gee et al., 2017; Kapping, 2021; Vestal, 2013.
	Intensification of workload	Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; Gee et al., 2017; Huynh et al., 2018; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2020b; Muir & Keim-Malpas, 2020; Vestal, 2013; Wozniak et al., 2020.
Behaviours associated with change fatigue	Exhaustion	Brown & Abuatiq, 2020; Camilleri et al., 2019; Davis, 2002; McMillan & Perron, 2020b; Muir et al., 2021.
	Powerlessness	Brown & Abuatiq, 2020; Davis, 2002; Ead, 2015; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir & Keim-Malpas, 2020; Muir et al., 2021; Reineck, 2007; Vestal, 2013.
	Passive acceptance	Brown, 2016; Brown & Abuatiq, 2020; McMillan & Perron, 2013, 2020b.
Consequences of change fatigue	Individual consequences	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Camilleri et al., 2019; Davis, 2002; Ead, 2015; Kapping, 2021; Mayer & Hammelef, 2013; McMillan, 2018; McMillan & Perron, 2013, 2020b.
	Organizational consequences	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Camilleri et al., 2019; Ead, 2015; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021; Szumilas, 2015; Tracy, 2006; Vestal, 2013.
Change Fatigue Mitigation Strategies	Resilience	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Summer Bryant, 2020; Ead, 2015; Mayer & Hammelef, 2013; McMillan & Perron, 2020b; Szumilas, 2015.
	Change Management Practices	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Summer Bryant, 2020; Camilleri et al., 2019; Ead, 2015; Kapping, 2021; Mayer & Hammelef, 2013; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021; Tracy, 2006; Valusek, 2007; Vestal, 2013.
	Political agency	Summer Bryant, 2020; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021.

Huynh et al., 2018). Contrary to homogenous definitions, which presume nurses passively accept changes, authors asserted that nurses question the value and objectives of change (Reineck, 2007; Tracy, 2006), indicating nurses actively question change. Metusela et al. (2021) provided a literal description indicating change fatigue was observed as nurses working longer hours to manage change stress. There is much variability among conceptual definitions of change fatigue in the nursing literature, with some authors referring to change fatigue without a definition (Davis, 2002; Ead, 2015; Gee et al., 2017; Muir & Keim-Malpas, 2020; Wozniak et al., 2020).

## 4.2 | Factors preceding change fatigue

### 4.2.1 | Rapid and continuous change

Authors suggested that rapid and continuous practice initiatives have become the norm due to the constant need to improve health-care delivery (Brown et al., 2018; Davis, 2002; McMillan, 2018; McMillan & Perron, 2013; Muir et al., 2021; Vestal, 2013). The current healthcare landscape of continued improvement results in

Change fatigue in nursing literature search flow diagram (Page et al., 2021)

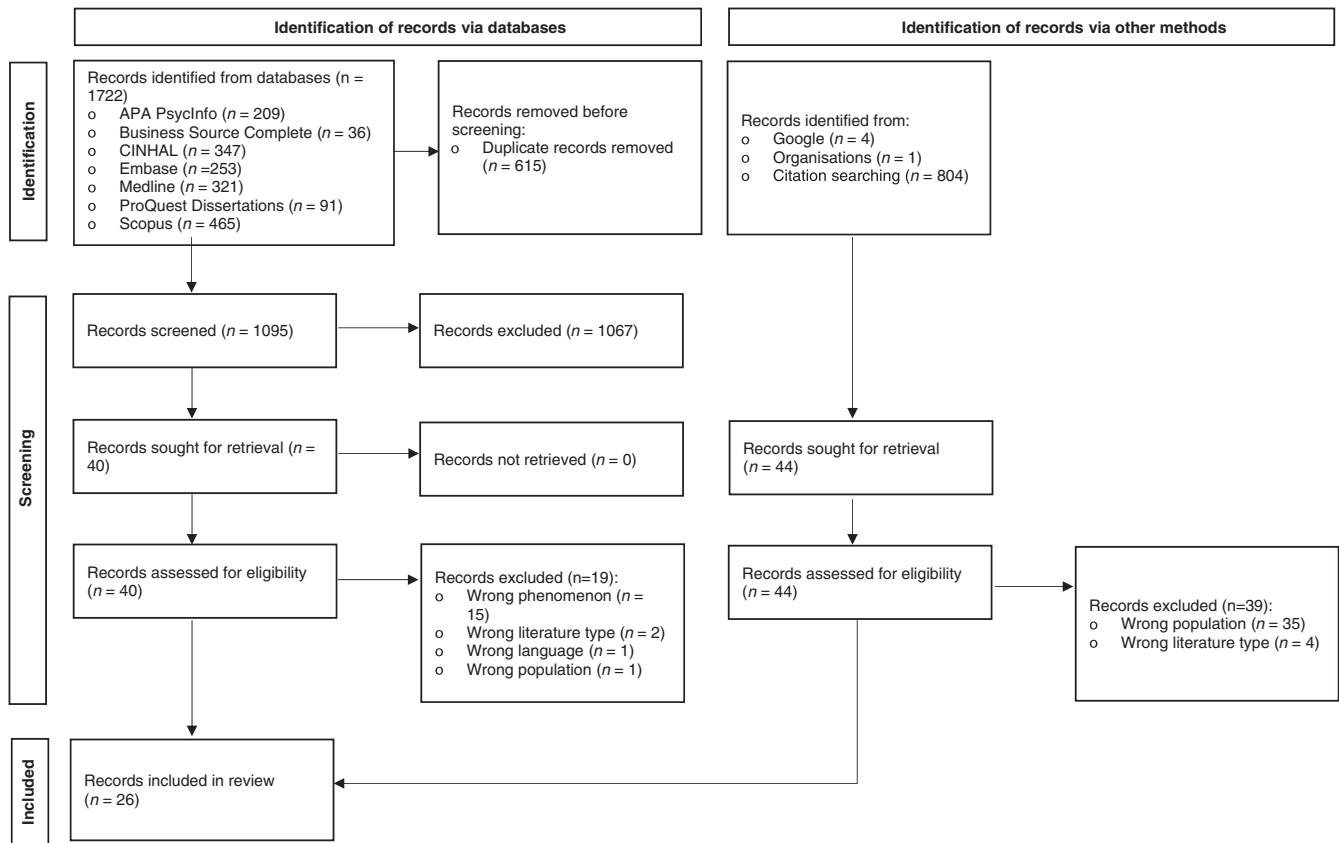


FIGURE 1 Change fatigue in nursing literature search flow diagram (Page et al., 2021).

TABLE 4 Demographic characteristics of included records

Research type	Number of included studies	Reference
Text and opinion	10	Summer Bryant, 2020; Davis, 2002; Ead, 2015; Mayer & Hammelef, 2013; McMillan & Perron, 2013; Reineck, 2007; Szumilas, 2015; Tracy, 2006; Valusek, 2007; Vestal, 2013.
Qualitative	4	McMillan, 2018; McMillan & Perron, 2020b; McMillan & Perron, 2021; Muir et al., 2021.
Quantitative	6	Brown, 2016; Brown et al., 2018; Camilleri et al., 2019; Havaei et al., 2021; Huynh et al., 2018; Kapping, 2021.
Mixed methods	4	Lind et al., 2018; Metusela et al., 2021; Muir & Keim-Malpas, 2020; Wozniak et al., 2020.
Review	2	Brown & Abuatiq, 2020; Gee et al., 2017.

increasing intensity of change, challenging nurses' ability to adapt and cope in the workplace, leaving them vulnerable to change fatigue (Brown et al., 2018; Lind et al., 2018; Vestal, 2013). In a qualitative study by McMillan, participants reported, "it has been years and years of change for all staff. It just hasn't stopped and we just haven't gotten our feet back underneath us" (2018, p. 80). McMillan and Perron (2020b) explained that rapid and continuous change restructures how and when patient care is provided. For example, Havaei et al. (2021) reported nurses have experienced change fatigue during the covid-19 pandemic due to frequent changes in policies and procedures requiring them to quickly respond and adapt as evidence evolves. The experience of continuous change exacerbates change fatigue which can impair the healthcare system's ability to function

and achieve sustainable change, ultimately affecting the quality of care provided (Lind et al., 2018; Szumilas, 2015; Tracy, 2006). Additionally, individuals become fatigued by the confluence of rapid changes, lack of recovery periods and the constant pressure of new mandates (Camilleri et al., 2019; Davis, 2002; Ead, 2015; Lind et al., 2018; McMillan & Perron, 2013).

#### 4.2.2 | Lack of control

Several authors recognized that individuals attempt to maintain stability and balance in their environment but experience fatigue, burnout and a lack of control with turbulent change (Davis, 2002;

TABLE 5 Summary of included empirical articles

Reference, location	Aim, sample, setting	Research design and methods	Key findings
Brown, 2016, USA	The purpose of the doctoral dissertation was to determine if a relationship among change fatigue, resilience and job satisfaction of 535 novice or experienced hospital staff nurses existed.	Quantitative: A descriptive correlational design was used, participants completed an online survey, using three tools: Change Fatigue Scale, Connor-Davidson Resilience Scale, and McCloskey/Mueller Satisfaction Scale.	Findings reported a significant difference between novice and experienced staff nurses in change fatigue ( $p = .003$ ), resilience ( $p = .01$ ), and job satisfaction ( $p = .04$ ). Experienced nurses had higher change fatigue, resilience and job satisfaction mean scores. A significant negative association between change fatigue and job satisfaction ( $p = .000$ ) and change fatigue and resilience ( $p = .002$ ). Multiple linear regression found that years of experience were not significant with change fatigue, however, education, gender and hospital size were predictor variables. In addition, as the size of facility and number of beds increased, change fatigue increased, and as education increased, change fatigue decreased. The study provided new knowledge of the relationship among change fatigue, resilience and job satisfaction of hospital staff nurses. New knowledge will assist nursing leaders to become aware of the effects of change fatigue and develop interventions to prevent change fatigue of hospital staff nurses, which in turn may increase job satisfaction and retention rates.
Brown & Abuatiq, 2020, USA	An exploration of resilience and how resilience training for nurses can help protect against the negative effects of stress caused by organizational change.	Review: A literature review adapted from a doctoral dissertation, included 11 articles.	Two main themes were identified: (1) resilience and organizational change for nurses and (2) resilience training for nurses in clinical practice. Authors noted understanding personal resilience is crucial to drive effective change because people who possess high levels of resilience can readily accept change without experiencing traumatic and debilitating consequences. Change fatigue in nurses is a negative effect of constant organizational change that has been minimally researched.
Brown et al., 2018, USA	The purpose of the study was to examine relationships between change fatigue, resilience and job satisfaction among 521 novice and seasoned hospital staff nurses.	Quantitative: A descriptive correlational design was employed. Participants completed three online surveys: Change Fatigue Scale, Connor-Davidson Resilience Scale, and McCloskey/Mueller Satisfaction Scale.	A multiple regression model showed job satisfaction had a statistically significant negative association with change fatigue ( $p < .001$ ) and significant positive association with resilience ( $p < .001$ ). A linear trend was found with hospital size and change fatigue ( $p = .001$ ) and education level and resilience ( $p = .03$ ). The results are consistent with job satisfaction among hospital nursing staff being negatively influenced by change fatigue and positively influenced by resilience. Change fatigue may be increased by larger hospital size, and resilience may be increased by higher educational level of hospital staff nurses.
Camilleri et al., 2019, Australia	To evaluate the experience of change fatigue in frontline nursing staff following large-scale organizational change and determine whether improved teamwork perception scores can mitigate the experience of change fatigue. Participants included nurses in an established team ( $n = 225$ ), and nurses in a newly reconfigured team ( $n = 521$ ).	Quantitative: An online questionnaire was used to survey a cross section of frontline nurses from two distinct cohorts.	Frontline nurses who transitioned in an established team reported higher levels of change fatigue following large-scale change, compared with those in a new, reconfigured team ( $p = .013$ ). There is a small significant negative correlation between perception of teamwork and change fatigue scores. Regardless of team type, high levels of change fatigue are reported by frontline nursing staff following large-scale organizational change. Established teams have a higher perceived level of teamwork in all domains when compared with a new team in the same change conditions. It is unlikely that the perception of teamwork has any real-world impact on the experience of change fatigue.



TABLE 5 (Continued)

Reference, location	Aim, sample, setting	Research design and methods	Key findings
Gee et al., 2017, United Kingdom	The aim of this study was to identify the factors contributing to lasting change in practice following a recovery-based training intervention for inpatient mental health rehabilitation staff.	Review: A rapid realist review methodology was used to generate and prioritize programme theories. Stakeholders validated and prioritized emerging programme theories and theories were refined using literature case studies.	Fifty-one relevant documents fed into 49 programme theories articulating seven mechanisms for lasting change. Prioritized mechanisms were staff receptiveness to change; and staff feeling encouraged, motivated and supported by colleagues and management to change. Lasting change can be facilitated by collaborative action planning, regular collaborative meetings, appointing a change agent, explicit management endorsement and prioritization and modifying organizational structures. Conversely, a challenging organizational climate, or a prevalence of 'change fatigue', may block change. Pre-intervention exploration may help identify any potential barriers to embedding recovery in the organizational culture.
Havaei et al., 2021, Canada	The purpose of this study was to examine the impact of COVID-19 workplace conditions on nurses' mental health outcomes. An electronic survey was emailed to nurses in Canada with a total of 3676 responses.	Quantitative: A cross-sectional correlational design was used.	The study showed concerning prevalence rates for post-traumatic stress disorder (47%), anxiety (38%), depression (41%) and high emotional exhaustion (60%). Negative ratings of workplace relations, organizational support, organizational preparedness, workplace safety and access to supplies and resources were associated with higher scores on all of the adverse mental health outcomes included in this study. Better workplace policies and practices are required to prevent and mitigate nurses' suboptimal work conditions, given their concerning mental health self-reports during the COVID-19 pandemic.
Huynh et al., 2018, USA	The association of self-reported adaptive reserve (AR) and burnout among 119 healthcare providers was studied with self-administered, online surveys.	Quantitative: A survey containing a 23-item AR scale and burnout inventory questions was sent to a convenience sample of nurses, house staff team members, and hospitalists.	Ordinal regression analyses were used to examine the association between AR and burnout. Eighty per cent of participants reported either level 1 or 2 burnout. Participants reporting higher burnout were about three times more likely to report lower AR levels. AR is strongly associated with self-reported burnout by physicians and nurses providing inpatient care at this medical centre. Evidence supports the positive association of AR to successful change implementation in ambulatory settings. Related literature shows that when a team faces the constant pressure of transformative change but lacks one or more of the characteristics of AR, change fatigue results.
Kapping, 2021, USA	The purpose of this study was to determine if there is a relationship between (a) job satisfaction and change fatigue and (b) organizational commitment and change fatigue in nurses who work in an outpatient clinical environment. Online surveys were administered to 136 outpatient nurses.	Quantitative: A correlational design used three tools: McCloskey/Mueller Satisfaction Scale, the Change Fatigue Scale and the Unidimensional Target Neutral Commitment Measures.	Results showed a statistically significant relationship between change fatigue and job satisfaction was weakly correlated ( $p = .026$ ), with a weak positive correlation between organizational commitment and change fatigue ( $p = .046$ ). Results may impact on social change through raising awareness of what the nurse experiences during change initiatives while potentially improving staff retention. Leadership teams may benefit from monitoring the amount and timing of initiatives being introduced to potentially decrease change fatigue from occurring.

(Continues)

TABLE 5 (Continued)

Reference, location	Aim, sample, setting	Research design and methods	Key findings
Lind et al., 2018, Sweden	The study aimed to explore the feasibility of a pilot version of a strategy for introducing the Integrated Palliative care Outcome Scale (IPOS) in acute care settings. For comparative reasons it was also tested in a palliative care unit.	Mixed methods: A process evaluation was conducted including collecting quantitative data and performing interviews with healthcare professionals.	The prevalence of completed IPOS in the patient's records varied from 6% to 44% in the acute care settings. The qualitative results showed opposing perspectives concerning the training provided. In the acute care settings, a need for an improved culture about palliative care was identified. A context characterized by a constantly increasing workload, a feeling of constantly on-going changes and a feeling of change fatigue were found at all units.
McMillan, 2018, Canada	The aim of this doctoral dissertation was to explore the nature of frontline nurses' experiences of living with rapid and continuous organizational change in healthcare. A component of this research was to explore the opportunity of change fatigue in nurses.	Qualitative: A critical hermeneutic design was used to explore concepts of organizational change, experience of change, change fatigue and power and voice at a hospital in Canada with a sample of 14 Registered Nurses.	Organizational change challenges healthcare providers in a variety of ways because it restructures how and when patient care delivery is provided, changing ways in which nurses must carry out their work. Nurses recognized that many change initiatives reflected an ideological shift in healthcare that supported a culture of service, while sacrificing a culture of care. A culture of service prioritized cost-savings and efficiency, which saw nurses lose the time and resources required to provide quality, safe care. Nurses felt morally responsible to uphold a culture of care, which proved challenging, and at times unobtainable. The inability to provide quality, safe care resulted in a multitude of negative emotional repercussions, fostering moral distress. Nurses exhibited elements of change fatigue, contributing to feelings of voicelessness and powerlessness in their workplace. Organizational change must be re-conceptualized in ways that ensure change initiatives uphold institutional integrity and better support the provision of morally authentic nursing practice. Healthcare organizations should place nurses at the forefront of planning, implementation, and evaluation of change initiatives to alleviate the many negative experiences of organizational change noted in this study.
McMillan & Perron, 2020b, Canada	This adapted doctoral dissertation examined nurses' experiences of rapid and continuous organizational change, examining the concept of change fatigue.	Qualitative: A critical hermeneutic approach was used. Face-to-face interviews were conducted with 14 Registered Nurses.	Nurses did experience many of the core elements of change fatigue noted in the non-nursing literature, including exhaustion, apathy, powerlessness and burnout. Two additional themes were identified pertaining to nurses' experience of change fatigue, including the intensification of nursing work, and repeated and ongoing self-sacrifice. The negative experiences associated with change fatigue are important for administrators and other stakeholders to recognize and acknowledge, as they must alleviate change fatigue in their institutions to preserve the wellbeing of nurses. This knowledge is also important to nursing scholars, who may further research the topic and embed it into nursing curricula.
McMillan & Perron, 2021, Canada	The purpose of this inquiry was to explore the nature of frontline nurses' experiences of rapid and continuous change.	Qualitative: A critical hermeneutic design was applied with 14 Registered Nurses at an hospital in Canada.	The findings suggest that acts of resistance to change are not overt, but rather covert behaviours in micro-ethical moments. Nurses engaged in resistance as means to provide morally authentic care. These acts were used to take back power over their practice amidst feelings of powerlessness. When participants described the concept of power, they understood it solely in the context of feeling powerless in the planning, implementation and evaluation of organizational change initiatives. Nurses' engagement with resistant behaviours in the context of organizational change demonstrated ethical action and political agency that enabled morally authentic nursing practice. The findings offer new understandings and can be used when considering the ethical dimensions of nursing work amidst rapid changes in healthcare.

TABLE 5 (Continued)

Reference, location	Aim, sample, setting	Research design and methods	Key findings
Metusela et al., 2021, Australia	The study examined the experiences of seven general practices in Australia that implemented projects aligned with Patient Centred Medical Home (PCMH) values and goals supported by their local Primary Health Network.	Mixed method: Data were collected over a 12-month period, including semi-structured interviews, participant observation and practice data to present a detailed study.	Facilitators implementing successful, sustainable change included the capacity and willingness of practices to undertake change; practice engagement with a shared vision towards PCMH change; engaged leadership; training and support; and structures and processes required to provide team-based, data driven care. Barriers to implementation included change fatigue, challenges of continued engaged leadership and insufficient time to implement PCMH change. The study examined the experiences of implementing PCMH initiatives and described the facilitators and barriers to PCMH change. The findings provide guidance for primary health networks that are interested in undertaking similar quality improvement projects.
Muir & Keim-Malpas, 2020, USA	To assess the feasibility of a pilot mindfulness intervention programme, the Emergency Resiliency Initiative (ERI), as well as to investigate changes in burnout scores and key drivers to burnout among registered nurses (RNs) and patient care technicians (PCTs) in an emergency department (ED).	Mixed method: A pre/post study with data collection points before and after the 3-month intervention with 35 participants. Interventions included three mindfulness sessions. Burnout scores were assessed using the Maslach Burnout Inventory.	From the pre- ( $n = 35$ ) to post- ( $n = 26$ ) intervention period there was a significant increase in personal accomplishment scores ( $p = .01$ ) and decrease in emotional exhaustion scores ( $p = .03$ ) for RNs and PCTs combined. Qualitative interviews revealed five burnout-related themes: (a) prioritization distress, (b) change fatigue, (c) self-protection through superficiality, (d) intentional response and (e) community amid chaos. The ERI was a feasible and acceptable programme associated with improvements in burnout scores. Qualitative interviews revealed the positive impacts of mindfulness on ED clinician resiliency and identified future opportunities to address burnout.
Muir et al., 2021, USA	The purpose of this ethnographic study was to evaluate the cultural impacts of an emergency department (ED) move from an old to new physical space.	Qualitative: Ethnographic fieldwork was conducted over 14 months in an ED. Primary data sources included participant observations and semi-structured interviews with ( $n = 39$ ) emergency nurses, non-nurse clinicians and unit administrators.	One cross-cutting theme, decisional power, and three supporting themes inadequate move preparation, change fatigue and lack of change standardization were identified. Decisional power was the perceived influence certain ED groups had making move-related decisions over others. Change fatigue described the impact of frequent change implementation on participants' work processes, wellbeing and job satisfaction. Lack of change standardization described power differentials between nurses striving to standardize new move-related processes and physicians implementing work styles discordant with such processes. Findings can inform recommendations for healthcare policy and organizational operations such as: (1) including frontline stakeholder perspectives in move-related decisions; (2) allocating adequate time for clinician/employee training/education in the pre-move period; (3) assessing clinician/employee wellbeing throughout move implementation; (4) increasing unit administrator sensitivity to clinician change fatigue.
Wozniak et al., 2020, Canada	The study assessed the context in which a hip Fracture Liaison Service was implemented.	Mixed methods: Semi-structured interviews were conducted with 21 key informants at two time points to understand organizational readiness, facilitators and barriers to change.	Findings suggested that the use of several strategies, including demonstrating value, providing resources and selecting appropriate sites, and using change readiness tools were important to implementation, in the context of change fatigue. The study revealed an effective change management approach neutralized change fatigue.

TABLE 6 Summary of included theoretical articles

Reference, location	Key findings
Summer Bryant, 2020, USA	Change is constant in nursing. In the first few months of the covid-19 pandemic change came faster than ever in healthcare settings. Perhaps the most control we can have over it is how we react and adapt to it. One way to react to change is to be involved in the change process. Being involved with decision-making in the current environment ensures nurses' voices are amplified about patient care during the pandemic. However, even though nurses may be pretty good at change, it takes a toll on us. Change fatigue can plague our resilience, and cause stress and burnout. We must take care of ourselves; by getting involved in decision-making and rebuilding resilience through regular self-care.
Davis, 2002, United Kingdom	Since the 1980s the National Health Service has been repeatedly restructured and the government is poised for yet another overhaul. It is unclear if such storms of upheaval make nurses' lives any better. Nurses are faced with incessant changes and have been unsupported on under-resourced wards. The majority of nurses have become quite cynical about all the change because it goes on in the background and no effort is made to involve them in it. They just get on with their jobs and are busy holding the whole thing together. But the danger is that constant change is massively disruptive and makes too little real change at grassroots level. There is structural change fatigue in the National Health Service and people have simply had enough.
Ead, 2015, Canada	In the fast-paced world of healthcare, it is not uncommon for nurses to have days where they are pushed to their limits. Despite these pressures, each year, new initiatives are shared in organizations that the nurses must learn, embrace, and include in their practice. Each new initiative can be additive to the nurse's workload; most changes are not time neutral but require staff to expend an allotment of time from their day to complete. When adopting new practice, it is not realistic to add on to workload and stretched resources long term. Workload needs to be addressed by employing workload measurement tools and principles of human factors engineering to better support the provision of optimal patient care.
Mayer & Hammelef, 2013, USA	We need to realize that change is not linear; there are ups and downs, starts and stops. It can take a long time to perceive benefits from a change, which can lead to frustration. Change fatigue is different from resistance to change. With change fatigue, staff can become disengaged and apathetic, often feeling disempowered, burnt out, disillusioned and passive about changes being introduced. Signs of change fatigue may include questioning the value and objectives of the change, diverting resources to other initiatives, showing impatience with the pace of change, and key leaders no longer being visibly engaged with the change.
McMillan & Perron, 2013, Canada	The concept of change fatigue has evolved from the discipline of management as a means to explore organization change and its associated triumphs and failures. Change fatigue has typically been described as change resistance. Concept clarification has highlighted the striking differences and few similarities that exist between the concepts. Further exploration and subsequent research on the concept of change fatigue is needed in the discipline of nursing. The concept not only presents new and alternative perspectives on the processes of organization change but also provides opportunity for theory development that recognizes the impact organizational change has on nurses.
Reineck, 2007, USA	Implementing change in organizations is a key nursing leadership competency. Models of successful change illustrate useful concepts for leaders. Change fatigue is a result of relentless change, during which employees lose trust. It is one reason nurse leaders search for effective models of change management. Successful change models include careful use of power, reason, re-education, structure, behaviour and technology. Learning from models may help nurse leaders avoid change fatigue and may promote safer systems of care.
Szumilas, 2015, USA	Healthcare's landscape is constantly changing. Healthcare organizations are challenged to balance the provision of safe care with the allocation of essential resources. Institutions are poised to recognize that a constantly changing practice environment is extremely stressful. Continuous change overtime creates symptoms of fatigue, and burnout, which can compound already existing stressors, cripple a unit team members' commitment and ultimately affect the quality of care. Nurses' ability to adjust to change must be self-realized. Nurses have to make conscious decisions to become activists in the care they provide.
Tracy, 2006, USA	Current changes in healthcare organizations are intended to improve patient safety. However, when continuous changes are underway, few succeed, they may recycle and return with a new name. Employees find it difficult to see the underlying logic or purpose of the change, and ironically implementing multiple safety initiatives at once may actually jeopardize patient safety. With so much change occurring there is no time to get input from those affected by it, no time to fully evaluate progress and adjust. It is recommended to focus on the vital few changes rather than the valuable many.
Valusek, 2007, USA	Change fatigue refers to impairments in an individual's and organization's ability to cope with the ever-increasing scope and pace of change. The creation of a change calendar tool to prevent change fatigue in healthcare as it proactively assesses and schedules changes across the organization to reduce the amount of distraction and change fatigue.

TABLE 6 (Continued)

Reference, location	Key findings
Vestal, 2013, USA	Changes in clinical care, work processes, technology and professional issues all converge at the point of care and are expected to be carefully orchestrated by staff nurses each time they engage with a patient or a team member. This confluence of change creates a tsunami of pressures on care providers. It is common to hear about fatigue, alarm fatigue, compassion fatigue and work hours fatigue. The potential for change fatigue is bound to be a factor as healthcare races forward into the future. Findings suggest, acknowledging change is necessary but can be hard on the staff who must adapt to the constantly changing expectations. Ensure leaders have an accurate picture of the number and magnitude of changes underway. Consider how to prevent communication overload and consider resources needed to implement changes.

Gee et al., 2017; Vestal, 2013). For example, Brown and Abuatiq (2020) suggested nurses' wellbeing may be affected if the rate of change is perceived as too frequent. Davis agreed, acknowledging "nurses will suffer in the turbulence created in the process" (2002, p. 24). Excessive change can impair nurses' ability to cope and adapt to change, creating a sense of uncertainty and a lack of control (Ead, 2015; Kapping, 2021).

#### 4.2.3 | Intensification of workload

When the focus is on the quantity of change, not quality, this can lead to unintended consequences and change fatigue (Brown & Abuatiq, 2020; Camilleri et al., 2019; Kapping, 2021; Wozniak et al., 2020). Authors reported saturation effect or lack of lulls between changes can lead to change fatigue (Brown et al., 2018; McMillan & Perron, 2020b). Authors described an intensification of workload results in a blitz of change initiatives, in which staff are expected to alter their practice and implement the changes with a lack of resources (Muir & Keim-Malpas, 2020; Vestal, 2013). In a cross-sectional study, healthcare teams who faced constant change but lacked the ability to make or sustain change, known as adaptive reserve, experienced change fatigue (Huynh et al., 2018).

### 4.3 | Behaviours associated with change fatigue

#### 4.3.1 | Exhaustion

Several authors explored exhaustion as associated with rapid and continuous change (Brown & Abuatiq, 2020; Camilleri et al., 2019; Davis, 2002; McMillan & Perron, 2020b; Muir et al., 2021). Davis (2002) suggested the pace of change had detrimental consequences causing stress, tiredness and exhaustion. For example, in a qualitative study evaluating the impact of changes to a physical space in an emergency department, one participant shared, "just think that when you're...overworked, stressed out, nervous, people don't sleep. I hear people all the time telling me they cannot sleep before work. That is terrifying to me. Can you imagine how the patients must feel?" (Muir et al., 2021, p. 5). Another participant reinforced the feeling of exhaustion, "it was just really tiring, it was just

one thing [change] after another, it just tired people out" (McMillan & Perron, 2020b, p. 2630).

#### 4.3.2 | Powerlessness

Several authors recognized nurses are not immune to the effects of constant change (Brown & Abuatiq, 2020; Davis, 2002). Most concerning, the impact of change places significant pressure on nurses to carry out changes with a lack of accompanying support (Davis, 2002; McMillan & Perron, 2013; Muir & Keim-Malpas, 2020; Vestal, 2013). For example, a qualitative study participant reported feeling stressed, insecure, and anxious about the new changes expected in practice (Muir et al., 2021). Muir et al. (2021) elaborated the adverse effects of change fatigue were derived from the decisional power of those planning and implementing change. Several authors acknowledged that change management is often predominantly focused from a 'top-down' approach with a lack of consideration for the end-users, contributing to alienation, dissolution, and powerlessness (McMillan, 2018; McMillan & Perron, 2013; Reineck, 2007). Authors also identified that nurses attempt to share their concerns about ongoing change, but lack of acknowledgement creates dissent due to a perceived low level of influence, lack of collaborative decision-making, and powerlessness due to fear of speaking out and reprisal (Ead, 2015; McMillan, 2018; McMillan & Perron, 2013). In addition, several participants expressed the lack of decision-making took away power, influence, and control over proposed changes (McMillan & Perron, 2020b). McMillan (2018) recognized nurses have a moral responsibility to uphold a standard of care, and this becomes jeopardized in the context of rapid change and change fatigue, resulting in moral distress.

#### 4.3.3 | Passive acceptance

McMillan and Perron (2020b) identified that the passive acceptance of change resulted from individuals not questioning the value of new change initiatives and being unable to differentiate change fatigue from resistance. Investigators have reported change management leaders often misinterpret this diametric response as it is often not explicitly felt or observed and could be mistaken for acceptance



(McMillan & Perron, 2013). McMillan and Perron (2013) corroborated their claim explaining passive behaviours are manifested by staff becoming disengaged, apathetic, and ambivalent, showing no signs of resistance. For example, participants shared that continuous workplace change as feeling robotic and numb towards the change process, portraying passive acceptance of change. Due to the passive behaviour associated with change fatigue, it is often unnoticed and under-researched (Brown, 2016; Brown & Abuatiq, 2020; McMillan & Perron, 2013).

## 4.4 | Consequences of change fatigue

### 4.4.1 | Individual consequences

During rapid or unremitting change, change fatigue can manifest as individuals' emotional or behavioural reactions. Emotional reactions include apathy, passive acceptance, emotional exhaustion, withdrawal, stress, disempowerment, disengagement, disillusionment, ambivalence, grief, uncertainty, burnout, resignation, and moral distress (Brown, 2016; Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; Davis, 2002; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013, 2020b). Similarly, descriptions of behavioural outcomes are silent dissent, decreased work and life satisfaction, self-sacrifice, increased rates of absenteeism, work disability, loss of productivity, decreased organizational commitment, low morale, lack of employer trust, and may influence nurses' decision to leave the profession (Brown, 2016; Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; Ead, 2015; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013, 2020b). Several authors recognized the passive or silent nature of change fatigue causes outcomes to go unnoticed and understanding the impact of change fatigue has important ramifications for nurses' health and wellbeing (Brown & Abuatiq, 2020; Kapping, 2021; Mayer & Hammelef, 2013; McMillan & Perron, 2020b).

In addition, authors who investigated change fatigue have documented a high incidence of burnout among nurses who experience rapid or continuous change (McMillan & Perron, 2013, 2020b). Although authors did not explicitly indicate a correlated or cyclical relationship between burnout and change fatigue, the two concepts are often experienced concurrently (McMillan & Perron, 2020b). McMillan and Perron (2020b) elucidated burnout was directly related to the impact of ongoing change, increased workloads, and lack of support that nurses experienced. McMillan and Perron (2020b) shared a participant excerpt indicating nurses were sacrificing their personal time in an attempt to stay current with organizational change due to the intensification of workload and lack of paid time, fostering feelings of burnout. Some authors also described that burnout is related to increased exhaustion, staff withdrawal, resentment, and overall negative feelings about organizational change (McMillan & Perron, 2013). Overall, McMillan and Perron (2013) explicated that the experience of

change fatigue and burnout are detrimental to nurses and the profession.

### 4.4.2 | Organizational consequences

Authors have also acknowledged the organizational impact of change fatigue due to unprecedented change rates (McMillan & Perron, 2020b). Outcomes include increased absenteeism, turnover rates, decreased organizational productivity and commitment, decreased job satisfaction, low morale, moral distress, difficulties retaining nurses, and latent change failure (Brown & Abuatiq, 2020; Brown et al., 2018; Ead, 2015; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013; Muir et al., 2021; Szumilas, 2015; Tracy, 2006). Several authors measured change fatigue using a validated scale (Berneth et al., 2011) in their respective studies (Brown, 2016; Brown et al., 2018; Camilleri et al., 2019; Kapping, 2021) however this tool was intended for use in business organizations. In a quantitative study examining change fatigue experienced by nursing teams, authors found established teams experienced change fatigue more often than newly established teams (Camilleri et al., 2019). Camilleri et al. (2019) stated established teams are faced with unremitting change compounding the effects of change fatigue. Similarly, Brown et al. (2018) noted a statistically significant association between novice nurses experiencing lower change fatigue scores than experienced nurses. However, variability in the literature identified new graduate nurses experiencing more vulnerability to the effects of change fatigue (Vestal, 2013). A study in an acute care hospital found that change fatigue negatively impacts job satisfaction and is positively influenced by resilience, with a weak correlation between job satisfaction and years of experience (Brown et al., 2018). Many authors have recognized the sequelae of change fatigue may adversely affect patient safety and quality of patient care (Camilleri et al., 2019; McMillan, 2018; McMillan & Perron, 2020b; Szumilas, 2015; Tracy, 2006). Authors have recognized administrators have responsibilities in preventing and mitigating change fatigue (Brown, 2016; Brown et al., 2018; Camilleri et al., 2019; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013, 2020b; Vestal, 2013).

## 4.5 | Change fatigue mitigation strategies

### 4.5.1 | Resilience

Several of the included study authors emphasized resilience as a strategy to ameliorate change fatigue (Brown, 2016; Brown & Abuatiq, 2020; Brown et al., 2018; Ead, 2015; Mayer & Hammelef, 2013; McMillan & Perron, 2020b; Summer Bryant, 2020; Szumilas, 2015). Brown and Abuatiq (2020) defined resilience as an individual's ability to manage and recover from adversity with access to appropriate resources. Several authors suggested that offering resilience training may counteract



change fatigue in organizations (Brown & Abuatiq, 2020). Brown et al. (2018) have recognized resilience can benefit individuals who endure unprecedented and turbulent change. However, McMillan and Perron (2020b) found the deleterious effects of change fatigue can impair nurses' innate resilience, causing stress and burnout. Thus, authors proposed resilience practices and training by emphasizing self-care or increasing individuals' or collectives' adaptive reserve by improving communication, team relationships, and trust (Mayer & Hammelef, 2013; Summer Bryant, 2020). Brown et al. (2018) suggested job satisfaction of nurses has a statistically positive association with resilience. However, some authors offer other disciplines report positive effects from resilience training but recognized a lack of research involving nurses and the experience of change fatigue (Brown et al., 2018).

#### 4.5.2 | Change management practices

Change fatigue is often undetected due to the passive nature of the phenomenon, and managers must be cognizant of the negative effects experienced by nurses (Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; McMillan & Perron, 2013). McMillan and Perron (2013) scrutinized the discordance in current change management practices and encouraged leaders to contemplate improving staff engagement, leadership and organizational strategies, and political and organizational culture influences. Ead (2015) unveiled many recommendations for change leaders, such as considering an optimal number of change initiatives per quarter while being abreast of the role of saturation effect. Ead (2015) also encouraged leaders to deliberate on the metrics used to guide the number, magnitude, timing, and delivery of change initiatives, such as considering the volume of concurrent change, the workload of staff, and recognizing the role of human factors engineering. Change leaders should be encouraged to schedule change initiatives and focus on critical or need-to-know content rather than prolific communication (Valusek, 2007; Vestal, 2013). Several authors urge leaders to consider the essential changes necessary to improve patient care delivery and reconsider implementing inessential or discordant change (Muir et al., 2021; Tracy, 2006).

Numerous authors advocated for well-planned change management practices that recognize grace periods between change efforts (Kapping, 2021; Mayer & Hammelef, 2013; McMillan & Perron, 2013; Vestal, 2013). For example, authors advocated to consult frontline nurses or end-users and encourage nurses' voices to be heard in decision-making to foster engagement and sustainable change (McMillan, 2018; McMillan & Perron, 2020b; Muir et al., 2021; Summer Bryant, 2020). McMillan (2018) suggested using beta testing with a sample practice area first to ensure issues reported could be remedied before implementation. Authors have advocated for change leaders to consider assessing staff experience with change fatigue using validated tools before implementing change (Brown, 2016; Brown et al., 2018; Camilleri et al., 2019; Ead, 2015; Kapping, 2021; Muir et al., 2021).

#### 4.5.3 | Political agency

Many authors articulated the power and influence of nurses' voices in change management as a strategy to overcome change fatigue (McMillan, 2018; McMillan & Perron, 2020b; Summer Bryant, 2020). Critical theory was noted in several studies to understand change fatigue (McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021). Specifically, the theory explores dominant discourses and practices that foster power inequities in relationships (McMillan & Perron, 2013). McMillan (2018) noted the discrepancy between managerial perspectives dominated in healthcare organizations and the incongruity with frontline nursing perspectives. Nurses should recognize the power inequities in change management practices, and McMillan (2018) challenges them to not passively accept changes and use their voice as a counter-narrative to question change. Furthermore, McMillan (2018) claims to enhance our understanding of the complexity of organizational change, nurses must have their voices heard without fear of reprisal and become political agents.

## 5 | DISCUSSION

In this integrative review, we summarized current knowledge about change fatigue in nursing, including how change fatigue affects nurses, the nursing profession, and how to prevent and overcome it. We identified themes in the examined literature illustrating change fatigue's multidimensional and multifactorial nature.

Few authors provided homogenous definitions and a unified understanding of change fatigue, while some authors proposed divergent definitions, and others provided no context for their use of the concept. Overall, there is evidence an accepted conceptual definition of change fatigue in nursing is lacking. In addition, there are examples of how nurses experience change fatigue in practice. Most notably, the experience of change fatigue is intensified by lasting change, a lack of control when incorporating change in practice, and the subsequent intensification of workload. Moreover, many associated behaviours emanate the experience of change fatigue, including exhaustion, powerlessness and passive acceptance of change. Several repercussions of change fatigue are outlined, including the effect on an individual and the organization. Lastly, many authors provided mitigation strategies to assuage the experience of change fatigue, including a focus on resiliency, adapted change management practices and employing the role of a political agency.

The results synthesized from the articles situate well with the underpinnings of CST. Authors have identified the concept of change fatigue as under-researched in the literature (Brown et al., 2018; McMillan & Perron, 2013, 2020b), with a lack of literature identifying an associated theoretical framework. Numerous authors reported nurses feel overwhelmed, exhausted, stressed, disillusioned, burnt out and powerless with rapid and continuous change in their workplace (Brown & Abuatiq, 2020; Brown et al., 2018; Kapping, 2021; Mayer & Hammelef, 2013; McMillan & Perron, 2013, 2020b). The application of CST proves useful to view the dominant

discourses and practices that foster power inequities in relationships (McMillan, 2018; Sumner, 2007; Weaver & Olson, 2006). CST illuminates the oppression of nurses by liberating their underrepresented voices and encouraging them to practice political agency, elucidating the power and authority in change management (McMillan, 2018).

Many authors reported that frequent organizational change causes change fatigue (Brown et al., 2018; Davis, 2002; McMillan, 2018; McMillan & Perron, 2013; Muir & Keim-Malpas, 2020; Vestal, 2013). Change fatigue has been well-known in the business discipline as a means to explore organizational change (McMillan & Perron, 2013), but it is a novel concept in the nursing discipline, even though healthcare is facing unprecedented changes given the global pandemic (Havaei et al., 2021). Although much research recognizes the burden of organizational change on employees, few studies have explored the impact of rapid and continuous change and change fatigue in nursing (McMillan, 2018).

### 5.1 | Areas for future research

A qualitative examination of change fatigue in nursing practice that is acutely aware of the political structures that govern change processes in large neoliberal institutions such as healthcare is needed. For example, McMillan and Perron (2020b) refer to neoliberal agendas impacting managerialism that focus on efficiency, productivity and cost containment, resulting in immense fiscal restraint and increased pressure on nurses to do more with less. Further research is needed to determine the relationship between change fatigue, burnout and change avoidance. Studying concepts using validated tools would provide information to determine if there is a directional relationship wherein one concept exacerbates the other or if change fatigue is a component of burnout or avoidance. Understanding this aspect of nurses' experience of change fatigue is important to appreciate as it has the potential to interfere with the direction of organizational change and may uncover specific strategies on how to mitigate the concepts from occurring. Important future work also includes the development of a validated tool change leaders could employ to measure change fatigue when considering new change initiatives for nursing practice or education. Ead (2015) includes reference to workload measurement tools, human factors engineering and a change fatigue measurement scale (Bernerth et al., 2011); creating a validated tool encompassing these metrics and representing the complexity and nuances of the nursing profession would be favourable. No studies were found that examined the differences in change fatigue based on stratified changes, countries, or healthcare systems, which highlights key areas for future investigation. More research is also needed to explore the best strategies for knowledge translation and awareness of change fatigue education.

### 5.2 | Implications for nursing practice

Nursing leaders must be perceptive to the deleterious effects of rapid and continuous change experienced by nurses. Leaders have an opportunity to foster engagement of frontline or end-user nurses

in change management practices and should consider validated tools to use in practice to assess change fatigue before implementing change. In addition to broadening understanding of change fatigue, study findings may also inspire nurses to practice resiliency and become political agents in change management.

### 5.3 | Limitations

Despite a robust search strategy, some literature may have been missed by limiting the initial search to available studies written in English. In addition, authors have much variability in defining the phenomenon of change fatigue, and sometimes change fatigue is used interchangeably with other concepts excluded from the review. Furthermore, all studies were included regardless of the outcome of the critical appraisal process. Lastly, as there is no gold standard for some components of the integrative review process, this may have impacted the rigour of this review.

## 6 | CONCLUSION

Change is constant in nursing practice, and it is required for nurses to stay current with safe, competent and evidence-based practice. However, the repercussion of attempting to keep up with evidence-based practice due to the institutions implementation strategies and timing without consideration of nursing workload has introduced the concept of change fatigue. Change fatigue has detrimental effects on nurses, the profession, healthcare organizations and patient care. This integrative review has further developed an understanding of how change fatigue affects nurses, the nursing profession, and highlighted strategies to prevent and overcome it. The findings from this review can be used to inform future changes to nursing policy and practice while being mindful of their impact.

### AUTHOR CONTRIBUTIONS

LB and CS conceived the study; LB and CS developed the study design; all authors contributed to key background literature and knowledge on change fatigue in nursing; LB and CS created the proposed search strategy; LB drafted the review manuscript; LB, CS and LN edited the review manuscript; all authors read and approved the final manuscript. LB is the guarantor of this review.

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**CONFLICT OF INTEREST**

The authors have declared no conflict of interest.

**PEER REVIEW**

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**DATA AVAILABILITY STATEMENT**

The data that support the findings of this study are available from the corresponding author upon reasonable request.

**ETHICS STATEMENT**

Ethics approval was not required for this integrative review.

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# Change fatigue in nursing: An integrative review

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## Abstract

**Aims:** To synthesize the empirical and theoretical literature on change fatigue in nursing, including how change fatigue affects nurses, the nursing profession and strategies to prevent and overcome it.

**Background:** Change fatigue refers to the overwhelming feelings of stress, exhaustion and burnout associated with rapid and continuous change across healthcare organizations. Change fatigue can affect nurses' wellbeing, yet there is a distinct lack of literature which synthesizes the relationship between cumulative organizational change and nurses' wellbeing.

**Design:** Integrative review following Toronto and Remington and Whittemore and Knafl methodology.

**Data Sources:** Searches were conducted in CINAHL, Embase, Medline, APA PsycInfo, Scopus, Business Source Complete and ProQuest Dissertations & Theses Global in January 2022.

**Review Methods:** A comprehensive search was conducted to identify literature on change fatigue in nursing. Included literature were critically appraised for methodological quality. Data from each article were abstracted and thematically analysed.

**Results:** Twenty-six articles were included in this review, including 14 empirical studies, 10 theoretical papers and two literature reviews. Five main themes described in the literature included: definitions, preceding factors, associated behaviours, consequences and mitigation strategies for change fatigue.

**Conclusion:** This review highlights the impact of rapid and continuous change on nurses and nursing practice. Further research is needed to explore the relationship between change fatigue and burnout, understand how and why nurses withdraw or avoid change, and to develop a metric to measure change fatigue when considering new change initiatives.

**Impact:** Findings from this review generated an improved understanding of how change fatigue affects nurses, the nursing profession and strategies to prevent and overcome it. This paper provides practical recommendations for future research, direction for nursing educators and leaders, and encourages nurses to practice political agency with change management.

**Patient or Public Contribution:** This project was an integrative review of the literature therefore no patient or public contribution was necessary.

## KEYWORDS

burnout, change fatigue, healthcare, nurses, nursing, organizational change, political agency, rapid and continuous change, resiliency, workplace change



## 1 | INTRODUCTION

Healthcare's changing landscape is driven by the need for continuous improvement in the provision of care (MacPhee, 2007; McMillan & Perron, 2020a). Amidst competing priorities, healthcare organizations face challenges implementing and sustaining multiple changes to facilitate best practices and ensure healthcare providers deliver safe, competent care (MacPhee, 2007). Numerous co-occurring changes often create an overwhelming volume of initiatives and expectations in practice (Bernerth et al., 2011; MacPhee, 2007; Torppa & Smith, 2011). When changes are implemented, healthcare providers are expected to adjust their practice and balance numerous competing priorities. The continued pressure for change contributes to a phenomenon experienced by many healthcare providers, termed change fatigue (Bernerth et al., 2011; McMillan & Perron, 2020a).

## 2 | BACKGROUND

Organizational change research has primarily focused on change resistance, and historically, change failure has thought to be due to change resistance; behaviours that threaten the success of change initiatives (Bernerth et al., 2011; de Vries & de Vries, 2021; Orlando, 2014; Ouedraogo & Ouakouak, 2021; Torppa & Smith, 2011). However, in recent years, authors have identified another phenomenon, change fatigue, which threatens the success of change implementation and has detrimental effects on individuals (Bernerth et al., 2011; de Vries & de Vries, 2021; MacPhee, 2007; Orlando, 2014; Ouedraogo & Ouakouak, 2021; Torppa & Smith, 2011; Wynen et al., 2019).

The changing landscape in healthcare is fuelled by reforms in innovation, technology, quality improvement, fiscal restraint, restructuring and optimization efforts in response to increased demand for access to services and, in recent years, the global pandemic (Bruce & English, 2020; de Vries & de Vries, 2021; MacPhee, 2007; Ouedraogo & Ouakouak, 2021; Wynen et al., 2019). Among healthcare providers, nurses have experienced high levels of stress, burnout and exhaustion due to increasing workplace demands and rapid and continuous organizational change (McMillan & Perron, 2020a). The result has created change fatigue, a complex, multifaceted phenomenon exacerbated by the need for continuous improvement in healthcare (Bernerth et al., 2011; Jantzen et al., 2017). Continuous improvement causes numerous co-occurring change agendas, resulting in an incessant and overwhelming inundation of initiatives (Bernerth et al., 2011; Ouedraogo & Ouakouak, 2021). Leaders who promote organizational change acknowledge that nurses are often expected to carry out new initiatives, continually acclimatize to changes and balance numerous competing change agendas among their already challenging workload (McMillan & Perron, 2020a). Thus, in an environment with rapid and continuous change, nurses may struggle to maintain stability and control, leading to disengagement, burnout, apathy and change fatigue (Brown & Cregan, 2008; Wynen et al., 2019). Exploring and understanding the phenomenon of change fatigue has implications for patient care, nurses' wellbeing and the nursing profession.

McMillan and Perron (2020b) argued that administrators' decisions significantly impact nurses' experience of change fatigue. Specifically, they articulated that in a neoliberal healthcare landscape, there is an immense push to implement rapid changes, often without proper evaluation of readiness for change and engagement of frontline staff in the planning and preparation, which may inadvertently foster change fatigue (McMillan, 2018). A broad exploration of change fatigue in nursing is needed to examine the relationship between repeated organizational change and the impact on nurses' wellbeing.

## 3 | THE REVIEW

### 3.1 | Aim

The aim of this integrative review was to answer the following question: What is known about how nurses experience change fatigue?

### 3.2 | Design

The aim of an integrative review is to summarize what is known about a topic and communicate a synthesis of literature to a targeted community (Toronto & Remington, 2020). Integrative reviews provide a broad understanding of a specific phenomenon by encompassing diverse literature sources, assessing the quality of evidence, identifying gaps in the literature and recognizing future steps for research and practice (Russell, 2005). This integrative review was conducted following the six-step methods described by Toronto and Remington (2020) and Whittemore and Knafel (2005): (1) formulation of a broad review question, (2) systematic search of the literature, (3) critical appraisal of selected literature, (4) analysis and synthesis of the literature, (5) discussion of new knowledge and (6) dissemination of findings.

Experts suggest using a theoretical framework to guide the review process (Toronto & Remington, 2020). To critically understand the complex phenomenon of change fatigue and its impact on nurses, critical social theory (CST) provides a new perspective that is underrepresented in the current literature (McMillan & Perron, 2020a). Exploring change fatigue from a CST lens elucidates the inequality in change management; the power and authority in leaders' decision-making juxtaposed with the powerlessness and passive acceptance nurses experience with relentless change (Sumner, 2007; Weaver & Olson, 2006). Using CST, we can examine the underlying effects of powerlessness, subordination and oppression experienced by nurses undergoing rapid and continuous change. We integrated CST throughout the review process and in the interpretation of the review findings.

### 3.3 | Search methods

The following databases were searched in June 2021 and re-run in January 2022: CINAHL Plus with Full Text (Ebsco), MEDLINE(R)



and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily (OVID), APA PsycInfo (OVID), Business Source Complete (Ebsco), Scopus (Elsevier) and ProQuest Dissertations and Theses Global (ProQuest). No limits were placed on location or publication date. Search terms included: “change fatigue” OR (“organization or workplace change” OR “fatigue or stress or burnout or exhaustion or hardiness or powerless\* or apathy”) AND “nurs\*.” As change fatigue is not well defined and is under-researched, other commonly used terms noted in the literature were included among the search words. Keywords and search terms were consistent across all databases, and appropriate subject headings were used with the appropriate database. An example strategy from CINAHL has been supplied in Table S1. We conducted forward and backward citation chasing of included articles to identify additional literature. Commonly known change management organization websites, such as Prosci Inc. (Prosci Inc, 2022) and Google, were also searched using search terms “change fatigue” AND “nursing.”

Investigators exported all database records to Covidence to enable citation management, duplication removal and screening decisions. Two reviewers independently screened literature at title and abstract, and then full-text levels following strict inclusion and

exclusion criteria (Table 1). All disagreements were discussed, and consensus was achieved without requiring a third reviewer.

### 3.4 | Quality appraisal

Two reviewers conducted quality appraisal of each article independently, using Joanna Briggs Institute (JBI) checklists for each type of study design (Table 2). All disagreements were discussed to arrive at consensus on the appraisal scoring. All eligible articles were included in the review regardless of the appraisal outcome.

### 3.5 | Data abstraction

We created a data abstraction matrix table to extract pertinent information from each selected article (Toronto & Remington, 2020). Guided by the theoretical underpinnings of CST, the matrix table was created with different columns to abstract descriptive data from each article that would aid in answering the review question. Column titles included study methods, methodology, theories or frameworks, research aim or objective, authors' definition of change

TABLE 1 Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Literature type	Literature in published journals <ul style="list-style-type: none"> <li>• Experimental:               <ol style="list-style-type: none"> <li>(i) Qualitative</li> <li>(ii) Quantitative</li> <li>(iii) Mixed method</li> </ol> </li> <li>• Non-experimental:               <ol style="list-style-type: none"> <li>(i) Case reports</li> <li>(ii) Review</li> <li>(iii) Text, opinion, letters to the editor, editorials</li> </ol> </li> </ul> Grey literature (unpublished reports): <ul style="list-style-type: none"> <li>• Thesis and dissertation</li> <li>• White papers</li> </ul>	<ul style="list-style-type: none"> <li>• Social media</li> <li>• Blog posts</li> <li>• Media or newspaper</li> <li>• Magazine articles</li> <li>• Conference proceedings or abstracts</li> </ul>
Concept or phenomenon	Change fatigue	<ul style="list-style-type: none"> <li>• Change resistance</li> <li>• Change management</li> <li>• Change cynicism</li> <li>• Psychological uncertainty</li> <li>• Temporal ambiguity</li> </ul>
Area of practice	<ul style="list-style-type: none"> <li>• Nursing discipline               <ol style="list-style-type: none"> <li>(i) Any practice area</li> <li>(ii) Any level of nursing education background (i.e. student nurses, diploma or degree holder)</li> <li>(iii) Any nurse practice role (licensed practical nurse, graduate nurse, registered nurse, nurse clinician, nursing instructor, nurse practitioner, nurse manager, clinical nurse specialist)</li> <li>(iv) Educational institutions or clinical practice areas</li> </ol> </li> </ul>	<ul style="list-style-type: none"> <li>• Not in the nursing discipline</li> <li>• Unable to delineate nursing information in multidisciplinary studies</li> </ul>
Language	English language	Not in English language
Date range	No limit on date range	N/A
Geographical area	No limit on geographical setting	N/A

TABLE 2 Critical appraisal tools used

Research type	Checklist Title	Reference
Text and opinion	• JBI: Checklist for Text and Opinion	McArthur et al., 2015
Qualitative	• JBI: Checklist for Qualitative Research	Lockwood et al., 2015
Quantitative	• JBI: Checklist for Prevalence Studies	Munn et al., 2015
Mixed methods	• JBI: Checklist for Qualitative Research • JBI: Checklist for Prevalence Studies	Lockwood et al., 2015; Munn et al., 2015
Review	• JBI: Checklist for Systematic Reviews and Research Synthesis	Aromataris et al., 2015

fatigue, background, antecedents, outcomes, strategies and key results or findings. One reviewer completed the data abstraction and a second reviewer verified the accuracy.

### 3.6 | Synthesis

We used thematic analysis to identify and organize recurrent themes across multiple literature sources (Braun & Clarke, 2006). We synthesized data into five themes and 13 subthemes (Table 3). The team vetted all themes and subthemes, and disagreements were resolved through discussion.

## 4 | RESULTS

Our electronic and hand searches generated 2531 records which were screened for inclusion, and 84 underwent secondary full-text screening. Of these, 26 articles were included in the final synthesis. Figure 1 displays the flow of literature throughout our review. The 26 articles included 10 text or opinion, six quantitative, four qualitative, four mixed methods and two review-based articles (Table 4). A summary of all included studies is provided in Tables 5, 6. Two records were published as dissertations and as journal articles (Brown, 2016; Brown et al., 2018; McMillan, 2018; McMillan & Perron, 2020b, 2021). All studies were published between 2002 and 2021. Research was conducted in Australia ( $n = 2$ ), Canada ( $n = 7$ ), Europe ( $n = 3$ ) and the United States ( $n = 14$ ) in a variety of settings, some spanning multiple settings, including acute care, ambulatory care, community care, and in academic settings.

The results of the quality appraisal are presented in (Tables S2 to S5). The qualitative studies had congruency between research methodology, data collection, data analysis and results. However, in half of the qualitative studies (including mixed methods studies with qualitative arms) the authors failed to make clear statements about their philosophical worldview, cultural or theoretical location or the researcher influence on the study. The quantitative studies and mixed methods studies which included a quantitative arm were critically appraised to be of high quality. Only two of the mixed methods studies failed to provide depth in details about the participants and settings (Lind et al., 2018; Wozniak et al., 2020). In the text and opinion articles the authors clearly identified their opinions which were based on expertise and interest. However, in half of the text and opinion articles the authors failed to reference extant literature on change fatigue and were not clear if their opinions were a

result of analytical process. Only one author identified and logically defended any incongruence with literature (McMillan & Perron, 2013). Two reviews were included, and while one was appraised to be high quality (Gee et al., 2017), the other lacked details about the appraisal criteria, and process of data extraction and synthesis (Brown & Abuatiq, 2020).

Our thematic analysis of 26 articles yielded five themes and 13 subthemes, as presented in Table 3. Our theme development was informed by the theoretical tenets of CST, guided by the theoretical framework of critical management studies (CMS), which view the dominant discourses in change management practices that foster power inequities in nursing practice and illuminate the oppression, subordination and powerlessness nurses experience with rapid and continuous change (McMillan, 2018; Sumner, 2007; Weaver & Olson, 2006). Using CMS helped to recognize nurses experience of change fatigue remains significantly underrepresented in current literature (McMillan, 2018; McMillan & Perron, 2013, 2020b). In addition, using CST informed the development of mitigation strategies as the theory focuses on resolution of oppression, importance of autonomy and empowerment (Sumner, 2007; Weaver & Olson, 2006).

### 4.1 | Definitions of change fatigue

#### 4.1.1 | Homogenous definitions of change fatigue

Change fatigue was defined as an overwhelming feeling of stress, exhaustion and burnout associated with rapid and continuous change in the workplace, affecting nurses' overall health and wellbeing (Brown, 2016; Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; McMillan, 2018; McMillan & Perron, 2013, 2020b). Developing over time, change fatigue and relentless organizational change produces compounding adverse effects for nurses (Camilleri et al., 2019; Gee et al., 2017; Reineck, 2007; Szumilas, 2015). Change fatigue was also noted to be commonly mistaken for change resistance (Mayer & Hammelef, 2013; McMillan & Perron, 2013).

#### 4.1.2 | Divergent definitions of change fatigue

Although many authors reported homogeneity among their definitions of change fatigue, some had divergent definitions. For example, some authors recognized change fatigue manifests as a resistance to change or cynicism about change (Davis, 2002;

TABLE 3 Themes and sub-themes identified from the findings of the records

Themes	Sub-themes	Sources
Definitions of change fatigue	Homogenous definitions of change fatigue	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Summer Bryant, 2020; Camilleri et al., 2019; Gee et al., 2017; Kapping, 2021; Lind et al., 2018; Mayer & Hammelef, 2013; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir & Keim-Malpas, 2020; Muir et al., 2021; Reineck, 2007; Szumilas, 2015; Valusek, 2007.
	Divergent definitions of change fatigue	Davis, 2002; Huynh et al., 2018; Kapping, 2021; Mayer & Hammelef, 2013; Metusela et al., 2021; Reineck, 2007; Vestal, 2013.
	No definition provided	Davis, 2002; Ead, 2015; Gee et al., 2017; Muir & Keim-Malpas, 2020; Wozniak et al., 2020.
Factors preceding change fatigue	Rapid and continuous change	Brown et al., 2018; Camilleri et al., 2019; Davis, 2002; Ead, 2015; Havaei et al., 2021; Lind et al., 2018; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021; Szumilas, 2015; Tracy, 2006; Vestal, 2013.
	Lack of control	Brown & Abuatiq, 2020; Davis, 2002; Ead, 2015; Gee et al., 2017; Kapping, 2021; Vestal, 2013.
	Intensification of workload	Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; Gee et al., 2017; Huynh et al., 2018; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2020b; Muir & Keim-Malpas, 2020; Vestal, 2013; Wozniak et al., 2020.
Behaviours associated with change fatigue	Exhaustion	Brown & Abuatiq, 2020; Camilleri et al., 2019; Davis, 2002; McMillan & Perron, 2020b; Muir et al., 2021.
	Powerlessness	Brown & Abuatiq, 2020; Davis, 2002; Ead, 2015; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir & Keim-Malpas, 2020; Muir et al., 2021; Reineck, 2007; Vestal, 2013.
	Passive acceptance	Brown, 2016; Brown & Abuatiq, 2020; McMillan & Perron, 2013, 2020b.
Consequences of change fatigue	Individual consequences	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Camilleri et al., 2019; Davis, 2002; Ead, 2015; Kapping, 2021; Mayer & Hammelef, 2013; McMillan, 2018; McMillan & Perron, 2013, 2020b.
	Organizational consequences	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Camilleri et al., 2019; Ead, 2015; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021; Szumilas, 2015; Tracy, 2006; Vestal, 2013.
Change Fatigue Mitigation Strategies	Resilience	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Summer Bryant, 2020; Ead, 2015; Mayer & Hammelef, 2013; McMillan & Perron, 2020b; Szumilas, 2015.
	Change Management Practices	Brown, 2016; Brown et al., 2018; Brown & Abuatiq, 2020; Summer Bryant, 2020; Camilleri et al., 2019; Ead, 2015; Kapping, 2021; Mayer & Hammelef, 2013; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021; Tracy, 2006; Valusek, 2007; Vestal, 2013.
	Political agency	Summer Bryant, 2020; McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021.

Huynh et al., 2018). Contrary to homogenous definitions, which presume nurses passively accept changes, authors asserted that nurses question the value and objectives of change (Reineck, 2007; Tracy, 2006), indicating nurses actively question change. Metusela et al. (2021) provided a literal description indicating change fatigue was observed as nurses working longer hours to manage change stress. There is much variability among conceptual definitions of change fatigue in the nursing literature, with some authors referring to change fatigue without a definition (Davis, 2002; Ead, 2015; Gee et al., 2017; Muir & Keim-Malpas, 2020; Wozniak et al., 2020).

## 4.2 | Factors preceding change fatigue

### 4.2.1 | Rapid and continuous change

Authors suggested that rapid and continuous practice initiatives have become the norm due to the constant need to improve health-care delivery (Brown et al., 2018; Davis, 2002; McMillan, 2018; McMillan & Perron, 2013; Muir et al., 2021; Vestal, 2013). The current healthcare landscape of continued improvement results in

Change fatigue in nursing literature search flow diagram (Page et al., 2021)

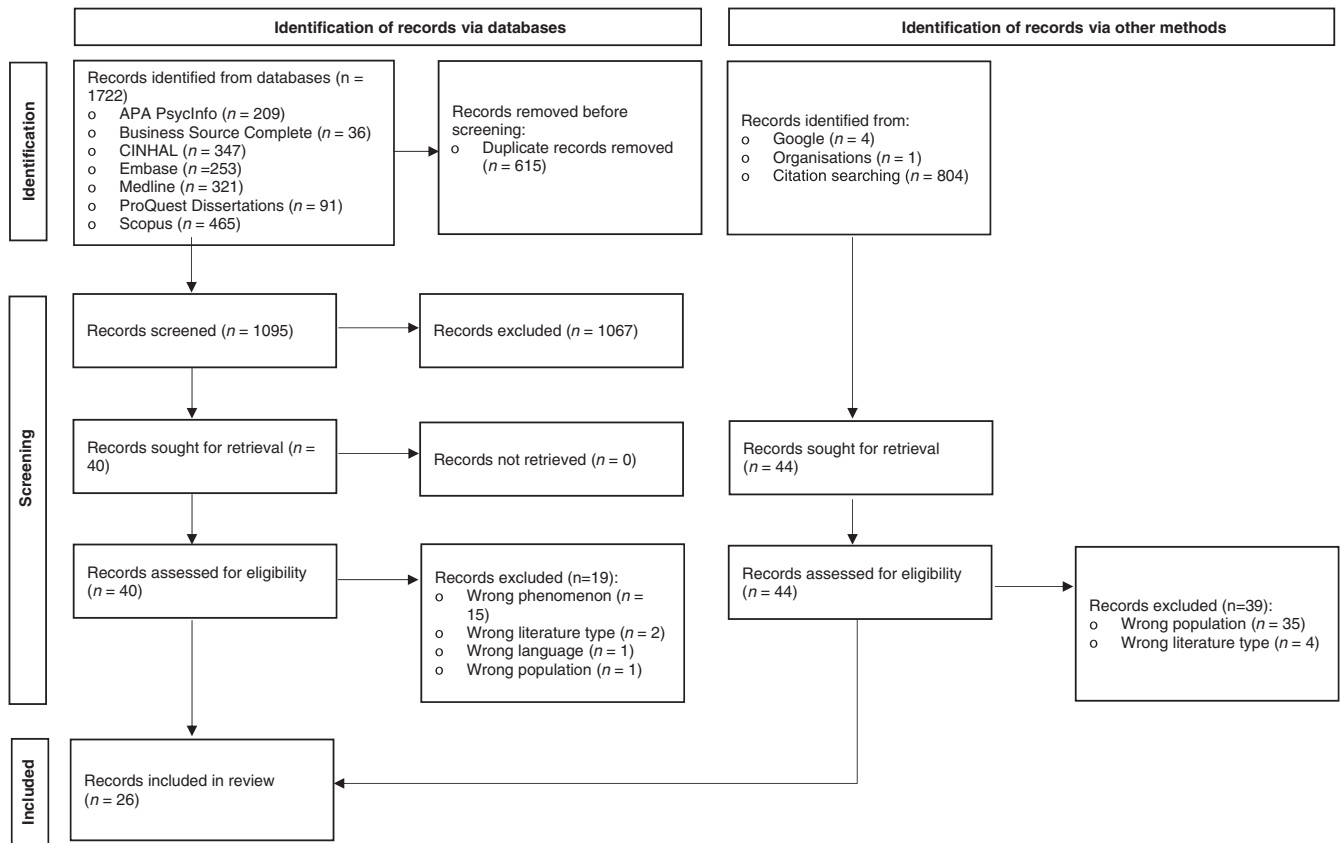


FIGURE 1 Change fatigue in nursing literature search flow diagram (Page et al., 2021).

TABLE 4 Demographic characteristics of included records

Research type	Number of included studies	Reference
Text and opinion	10	Summer Bryant, 2020; Davis, 2002; Ead, 2015; Mayer & Hammelef, 2013; McMillan & Perron, 2013; Reineck, 2007; Szumilas, 2015; Tracy, 2006; Valusek, 2007; Vestal, 2013.
Qualitative	4	McMillan, 2018; McMillan & Perron, 2020b; McMillan & Perron, 2021; Muir et al., 2021.
Quantitative	6	Brown, 2016; Brown et al., 2018; Camilleri et al., 2019; Havaei et al., 2021; Huynh et al., 2018; Kapping, 2021.
Mixed methods	4	Lind et al., 2018; Metusela et al., 2021; Muir & Keim-Malpas, 2020; Wozniak et al., 2020.
Review	2	Brown & Abuatiq, 2020; Gee et al., 2017.

increasing intensity of change, challenging nurses' ability to adapt and cope in the workplace, leaving them vulnerable to change fatigue (Brown et al., 2018; Lind et al., 2018; Vestal, 2013). In a qualitative study by McMillan, participants reported, "it has been years and years of change for all staff. It just hasn't stopped and we just haven't gotten our feet back underneath us" (2018, p. 80). McMillan and Perron (2020b) explained that rapid and continuous change restructures how and when patient care is provided. For example, Havaei et al. (2021) reported nurses have experienced change fatigue during the covid-19 pandemic due to frequent changes in policies and procedures requiring them to quickly respond and adapt as evidence evolves. The experience of continuous change exacerbates change fatigue which can impair the healthcare system's ability to function

and achieve sustainable change, ultimately affecting the quality of care provided (Lind et al., 2018; Szumilas, 2015; Tracy, 2006). Additionally, individuals become fatigued by the confluence of rapid changes, lack of recovery periods and the constant pressure of new mandates (Camilleri et al., 2019; Davis, 2002; Ead, 2015; Lind et al., 2018; McMillan & Perron, 2013).

#### 4.2.2 | Lack of control

Several authors recognized that individuals attempt to maintain stability and balance in their environment but experience fatigue, burnout and a lack of control with turbulent change (Davis, 2002;

TABLE 5 Summary of included empirical articles

Reference, location	Aim, sample, setting	Research design and methods	Key findings
Brown, 2016, USA	The purpose of the doctoral dissertation was to determine if a relationship among change fatigue, resilience and job satisfaction of 535 novice or experienced hospital staff nurses existed.	Quantitative: A descriptive correlational design was used, participants completed an online survey, using three tools: Change Fatigue Scale, Connor-Davidson Resilience Scale, and McCloskey/Mueller Satisfaction Scale.	Findings reported a significant difference between novice and experienced staff nurses in change fatigue ( $p = .003$ ), resilience ( $p = .01$ ), and job satisfaction ( $p = .04$ ). Experienced nurses had higher change fatigue, resilience and job satisfaction mean scores. A significant negative association between change fatigue and job satisfaction ( $p = .000$ ) and change fatigue and resilience ( $p = .002$ ). Multiple linear regression found that years of experience were not significant with change fatigue, however, education, gender and hospital size were predictor variables. In addition, as the size of facility and number of beds increased, change fatigue increased, and as education increased, change fatigue decreased. The study provided new knowledge of the relationship among change fatigue, resilience and job satisfaction of hospital staff nurses. New knowledge will assist nursing leaders to become aware of the effects of change fatigue and develop interventions to prevent change fatigue of hospital staff nurses, which in turn may increase job satisfaction and retention rates.
Brown & Abuatiq, 2020, USA	An exploration of resilience and how resilience training for nurses can help protect against the negative effects of stress caused by organizational change.	Review: A literature review adapted from a doctoral dissertation, included 11 articles.	Two main themes were identified: (1) resilience and organizational change for nurses and (2) resilience training for nurses in clinical practice. Authors noted understanding personal resilience is crucial to drive effective change because people who possess high levels of resilience can readily accept change without experiencing traumatic and debilitating consequences. Change fatigue in nurses is a negative effect of constant organizational change that has been minimally researched.
Brown et al., 2018, USA	The purpose of the study was to examine relationships between change fatigue, resilience and job satisfaction among 521 novice and seasoned hospital staff nurses.	Quantitative: A descriptive correlational design was employed. Participants completed three online surveys: Change Fatigue Scale, Connor-Davidson Resilience Scale, and McCloskey/Mueller Satisfaction Scale.	A multiple regression model showed job satisfaction had a statistically significant negative association with change fatigue ( $p < .001$ ) and significant positive association with resilience ( $p < .001$ ). A linear trend was found with hospital size and change fatigue ( $p = .001$ ) and education level and resilience ( $p = .03$ ). The results are consistent with job satisfaction among hospital nursing staff being negatively influenced by change fatigue and positively influenced by resilience. Change fatigue may be increased by larger hospital size, and resilience may be increased by higher educational level of hospital staff nurses.
Camilleri et al., 2019, Australia	To evaluate the experience of change fatigue in frontline nursing staff following large-scale organizational change and determine whether improved teamwork perception scores can mitigate the experience of change fatigue. Participants included nurses in an established team ( $n = 225$ ), and nurses in a newly reconfigured team ( $n = 521$ ).	Quantitative: An online questionnaire was used to survey a cross section of frontline nurses from two distinct cohorts.	Frontline nurses who transitioned in an established team reported higher levels of change fatigue following large-scale change, compared with those in a new, reconfigured team ( $p = .013$ ). There is a small significant negative correlation between perception of teamwork and change fatigue scores. Regardless of team type, high levels of change fatigue are reported by frontline nursing staff following large-scale organizational change. Established teams have a higher perceived level of teamwork in all domains when compared with a new team in the same change conditions. It is unlikely that the perception of teamwork has any real-world impact on the experience of change fatigue.

TABLE 5 (Continued)

Reference, location	Aim, sample, setting	Research design and methods	Key findings
Gee et al., 2017, United Kingdom	The aim of this study was to identify the factors contributing to lasting change in practice following a recovery-based training intervention for inpatient mental health rehabilitation staff.	Review: A rapid realist review methodology was used to generate and prioritize programme theories. Stakeholders validated and prioritized emerging programme theories and theories were refined using literature case studies.	Fifty-one relevant documents fed into 49 programme theories articulating seven mechanisms for lasting change. Prioritized mechanisms were staff receptiveness to change; and staff feeling encouraged, motivated and supported by colleagues and management to change. Lasting change can be facilitated by collaborative action planning, regular collaborative meetings, appointing a change agent, explicit management endorsement and prioritization and modifying organizational structures. Conversely, a challenging organizational climate, or a prevalence of 'change fatigue', may block change. Pre-intervention exploration may help identify any potential barriers to embedding recovery in the organizational culture.
Havaei et al., 2021, Canada	The purpose of this study was to examine the impact of COVID-19 workplace conditions on nurses' mental health outcomes. An electronic survey was emailed to nurses in Canada with a total of 3676 responses.	Quantitative: A cross-sectional correlational design was used.	The study showed concerning prevalence rates for post-traumatic stress disorder (47%), anxiety (38%), depression (41%) and high emotional exhaustion (60%). Negative ratings of workplace relations, organizational support, organizational preparedness, workplace safety and access to supplies and resources were associated with higher scores on all of the adverse mental health outcomes included in this study. Better workplace policies and practices are required to prevent and mitigate nurses' suboptimal work conditions, given their concerning mental health self-reports during the COVID-19 pandemic.
Huynh et al., 2018, USA	The association of self-reported adaptive reserve (AR) and burnout among 119 healthcare providers was studied with self-administered, online surveys.	Quantitative: A survey containing a 23-item AR scale and burnout inventory questions was sent to a convenience sample of nurses, house staff team members, and hospitalists.	Ordinal regression analyses were used to examine the association between AR and burnout. Eighty per cent of participants reported either level 1 or 2 burnout. Participants reporting higher burnout were about three times more likely to report lower AR levels. AR is strongly associated with self-reported burnout by physicians and nurses providing inpatient care at this medical centre. Evidence supports the positive association of AR to successful change implementation in ambulatory settings. Related literature shows that when a team faces the constant pressure of transformative change but lacks one or more of the characteristics of AR, change fatigue results.
Kapping, 2021, USA	The purpose of this study was to determine if there is a relationship between (a) job satisfaction and change fatigue and (b) organizational commitment and change fatigue in nurses who work in an outpatient clinical environment. Online surveys were administered to 136 outpatient nurses.	Quantitative: A correlational design used three tools: McCloskey/Mueller Satisfaction Scale, the Change Fatigue Scale and the Unidimensional Target Neutral Commitment Measures.	Results showed a statistically significant relationship between change fatigue and job satisfaction was weakly correlated ( $p = .026$ ), with a weak positive correlation between organizational commitment and change fatigue ( $p = .046$ ). Results may impact on social change through raising awareness of what the nurse experiences during change initiatives while potentially improving staff retention. Leadership teams may benefit from monitoring the amount and timing of initiatives being introduced to potentially decrease change fatigue from occurring.

(Continues)



TABLE 5 (Continued)

Reference, location	Aim, sample, setting	Research design and methods	Key findings
Lind et al., 2018, Sweden	The study aimed to explore the feasibility of a pilot version of a strategy for introducing the Integrated Palliative care Outcome Scale (IPOS) in acute care settings. For comparative reasons it was also tested in a palliative care unit.	Mixed methods: A process evaluation was conducted including collecting quantitative data and performing interviews with healthcare professionals.	The prevalence of completed IPOS in the patient's records varied from 6% to 44% in the acute care settings. The qualitative results showed opposing perspectives concerning the training provided. In the acute care settings, a need for an improved culture about palliative care was identified. A context characterized by a constantly increasing workload, a feeling of constantly on-going changes and a feeling of change fatigue were found at all units.
McMillan, 2018, Canada	The aim of this doctoral dissertation was to explore the nature of frontline nurses' experiences of living with rapid and continuous organizational change in healthcare. A component of this research was to explore the opportunity of change fatigue in nurses.	Qualitative: A critical hermeneutic design was used to explore concepts of organizational change, experience of change, change fatigue and power and voice at a hospital in Canada with a sample of 14 Registered Nurses.	Organizational change challenges healthcare providers in a variety of ways because it restructures how and when patient care delivery is provided, changing ways in which nurses must carry out their work. Nurses recognized that many change initiatives reflected an ideological shift in healthcare that supported a culture of service, while sacrificing a culture of care. A culture of service prioritized cost-savings and efficiency, which saw nurses lose the time and resources required to provide quality, safe care. Nurses felt morally responsible to uphold a culture of care, which proved challenging, and at times unobtainable. The inability to provide quality, safe care resulted in a multitude of negative emotional repercussions, fostering moral distress. Nurses exhibited elements of change fatigue, contributing to feelings of voicelessness and powerlessness in their workplace. Organizational change must be re-conceptualized in ways that ensure change initiatives uphold institutional integrity and better support the provision of morally authentic nursing practice. Healthcare organizations should place nurses at the forefront of planning, implementation, and evaluation of change initiatives to alleviate the many negative experiences of organizational change noted in this study.
McMillan & Perron, 2020b, Canada	This adapted doctoral dissertation examined nurses' experiences of rapid and continuous organizational change, examining the concept of change fatigue.	Qualitative: A critical hermeneutic approach was used. Face-to-face interviews were conducted with 14 Registered Nurses.	Nurses did experience many of the core elements of change fatigue noted in the non-nursing literature, including exhaustion, apathy, powerlessness and burnout. Two additional themes were identified pertaining to nurses' experience of change fatigue, including the intensification of nursing work, and repeated and ongoing self-sacrifice. The negative experiences associated with change fatigue are important for administrators and other stakeholders to recognize and acknowledge, as they must alleviate change fatigue in their institutions to preserve the wellbeing of nurses. This knowledge is also important to nursing scholars, who may further research the topic and embed it into nursing curricula.
McMillan & Perron, 2021, Canada	The purpose of this inquiry was to explore the nature of frontline nurses' experiences of rapid and continuous change.	Qualitative: A critical hermeneutic design was applied with 14 Registered Nurses at an hospital in Canada.	The findings suggest that acts of resistance to change are not overt, but rather covert behaviours in micro-ethical moments. Nurses engaged in resistance as means to provide morally authentic care. These acts were used to take back power over their practice amidst feelings of powerlessness. When participants described the concept of power, they understood it solely in the context of feeling powerless in the planning, implementation and evaluation of organizational change initiatives. Nurses' engagement with resistant behaviours in the context of organizational change demonstrated ethical action and political agency that enabled morally authentic nursing practice. The findings offer new understandings and can be used when considering the ethical dimensions of nursing work amidst rapid changes in healthcare.

TABLE 5 (Continued)

Reference, location	Aim, sample, setting	Research design and methods	Key findings
Metusela et al., 2021, Australia	The study examined the experiences of seven general practices in Australia that implemented projects aligned with Patient Centred Medical Home (PCMH) values and goals supported by their local Primary Health Network.	Mixed method: Data were collected over a 12-month period, including semi-structured interviews, participant observation and practice data to present a detailed study.	Facilitators implementing successful, sustainable change included the capacity and willingness of practices to undertake change; practice engagement with a shared vision towards PCMH change; engaged leadership; training and support; and structures and processes required to provide team-based, data driven care. Barriers to implementation included change fatigue, challenges of continued engaged leadership and insufficient time to implement PCMH change. The study examined the experiences of implementing PCMH initiatives and described the facilitators and barriers to PCMH change. The findings provide guidance for primary health networks that are interested in undertaking similar quality improvement projects.
Muir & Keim-Malpas, 2020, USA	To assess the feasibility of a pilot mindfulness intervention programme, the Emergency Resiliency Initiative (ERI), as well as to investigate changes in burnout scores and key drivers to burnout among registered nurses (RNs) and patient care technicians (PCTs) in an emergency department (ED).	Mixed method: A pre/post study with data collection points before and after the 3-month intervention with 35 participants. Interventions included three mindfulness sessions. Burnout scores were assessed using the Maslach Burnout Inventory.	From the pre- ( $n = 35$ ) to post- ( $n = 26$ ) intervention period there was a significant increase in personal accomplishment scores ( $p = .01$ ) and decrease in emotional exhaustion scores ( $p = .03$ ) for RNs and PCTs combined. Qualitative interviews revealed five burnout-related themes: (a) prioritization distress, (b) change fatigue, (c) self-protection through superficiality, (d) intentional response and (e) community amid chaos. The ERI was a feasible and acceptable programme associated with improvements in burnout scores. Qualitative interviews revealed the positive impacts of mindfulness on ED clinician resiliency and identified future opportunities to address burnout.
Muir et al., 2021, USA	The purpose of this ethnographic study was to evaluate the cultural impacts of an emergency department (ED) move from an old to new physical space.	Qualitative: Ethnographic fieldwork was conducted over 14 months in an ED. Primary data sources included participant observations and semi-structured interviews with ( $n = 39$ ) emergency nurses, non-nurse clinicians and unit administrators.	One cross-cutting theme, decisional power, and three supporting themes inadequate move preparation, change fatigue and lack of change standardization were identified. Decisional power was the perceived influence certain ED groups had making move-related decisions over others. Change fatigue described the impact of frequent change implementation on participants' work processes, wellbeing and job satisfaction. Lack of change standardization described power differentials between nurses striving to standardize new move-related processes and physicians implementing work styles discordant with such processes. Findings can inform recommendations for healthcare policy and organizational operations such as: (1) including frontline stakeholder perspectives in move-related decisions; (2) allocating adequate time for clinician/employee training/education in the pre-move period; (3) assessing clinician/employee wellbeing throughout move implementation; (4) increasing unit administrator sensitivity to clinician change fatigue.
Wozniak et al., 2020, Canada	The study assessed the context in which a hip Fracture Liaison Service was implemented.	Mixed methods: Semi-structured interviews were conducted with 21 key informants at two time points to understand organizational readiness, facilitators and barriers to change.	Findings suggested that the use of several strategies, including demonstrating value, providing resources and selecting appropriate sites, and using change readiness tools were important to implementation, in the context of change fatigue. The study revealed an effective change management approach neutralized change fatigue.

TABLE 6 Summary of included theoretical articles

Reference, location	Key findings
Summer Bryant, 2020, USA	Change is constant in nursing. In the first few months of the covid-19 pandemic change came faster than ever in healthcare settings. Perhaps the most control we can have over it is how we react and adapt to it. One way to react to change is to be involved in the change process. Being involved with decision-making in the current environment ensures nurses' voices are amplified about patient care during the pandemic. However, even though nurses may be pretty good at change, it takes a toll on us. Change fatigue can plague our resilience, and cause stress and burnout. We must take care of ourselves; by getting involved in decision-making and rebuilding resilience through regular self-care.
Davis, 2002, United Kingdom	Since the 1980s the National Health Service has been repeatedly restructured and the government is poised for yet another overhaul. It is unclear if such storms of upheaval make nurses' lives any better. Nurses are faced with incessant changes and have been unsupported on under-resourced wards. The majority of nurses have become quite cynical about all the change because it goes on in the background and no effort is made to involve them in it. They just get on with their jobs and are busy holding the whole thing together. But the danger is that constant change is massively disruptive and makes too little real change at grassroots level. There is structural change fatigue in the National Health Service and people have simply had enough.
Ead, 2015, Canada	In the fast-paced world of healthcare, it is not uncommon for nurses to have days where they are pushed to their limits. Despite these pressures, each year, new initiatives are shared in organizations that the nurses must learn, embrace, and include in their practice. Each new initiative can be additive to the nurse's workload; most changes are not time neutral but require staff to expend an allotment of time from their day to complete. When adopting new practice, it is not realistic to add on to workload and stretched resources long term. Workload needs to be addressed by employing workload measurement tools and principles of human factors engineering to better support the provision of optimal patient care.
Mayer & Hammelef, 2013, USA	We need to realize that change is not linear; there are ups and downs, starts and stops. It can take a long time to perceive benefits from a change, which can lead to frustration. Change fatigue is different from resistance to change. With change fatigue, staff can become disengaged and apathetic, often feeling disempowered, burnt out, disillusioned and passive about changes being introduced. Signs of change fatigue may include questioning the value and objectives of the change, diverting resources to other initiatives, showing impatience with the pace of change, and key leaders no longer being visibly engaged with the change.
McMillan & Perron, 2013, Canada	The concept of change fatigue has evolved from the discipline of management as a means to explore organization change and its associated triumphs and failures. Change fatigue has typically been described as change resistance. Concept clarification has highlighted the striking differences and few similarities that exist between the concepts. Further exploration and subsequent research on the concept of change fatigue is needed in the discipline of nursing. The concept not only presents new and alternative perspectives on the processes of organization change but also provides opportunity for theory development that recognizes the impact organizational change has on nurses.
Reineck, 2007, USA	Implementing change in organizations is a key nursing leadership competency. Models of successful change illustrate useful concepts for leaders. Change fatigue is a result of relentless change, during which employees lose trust. It is one reason nurse leaders search for effective models of change management. Successful change models include careful use of power, reason, re-education, structure, behaviour and technology. Learning from models may help nurse leaders avoid change fatigue and may promote safer systems of care.
Szumilas, 2015, USA	Healthcare's landscape is constantly changing. Healthcare organizations are challenged to balance the provision of safe care with the allocation of essential resources. Institutions are poised to recognize that a constantly changing practice environment is extremely stressful. Continuous change overtime creates symptoms of fatigue, and burnout, which can compound already existing stressors, cripple a unit team members' commitment and ultimately affect the quality of care. Nurses' ability to adjust to change must be self-realized. Nurses have to make conscious decisions to become activists in the care they provide.
Tracy, 2006, USA	Current changes in healthcare organizations are intended to improve patient safety. However, when continuous changes are underway, few succeed, they may recycle and return with a new name. Employees find it difficult to see the underlying logic or purpose of the change, and ironically implementing multiple safety initiatives at once may actually jeopardize patient safety. With so much change occurring there is no time to get input from those affected by it, no time to fully evaluate progress and adjust. It is recommended to focus on the vital few changes rather than the valuable many.
Valusek, 2007, USA	Change fatigue refers to impairments in an individual's and organization's ability to cope with the ever-increasing scope and pace of change. The creation of a change calendar tool to prevent change fatigue in healthcare as it proactively assesses and schedules changes across the organization to reduce the amount of distraction and change fatigue.

TABLE 6 (Continued)

Reference, location	Key findings
Vestal, 2013, USA	Changes in clinical care, work processes, technology and professional issues all converge at the point of care and are expected to be carefully orchestrated by staff nurses each time they engage with a patient or a team member. This confluence of change creates a tsunami of pressures on care providers. It is common to hear about fatigue, alarm fatigue, compassion fatigue and work hours fatigue. The potential for change fatigue is bound to be a factor as healthcare races forward into the future. Findings suggest, acknowledging change is necessary but can be hard on the staff who must adapt to the constantly changing expectations. Ensure leaders have an accurate picture of the number and magnitude of changes underway. Consider how to prevent communication overload and consider resources needed to implement changes.

Gee et al., 2017; Vestal, 2013). For example, Brown and Abuatiq (2020) suggested nurses' wellbeing may be affected if the rate of change is perceived as too frequent. Davis agreed, acknowledging "nurses will suffer in the turbulence created in the process" (2002, p. 24). Excessive change can impair nurses' ability to cope and adapt to change, creating a sense of uncertainty and a lack of control (Ead, 2015; Kapping, 2021).

#### 4.2.3 | Intensification of workload

When the focus is on the quantity of change, not quality, this can lead to unintended consequences and change fatigue (Brown & Abuatiq, 2020; Camilleri et al., 2019; Kapping, 2021; Wozniak et al., 2020). Authors reported saturation effect or lack of lulls between changes can lead to change fatigue (Brown et al., 2018; McMillan & Perron, 2020b). Authors described an intensification of workload results in a blitz of change initiatives, in which staff are expected to alter their practice and implement the changes with a lack of resources (Muir & Keim-Malpas, 2020; Vestal, 2013). In a cross-sectional study, healthcare teams who faced constant change but lacked the ability to make or sustain change, known as adaptive reserve, experienced change fatigue (Huynh et al., 2018).

### 4.3 | Behaviours associated with change fatigue

#### 4.3.1 | Exhaustion

Several authors explored exhaustion as associated with rapid and continuous change (Brown & Abuatiq, 2020; Camilleri et al., 2019; Davis, 2002; McMillan & Perron, 2020b; Muir et al., 2021). Davis (2002) suggested the pace of change had detrimental consequences causing stress, tiredness and exhaustion. For example, in a qualitative study evaluating the impact of changes to a physical space in an emergency department, one participant shared, "just think that when you're...overworked, stressed out, nervous, people don't sleep. I hear people all the time telling me they cannot sleep before work. That is terrifying to me. Can you imagine how the patients must feel?" (Muir et al., 2021, p. 5). Another participant reinforced the feeling of exhaustion, "it was just really tiring, it was just

one thing [change] after another, it just tired people out" (McMillan & Perron, 2020b, p. 2630).

#### 4.3.2 | Powerlessness

Several authors recognized nurses are not immune to the effects of constant change (Brown & Abuatiq, 2020; Davis, 2002). Most concerning, the impact of change places significant pressure on nurses to carry out changes with a lack of accompanying support (Davis, 2002; McMillan & Perron, 2013; Muir & Keim-Malpas, 2020; Vestal, 2013). For example, a qualitative study participant reported feeling stressed, insecure, and anxious about the new changes expected in practice (Muir et al., 2021). Muir et al. (2021) elaborated the adverse effects of change fatigue were derived from the decisional power of those planning and implementing change. Several authors acknowledged that change management is often predominantly focused from a 'top-down' approach with a lack of consideration for the end-users, contributing to alienation, dissolution, and powerlessness (McMillan, 2018; McMillan & Perron, 2013; Reineck, 2007). Authors also identified that nurses attempt to share their concerns about ongoing change, but lack of acknowledgement creates dissent due to a perceived low level of influence, lack of collaborative decision-making, and powerlessness due to fear of speaking out and reprisal (Ead, 2015; McMillan, 2018; McMillan & Perron, 2013). In addition, several participants expressed the lack of decision-making took away power, influence, and control over proposed changes (McMillan & Perron, 2020b). McMillan (2018) recognized nurses have a moral responsibility to uphold a standard of care, and this becomes jeopardized in the context of rapid change and change fatigue, resulting in moral distress.

#### 4.3.3 | Passive acceptance

McMillan and Perron (2020b) identified that the passive acceptance of change resulted from individuals not questioning the value of new change initiatives and being unable to differentiate change fatigue from resistance. Investigators have reported change management leaders often misinterpret this diametric response as it is often not explicitly felt or observed and could be mistaken for acceptance

(McMillan & Perron, 2013). McMillan and Perron (2013) corroborated their claim explaining passive behaviours are manifested by staff becoming disengaged, apathetic, and ambivalent, showing no signs of resistance. For example, participants shared that continuous workplace change as feeling robotic and numb towards the change process, portraying passive acceptance of change. Due to the passive behaviour associated with change fatigue, it is often unnoticed and under-researched (Brown, 2016; Brown & Abuatiq, 2020; McMillan & Perron, 2013).

## 4.4 | Consequences of change fatigue

### 4.4.1 | Individual consequences

During rapid or unremitting change, change fatigue can manifest as individuals' emotional or behavioural reactions. Emotional reactions include apathy, passive acceptance, emotional exhaustion, withdrawal, stress, disempowerment, disengagement, disillusionment, ambivalence, grief, uncertainty, burnout, resignation, and moral distress (Brown, 2016; Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; Davis, 2002; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013, 2020b). Similarly, descriptions of behavioural outcomes are silent dissent, decreased work and life satisfaction, self-sacrifice, increased rates of absenteeism, work disability, loss of productivity, decreased organizational commitment, low morale, lack of employer trust, and may influence nurses' decision to leave the profession (Brown, 2016; Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; Ead, 2015; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013, 2020b). Several authors recognized the passive or silent nature of change fatigue causes outcomes to go unnoticed and understanding the impact of change fatigue has important ramifications for nurses' health and wellbeing (Brown & Abuatiq, 2020; Kapping, 2021; Mayer & Hammelef, 2013; McMillan & Perron, 2020b).

In addition, authors who investigated change fatigue have documented a high incidence of burnout among nurses who experience rapid or continuous change (McMillan & Perron, 2013, 2020b). Although authors did not explicitly indicate a correlated or cyclical relationship between burnout and change fatigue, the two concepts are often experienced concurrently (McMillan & Perron, 2020b). McMillan and Perron (2020b) elucidated burnout was directly related to the impact of ongoing change, increased workloads, and lack of support that nurses experienced. McMillan and Perron (2020b) shared a participant excerpt indicating nurses were sacrificing their personal time in an attempt to stay current with organizational change due to the intensification of workload and lack of paid time, fostering feelings of burnout. Some authors also described that burnout is related to increased exhaustion, staff withdrawal, resentment, and overall negative feelings about organizational change (McMillan & Perron, 2013). Overall, McMillan and Perron (2013) explicated that the experience of

change fatigue and burnout are detrimental to nurses and the profession.

### 4.4.2 | Organizational consequences

Authors have also acknowledged the organizational impact of change fatigue due to unprecedented change rates (McMillan & Perron, 2020b). Outcomes include increased absenteeism, turnover rates, decreased organizational productivity and commitment, decreased job satisfaction, low morale, moral distress, difficulties retaining nurses, and latent change failure (Brown & Abuatiq, 2020; Brown et al., 2018; Ead, 2015; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013; Muir et al., 2021; Szumilas, 2015; Tracy, 2006). Several authors measured change fatigue using a validated scale (Bernerth et al., 2011) in their respective studies (Brown, 2016; Brown et al., 2018; Camilleri et al., 2019; Kapping, 2021) however this tool was intended for use in business organizations. In a quantitative study examining change fatigue experienced by nursing teams, authors found established teams experienced change fatigue more often than newly established teams (Camilleri et al., 2019). Camilleri et al. (2019) stated established teams are faced with unremitting change compounding the effects of change fatigue. Similarly, Brown et al. (2018) noted a statistically significant association between novice nurses experiencing lower change fatigue scores than experienced nurses. However, variability in the literature identified new graduate nurses experiencing more vulnerability to the effects of change fatigue (Vestal, 2013). A study in an acute care hospital found that change fatigue negatively impacts job satisfaction and is positively influenced by resilience, with a weak correlation between job satisfaction and years of experience (Brown et al., 2018). Many authors have recognized the sequelae of change fatigue may adversely affect patient safety and quality of patient care (Camilleri et al., 2019; McMillan, 2018; McMillan & Perron, 2020b; Szumilas, 2015; Tracy, 2006). Authors have recognized administrators have responsibilities in preventing and mitigating change fatigue (Brown, 2016; Brown et al., 2018; Camilleri et al., 2019; Kapping, 2021; McMillan, 2018; McMillan & Perron, 2013, 2020b; Vestal, 2013).

## 4.5 | Change fatigue mitigation strategies

### 4.5.1 | Resilience

Several of the included study authors emphasized resilience as a strategy to ameliorate change fatigue (Brown, 2016; Brown & Abuatiq, 2020; Brown et al., 2018; Ead, 2015; Mayer & Hammelef, 2013; McMillan & Perron, 2020b; Summer Bryant, 2020; Szumilas, 2015). Brown and Abuatiq (2020) defined resilience as an individual's ability to manage and recover from adversity with access to appropriate resources. Several authors suggested that offering resilience training may counteract



change fatigue in organizations (Brown & Abuatiq, 2020). Brown et al. (2018) have recognized resilience can benefit individuals who endure unprecedented and turbulent change. However, McMillan and Perron (2020b) found the deleterious effects of change fatigue can impair nurses' innate resilience, causing stress and burnout. Thus, authors proposed resilience practices and training by emphasizing self-care or increasing individuals' or collectives' adaptive reserve by improving communication, team relationships, and trust (Mayer & Hammelef, 2013; Summer Bryant, 2020). Brown et al. (2018) suggested job satisfaction of nurses has a statistically positive association with resilience. However, some authors offer other disciplines report positive effects from resilience training but recognized a lack of research involving nurses and the experience of change fatigue (Brown et al., 2018).

#### 4.5.2 | Change management practices

Change fatigue is often undetected due to the passive nature of the phenomenon, and managers must be cognizant of the negative effects experienced by nurses (Brown & Abuatiq, 2020; Brown et al., 2018; Camilleri et al., 2019; McMillan & Perron, 2013). McMillan and Perron (2013) scrutinized the discordance in current change management practices and encouraged leaders to contemplate improving staff engagement, leadership and organizational strategies, and political and organizational culture influences. Ead (2015) unveiled many recommendations for change leaders, such as considering an optimal number of change initiatives per quarter while being abreast of the role of saturation effect. Ead (2015) also encouraged leaders to deliberate on the metrics used to guide the number, magnitude, timing, and delivery of change initiatives, such as considering the volume of concurrent change, the workload of staff, and recognizing the role of human factors engineering. Change leaders should be encouraged to schedule change initiatives and focus on critical or need-to-know content rather than prolific communication (Valusek, 2007; Vestal, 2013). Several authors urge leaders to consider the essential changes necessary to improve patient care delivery and reconsider implementing inessential or discordant change (Muir et al., 2021; Tracy, 2006).

Numerous authors advocated for well-planned change management practices that recognize grace periods between change efforts (Kapping, 2021; Mayer & Hammelef, 2013; McMillan & Perron, 2013; Vestal, 2013). For example, authors advocated to consult frontline nurses or end-users and encourage nurses' voices to be heard in decision-making to foster engagement and sustainable change (McMillan, 2018; McMillan & Perron, 2020b; Muir et al., 2021; Summer Bryant, 2020). McMillan (2018) suggested using beta testing with a sample practice area first to ensure issues reported could be remedied before implementation. Authors have advocated for change leaders to consider assessing staff experience with change fatigue using validated tools before implementing change (Brown, 2016; Brown et al., 2018; Camilleri et al., 2019; Ead, 2015; Kapping, 2021; Muir et al., 2021).

#### 4.5.3 | Political agency

Many authors articulated the power and influence of nurses' voices in change management as a strategy to overcome change fatigue (McMillan, 2018; McMillan & Perron, 2020b; Summer Bryant, 2020). Critical theory was noted in several studies to understand change fatigue (McMillan, 2018; McMillan & Perron, 2013, 2020b; Muir et al., 2021). Specifically, the theory explores dominant discourses and practices that foster power inequities in relationships (McMillan & Perron, 2013). McMillan (2018) noted the discrepancy between managerial perspectives dominated in healthcare organizations and the incongruity with frontline nursing perspectives. Nurses should recognize the power inequities in change management practices, and McMillan (2018) challenges them to not passively accept changes and use their voice as a counter-narrative to question change. Furthermore, McMillan (2018) claims to enhance our understanding of the complexity of organizational change, nurses must have their voices heard without fear of reprisal and become political agents.

## 5 | DISCUSSION

In this integrative review, we summarized current knowledge about change fatigue in nursing, including how change fatigue affects nurses, the nursing profession, and how to prevent and overcome it. We identified themes in the examined literature illustrating change fatigue's multidimensional and multifactorial nature.

Few authors provided homogenous definitions and a unified understanding of change fatigue, while some authors proposed divergent definitions, and others provided no context for their use of the concept. Overall, there is evidence an accepted conceptual definition of change fatigue in nursing is lacking. In addition, there are examples of how nurses experience change fatigue in practice. Most notably, the experience of change fatigue is intensified by lasting change, a lack of control when incorporating change in practice, and the subsequent intensification of workload. Moreover, many associated behaviours emanate the experience of change fatigue, including exhaustion, powerlessness and passive acceptance of change. Several repercussions of change fatigue are outlined, including the effect on an individual and the organization. Lastly, many authors provided mitigation strategies to assuage the experience of change fatigue, including a focus on resiliency, adapted change management practices and employing the role of a political agency.

The results synthesized from the articles situate well with the underpinnings of CST. Authors have identified the concept of change fatigue as under-researched in the literature (Brown et al., 2018; McMillan & Perron, 2013, 2020b), with a lack of literature identifying an associated theoretical framework. Numerous authors reported nurses feel overwhelmed, exhausted, stressed, disillusioned, burnt out and powerless with rapid and continuous change in their workplace (Brown & Abuatiq, 2020; Brown et al., 2018; Kapping, 2021; Mayer & Hammelef, 2013; McMillan & Perron, 2013, 2020b). The application of CST proves useful to view the dominant



discourses and practices that foster power inequities in relationships (McMillan, 2018; Sumner, 2007; Weaver & Olson, 2006). CST illuminates the oppression of nurses by liberating their underrepresented voices and encouraging them to practice political agency, elucidating the power and authority in change management (McMillan, 2018).

Many authors reported that frequent organizational change causes change fatigue (Brown et al., 2018; Davis, 2002; McMillan, 2018; McMillan & Perron, 2013; Muir & Keim-Malpas, 2020; Vestal, 2013). Change fatigue has been well-known in the business discipline as a means to explore organizational change (McMillan & Perron, 2013), but it is a novel concept in the nursing discipline, even though healthcare is facing unprecedented changes given the global pandemic (Havaei et al., 2021). Although much research recognizes the burden of organizational change on employees, few studies have explored the impact of rapid and continuous change and change fatigue in nursing (McMillan, 2018).

### 5.1 | Areas for future research

A qualitative examination of change fatigue in nursing practice that is acutely aware of the political structures that govern change processes in large neoliberal institutions such as healthcare is needed. For example, McMillan and Perron (2020b) refer to neoliberal agendas impacting managerialism that focus on efficiency, productivity and cost containment, resulting in immense fiscal restraint and increased pressure on nurses to do more with less. Further research is needed to determine the relationship between change fatigue, burnout and change avoidance. Studying concepts using validated tools would provide information to determine if there is a directional relationship wherein one concept exacerbates the other or if change fatigue is a component of burnout or avoidance. Understanding this aspect of nurses' experience of change fatigue is important to appreciate as it has the potential to interfere with the direction of organizational change and may uncover specific strategies on how to mitigate the concepts from occurring. Important future work also includes the development of a validated tool change leaders could employ to measure change fatigue when considering new change initiatives for nursing practice or education. Ead (2015) includes reference to workload measurement tools, human factors engineering and a change fatigue measurement scale (Bernerth et al., 2011); creating a validated tool encompassing these metrics and representing the complexity and nuances of the nursing profession would be favourable. No studies were found that examined the differences in change fatigue based on stratified changes, countries, or healthcare systems, which highlights key areas for future investigation. More research is also needed to explore the best strategies for knowledge translation and awareness of change fatigue education.

### 5.2 | Implications for nursing practice

Nursing leaders must be perceptive to the deleterious effects of rapid and continuous change experienced by nurses. Leaders have an opportunity to foster engagement of frontline or end-user nurses

in change management practices and should consider validated tools to use in practice to assess change fatigue before implementing change. In addition to broadening understanding of change fatigue, study findings may also inspire nurses to practice resiliency and become political agents in change management.

### 5.3 | Limitations

Despite a robust search strategy, some literature may have been missed by limiting the initial search to available studies written in English. In addition, authors have much variability in defining the phenomenon of change fatigue, and sometimes change fatigue is used interchangeably with other concepts excluded from the review. Furthermore, all studies were included regardless of the outcome of the critical appraisal process. Lastly, as there is no gold standard for some components of the integrative review process, this may have impacted the rigour of this review.

## 6 | CONCLUSION

Change is constant in nursing practice, and it is required for nurses to stay current with safe, competent and evidence-based practice. However, the repercussion of attempting to keep up with evidence-based practice due to the institutions implementation strategies and timing without consideration of nursing workload has introduced the concept of change fatigue. Change fatigue has detrimental effects on nurses, the profession, healthcare organizations and patient care. This integrative review has further developed an understanding of how change fatigue affects nurses, the nursing profession, and highlighted strategies to prevent and overcome it. The findings from this review can be used to inform future changes to nursing policy and practice while being mindful of their impact.

### AUTHOR CONTRIBUTIONS

LB and CS conceived the study; LB and CS developed the study design; all authors contributed to key background literature and knowledge on change fatigue in nursing; LB and CS created the proposed search strategy; LB drafted the review manuscript; LB, CS and LN edited the review manuscript; all authors read and approved the final manuscript. LB is the guarantor of this review.

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**CONFLICT OF INTEREST**

The authors have declared no conflict of interest.

**PEER REVIEW**

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15546>.

**DATA AVAILABILITY STATEMENT**

The data that support the findings of this study are available from the corresponding author upon reasonable request.

**ETHICS STATEMENT**

Ethics approval was not required for this integrative review.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# School nursing: New ways of working with children and young people during the Covid-19 pandemic: A scoping review

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## Abstract

**Aim:** To examine how school nurse practice evolved as a result of the Covid-19 pandemic.

**Design:** A scoping review of international literature, conducted and reported in line with Arksey and O'Malley's (2005) framework.

**Data Sources:** Searches were conducted in September 2021. Ten databases were searched: The British Nursing Database, CINAHL, Cochrane Library, Consumer Health Database, Health and Medicine, Nursing and Allied Health, Public Health, PsycINFO, PubMed and Web of Science. Relevant grey literature was identified through hand searching.

**Review Methods:** A minimum of three reviewers independently screened articles and two reviewers independently undertook data extraction, with any decisions made collaboratively with the wider team. Much of the literature was not empirical work and so it was not possible to apply a traditional quality appraisal framework.

**Results:** Searches identified 554 papers (after deduplication) which were screened against title and abstract. Following the full-text review, 38 articles underwent data extraction and analysis. The review findings highlighted that school nurses adapted their practice to ensure they were able to continue providing their formal and informal school health offer to children, young people and their families and continued working closely with the multidisciplinary team. In addition, the expanded public health role generated by Covid-19 for school nurses' work was considerable, multi-layered and added to their routine workload. School nurses displayed resilience, adaptability and creativity in their response to delivering services during Covid-19.

**Conclusion:** School nurses took on a leading public health role during the Covid-19 pandemic. Some developments and practices were highlighted as beneficial to continue beyond the pandemic. However, formal evaluation is needed to identify which practices may merit integration into routine practice. Continued investment in staff and infrastructure will be essential to ensuring school nurses continue to expand their practice and influence as public health experts.

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## Impact

**What problem did the study address?:** School nurses play a key role in delivering routine services (statutory and non-statutory) to young people and their families, as well as working extensively with other professionals to support and safeguard children and young people. During the Covid-19 pandemic, it was necessary for school nurses to develop and evolve their practices to be able to continue to deliver their services. However, there is little detail about the nature of these changes and if any may be of benefit to school nursing practice in the future.

**What were the main findings?:** During the pandemic, a range of innovative and adaptive practices were identified as being adopted by school nurses across the world to allow them to: i. continue providing their formal and informal school health offer to children, young people and their families, as well as continue working closely with other professionals and ii. carry out their expanded public health role.

**Where and on whom will the research have an impact?:** It is important to formally evidence the public health expertise of the school nurse. Further research and formal service evaluations (from both school nurses and children and family perspectives) of new school nursing practice which evolved as a result of Covid-19 are needed to identify those which may have value post-pandemic. Key stakeholders such as policy-makers and funders need to consider necessary investment in resources and infrastructure.

### KEYWORDS

adolescent health, family care, health services research, literature review, public health nursing, school nursing

## 1 | INTRODUCTION

This review presents a global perspective on the responses of school nurses (SNs) to the public health challenges of the Covid-19 pandemic. During the pandemic, SNs faced the challenge of delivering remote routine statutory and non-statutory services and multidisciplinary working, as well as an increased infection control and safeguarding role. This was alongside additional constraints on staffing through sickness and redeployment and personal additional caring and/or home-schooling responsibilities. Reports show that SNs responded positively and proactively to these demands, and there are many examples of SNs taking on new or expanded public health roles, as well as using creative and innovative practice to overcome barriers. This review brings these examples and evidence together from the literature to give an overview of new, adapted and extended practice, and the benefits and challenges of the changes required. Findings from this review highlight the specialist public health role of the SN. The review strengthens the evidence base regarding SN practice, which can in turn inform policy regarding the vital public health role of the SN, and be a resource for SNs regarding effective practice.

## 2 | BACKGROUND

The Covid-19 pandemic led to remote curriculum delivery for many children across the globe over a significant period of time.

This was followed by ongoing disrupted on-site schooling due to isolation requirements and/or sickness. SNs' informal and formal in-person contact with children, young people, their families and the multi-disciplinary team (MDT) was initially halted, and then interrupted with the ensuing changes in social contact guidance. For SNs this has been a significant challenge for maintaining both universal and targeted support for children and young people (CYP) as usual modes of contact through school drop-in sessions, classroom activities and in-person professional meetings were no longer viable. As lockdown extended, and isolation and shielding became a regular occurrence, it became apparent that safeguarding CYP was also a significant public health issue as child protection concerns and referrals increased. Several reports highlighted the increased vulnerability of CYP during the mandated lockdown periods (Green, 2020; United Nations [UN] Women, 2020; Young Minds, 2021).

This review presents a synthesis of change in school nursing practice in the international literature as a result of Covid-19, lockdowns and decreased in-person contact. The review included all direct practice delivery changes. It also sought to specifically foreground change in practice that relates to SNs' safeguarding work with CYP, their families, and the MDT. A global perspective was taken to facilitate an understanding of how SNs across nations responded to challenges in practice incurred by the pandemic, and widen the learning landscape.



### 3 | THE REVIEW

#### 3.1 | Aim(s)

This review identified the ways in which SN practices evolved as a result of the Covid-19 pandemic. We documented how SNs worked with CYP and their families, the wider SN community and the MDT. In doing so, we identify the benefits and challenges in SNs' new working practices. Recommendations are made to inform future practice in CYP's public health care; strengthen service delivery in the longer term; and inform policy going forward.

#### 3.2 | Design

This review was registered with PROSPERO (CRD42021296878). Throughout the design and conduct of the review, expert stakeholders (practising SNs, representatives of professional SN organizations) were consulted. The intention had been to undertake a systematic review to provide a quality appraisal of research evidence; however, due to the low number of empirical studies and wide range of includable grey literature, a scoping review was conducted, in line with Arksey and O'Malley's (2005) framework. As there was limited literature focusing on the impact on vulnerable children, a broad definition of 'vulnerable' to encompass all children (in addition to those requiring mandatory support and monitoring) was adopted. This decision was made in consideration of the social, economic and psychological challenges incurred by Covid-19 which increased the vulnerability of all CYP (Young Minds, 2021). The review is reported in line with the PRISMA guidelines for scoping reviews (Tricco et al., 2018).

#### 3.3 | Search methods

A broad initial search strategy was adopted due to an awareness that a range of different publication types may constitute relevant literature (i.e. providing examples of new ways SNs worked with CYP as a result of Covid-19). The framework for our searches was based on population: school nurses and condition/exposure: Covid-19. A range of specific terms within each category were identified. Search filters included the publication being available in English and published between 2019 and 2021.

Searches were conducted in 10 electronic databases, supplemented by hand searching a range of grey literature associated with SN professional organizations. Where full-text articles were not accessible, the authors were contacted directly to request access. The full search strategy is provided in Supplementary File S1.

#### 3.4 | Eligibility criteria

##### 3.4.1 | Inclusion

- All types of publications
- Sample/focus is SNs
- An actual change in SN practice
- Change in practice is the result of Covid-19

##### 3.4.2 | Exclusion

- Publication does not clearly include SNs
- Change in practice was not the result of Covid-19
- Publication does not report a specific change in practice but more generally discusses what could/should have happened

#### 3.5 | Search outcome

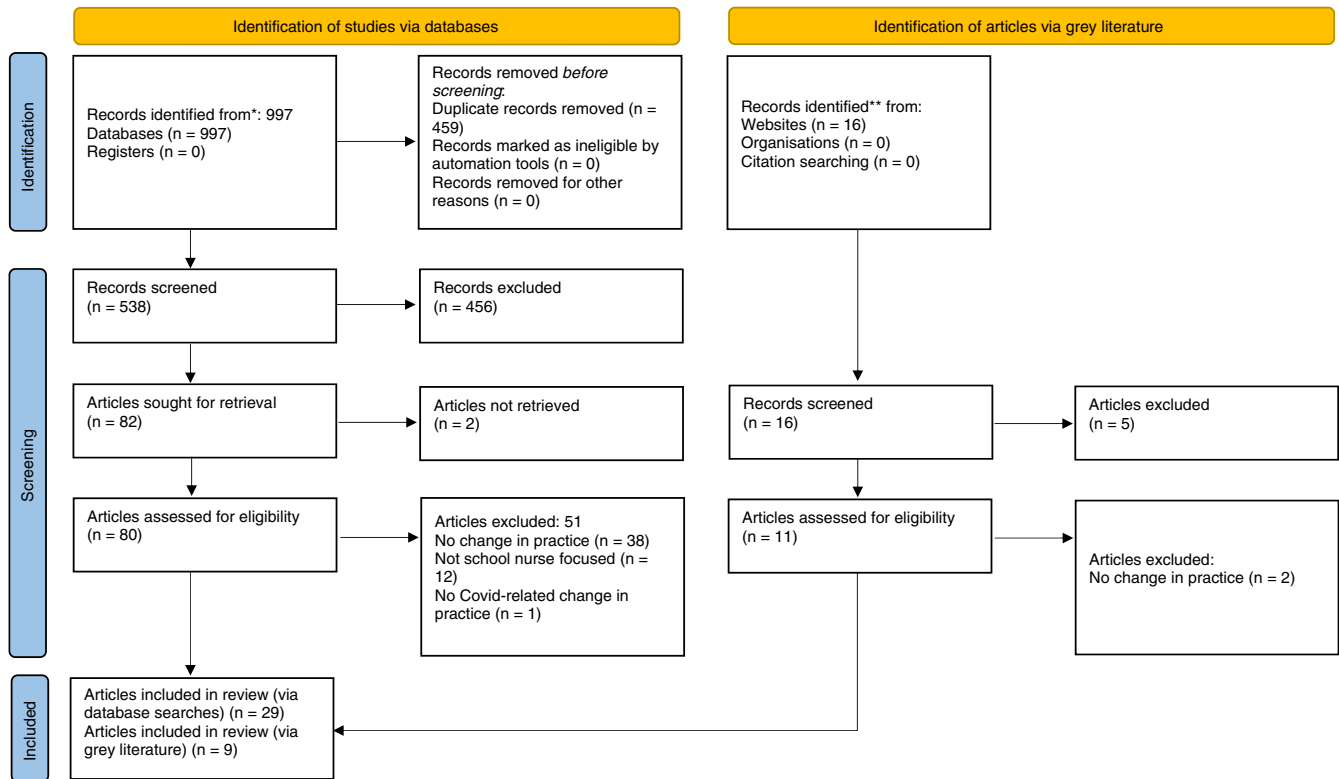
One thousand and thirteen references were identified from database searches ( $n = 997$ ) and grey literature searches ( $n = 16$ ). After deduplication five hundred and fifty-four references were included. After screening by title and abstract, 93 records were assessed as eligible for full-text review ( $n = 82$  database and  $n = 11$  grey literature). We excluded those articles where a full-text version could not be retrieved ( $n = 2$ ), leaving 91 records for full-text review, following which 38 articles were included (see Figure 1).

#### 3.6 | Screening

One reviewer (GC) undertook an initial filter of duplicates. A minimum of three of the four reviewers (GC, JA, SB and DS) independently screened all titles and abstracts and then full-texts of the identified relevant publications. Disagreements were resolved through discussion between the reviewers. During this process, pragmatic decisions had to be made around certain issues that lacked clarity within the articles. These decisions were made collaboratively, with at least three reviewers being involved in all inclusion decisions. The software package Rayyan was used to record screening decisions and justifications (Ouzzani et al., 2016).

We initially sought to capture innovative practice with a specific focus on CYP. However, early engagement with the literature highlighted accounts of diverse adaptations and extensions of existing practice, as well as discussion of the benefits and challenges to SNs fulfilling their role within the constraints of the pandemic. We therefore felt it was important to maximize the opportunity to document the full extent of what SNs were doing in their work with CYP, families and their partnership relationships.





**FIGURE 1** PRISMA 2020 flow diagram showing included searches of databases and grey literature. \*Databases: British Nursing Database, CINAHL (EBSCO), Cochrane Library, Consumer Health Database (ProQuest), Health and Medicine (ProQuest), Nursing and Allied Health (ProQuest), Public Health (ProQuest), PsycINFO, PubMed and Web of Science (Clarivate). \*\*Grey literature: School and Public Health Nurses Association (SAPHNA) and Community Practitioner (Community Practitioners' & Health Visitors' Association journal), Public Health England (PHE), Department of Health (DH), National Society for the Prevention of Cruelty to Children (NSPCC) and Early Intervention Foundation. From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: [10.1136/bmj.n71](https://doi.org/10.1136/bmj.n71). For more information, visit: <http://www.prisma-statement.org/>

### 3.7 | Quality appraisal

Much of the available literature obtained through our searches was not empirical research, therefore it was not possible to apply a traditional quality appraisal framework.

### 3.8 | Data abstraction

Following initial familiarization with the literature during a parallel phase of the project (survey development), subheadings were chosen for data extraction based on (1) topics and issues that were prominent in the literature, (2) the content we thought to be most appropriate for meaningfully answering our research questions and (3) input from our steering committee. Once the final list of 38 includable articles was identified, the relevant data from each article were extracted onto an Excel spreadsheet. The data extraction form was piloted using a sub-sample of 20 articles to ensure it was easy to use, able to be interpreted consistently and captured all relevant information.

The data extraction headings were developed through a preliminary iterative process by the two data extractors (GC and DS) (see [Table 1](#) for extraction headings). Data were extracted from each paper by one of two reviewers (GC or DS) with the other data extractor independently checking the extracted data for rigor and quality. Pragmatic decisions, uncertainties or disagreements were resolved through discussion between the independent reviewers in the first instance and wider project team as necessary.

### 3.9 | Synthesis

The headings of our data extraction sheet formed the framework for our synthesis. Two members of the team (GC and DS) independently grouped the extracted data to produce initial themes in the context of each heading (i.e. CYP, parents, etc.). Preliminary groupings were reviewed by another independent reviewer (SB) and extensively discussed (if necessary also with the wider team) until consensus was reached on the final themes.

## 4 | RESULTS

### 4.1 | Literature characteristics

The included publications were from the United States of America (USA) ( $n = 22$ ), the United Kingdom (UK) ( $n = 13$ ), Hong Kong ( $n = 2$ ) and Sweden ( $n = 1$ ). A range of publication types were represented: commentary (news, opinion pieces, editorials, etc.) ( $n = 27$ ), case studies ( $n = 5$ ), empirical research ( $n = 5$ ) and a service review ( $n = 1$ ). The included articles were published in 2022 ( $n = 1$ , originally published online in 2021), 2021 ( $n = 17$ ), 2020 ( $n = 15$ ) and some had no date ( $n = 5$ ). See [Table 1](#) for a summary of extracted data.

### 4.2 | Thematic findings

As proposed by Bradbury-Jones et al. (2021), a patterning table, summarizing the key ways SN practice changed and evolved during Covid-19, is presented in [Table 2](#). The identified patterns, advances, gaps, evidence and research recommendations are presented in [Table 3](#). Themes are organized based upon whether they relate to the ongoing school health offer or the new expanded SN role arising from Covid-19.

#### 4.2.1 | The continued school health offer

Themes that relate to the continued school health offer addressed how SNs adapted their practice to ensure they were able to continue providing formal and informal support to CYP and their families, and continue working closely with the MDT.

##### *Engagement with CYP and families*

Online or digital platforms were used for consultations or appointments with CYP (Barbee-Lee et al., 2021; Gingell & Spencer, n.d.; Marrapese et al., 2021; Martinsson et al., 2021; Unknown, n.d.; Various, 2020b; Waters, 2021; White, 2020a, 2020b). Technology was also used to maintain contact with CYP (Booher, 2020), including the use of ChatHealth (Evans, 2020; Unknown, 2020c; Various, 2020a; Various, 2020b), online platforms (White, 2020b) and social media (Combe, 2020a). Telephone calls replaced in-person health dialogues with CYP (Gingell & Spencer, n.d.; Martinsson et al., 2021; Various, 2020b), including for the conduct of routine health assessments and annual reviews (Tomkinson, n.d.; Unknown, 2020; Unknown, 2020c) and informal contacts with CYP (Combe, 2020a; Lee et al., 2021; Various, 2020a).

Technology and virtual platforms were also used in communications with parents (Barbee-Lee et al., 2021; Evans, 2020; Flaherty, 2020; Marrapese et al., 2021; Martinsson et al., 2021; Waters, 2021; White, 2020a). The purpose of these virtual interactions included formal care plan reviews (Various, 2020b), digital interventions (Gingell & Spencer, n.d.) and provision of informal advice

and support (Unknown, n.d.). SNs used telephone calls to communicate with parents for informal chats and check-ins (Lee et al., 2021), consultations (Gingell & Spencer, n.d.; Martinsson et al., 2021; Unknown, 2020c) and annual reviews (Unknown, 2020d). Changes to routine screening consultations, such as sending questionnaires to parents, were reported (Barbee-Lee et al., 2021). Email and post were also utilized with both CYP and parents (Tomkinson, n.d.; Unknown, 2020c; Unknown, 2020d).

Technology was reported as beneficial for ongoing CYP consultations (Martinsson et al., 2021), communications (Lee et al., 2021; Unknown, 2020c) and engagement (Gingell & Spencer, n.d.; Unknown, 2020). Remote options saved time for some SNs, CYP and families, although others felt the increased frequency of contacts increased demand (Martinsson et al., 2021). CYP were reported to prefer virtual over face-to-face contacts (Tomkinson, n.d.), citing ease of discussing personal/sensitive issues, and young carers appreciated the support this provided (White, 2020b). Informal feedback highlighted that SNs were able to gain a more in-depth understanding of CYP's home situation and families' needs (Tomkinson, n.d.; Martinsson et al., 2021; White, 2020b). Though not ideal, conducting telephone assessments allowed CYP to share new concerns without delays to appointments (Unknown, 2020d).

However, virtual platforms could negatively impact the quality of SNs' conversations with CYP and families (Martinsson et al., 2021). Video conferencing capabilities were necessary because some SNs felt telephone contacts were not sufficient (Gingell & Spencer, n.d.). Also highlighted was the impact of digital poverty and resulting unequal access to services (White, 2021). Increased contact with students and families—often via virtual platforms—made additional demands on SNs' time (Martinsson et al., 2021; White, 2020b; Yip et al., 2020). Some reported a change in methods of communication to electronic only (Hoke et al., 2021).

SNs utilized alternative environments to ensure service delivery continued. Venues such as children's centers and empty offices were used (Barbee-Lee et al., 2021; Evans, 2020). Various services were also delivered outdoors (Barbee-Lee et al., 2021; Combe, 2020a; Fauteux, 2021; Martinsson et al., 2021; White, 2020a; White, 2021). Outdoor meetups (such as walk-and-talk sessions) were reportedly beneficial for a range of reasons including providing a 'physical connection' that was missing from virtual communication and being viewed positively by CYP and their families (Various, 2020b), resulting in improved attendance from CYP (Driscoll et al., 2021) and relaxed engagement (Evans, 2020). SNs also collaborated to distribute resources such as food and school supplies via drop-offs and deliveries (Combe, 2020a; Fauteux, 2021; Robarge, 2021; Robinson, 2021). An extension to the timing of available services, such as routine vaccination access, was reported (White, 2021).

##### *Education (CYP and families)*

Virtual platforms were used to deliver routine health education (e.g. sexual health) to CYP and their families (Barbee-Lee et al., 2021; Fauteux, 2021; Flaherty, 2020; Marrapese et al., 2021; Martinsson et al., 2021; Unknown, 2020b; White, 2020b).

TABLE 1 Data extraction table

Article details	Change in practice					Feedback				
	Author(s), publication date	Source, Article type, Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Barbee-Lee, Seymour, Hett, Norris, Slack, Cartier, Haycox, Armstrong, & Herbert, 2021 September 2021	NASN School Nurse; Commentary; Santa Fe, New Mexico, USA	<ul style="list-style-type: none"> <li>Maintained social distancing, wore masks, and sanitised surfaces while conducting in-person routine screening (i.e. hearing, vision and dental)</li> <li>Conducted routine screening consultations via questionnaire with parents</li> <li>Dental referrals provided for students with concerns, in lieu of oral screenings</li> <li>Some aspects of sexual health education converted to an online platform</li> <li>Created and used a virtual nurse's office (accessible to students)</li> <li>Enforced school exclusions (per state guidelines)</li> <li>Wore PPE when working with symptomatic students or administering nebulizer treatments</li> <li>Identified isolation rooms on campus</li> <li>Drive-up vaccine clinics held at the district office (routine vaccinations)</li> <li>Coordinated with the district office to schedule students' routine vaccination appointments</li> <li>Liaised with the district's Office of Student Wellness to secure empty rooms at the district office to conduct in-person student screening appointments</li> </ul>	<ul style="list-style-type: none"> <li>Participated in virtual Q&amp;A sessions to answer questions related to new procedures and student safety</li> <li>Developed infographics with key information for families (Covid-19-related content)</li> <li>Created and used a virtual nurse's office (accessible to parents)</li> <li>Conducted hearing, vision and screening consultations via questionnaire with parents</li> </ul>	<ul style="list-style-type: none"> <li>Created and used a virtual nurse's office (accessible to staff)</li> </ul>	N/A	N/A	<ul style="list-style-type: none"> <li>Created the Daily Screening Tool form that school staff used to report self-screening responses</li> <li>Supported the development of a HIPAA-compliant standardised student wellness check-in form, completed daily by students (and reviewed daily by school wellness teams)</li> </ul>	N/A	N/A	
Booher, summer 2020	The Alaska Nurse; Commentary; Alaska, USA	<ul style="list-style-type: none"> <li>Remote communication with students during home working</li> <li>Taught students ways to stay safe, limit screen time, and make healthy choices</li> <li>Developed lesson plans to present in classrooms (Covid-19-related content, e.g. handwashing)</li> </ul>	N/A	<ul style="list-style-type: none"> <li>Supported custodians with proper disinfecting processes</li> </ul>	N/A	<ul style="list-style-type: none"> <li>Served as a "professional link" between the school district, health department, and emergency operations center</li> </ul>	N/A	N/A	N/A	
Bullard, McAlister & Chilton, March 2021	NASN School Nurse; Commentary; Texas, USA	N/A	N/A	N/A	N/A	N/A	<ul style="list-style-type: none"> <li>Developed an electronic pass system to use on campus to control the flow of students requiring nursing assistance</li> </ul>	N/A	N/A	

TABLE 1 (Continued)

Article details		Change in practice					Feedback		
Author(s), publication date	Source, Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Cogan, 2021	Journal of Psychosocial Nursing; Commentary; USA	N/A	N/A	N/A	- SN support groups were held twice weekly, via Zoom, to share experiences of being on the frontline of Covid-19 in school settings	N/A	N/A	N/A	- "Bearing the brunt" of parental refusal to comply with indoor masking, negative social responses to Covid-19 vaccinations, intimidation, bullying regarding quarantine requirements, and lack of cooperation with contact tracing protocols
Combe, July 2020a	NASN School Nurse; Commentary; USA	- Checked in on students with known health conditions (via telephone) - Outdoor distribution of instructional materials (no further details provided) - Outdoor medication pick-up points - Dropped by teachers' remote classrooms to connect with students - Produced a health promotion video addressing student fears about nurses and other health providers in PPE - Used social media to communicate with students to let them know they were missed and to encourage them to practise self-care	N/A	- Collaborated with school counsellors to produce a resource list to meet families' needs - Worked with teachers to identify students at risk for chronic absenteeism	- State SN organization held virtual town halls to connect with members (at times on a weekly basis)	- Worked with school food service partners to ensure that students dependent on school nutrition continued to have their needs met through drop offs and deliveries	N/A	- Time to research unique student health conditions, collaborate with paediatricians and other healthcare providers, and update Individualised Healthcare Plans without interruptions [relating to time spent working from home] - SN garnered a seat at the Executive Team table	- Managing work and family responsibilities within the same space and time, e.g. juggling multiple curbside grocery pick-up services, trying to stock up on essentials

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TABLE 1 (Continued)

Article details	Change in practice					Feedback				
	Author(s), publication date	Source, Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Combe, November 2020b	NASN School Nurse; Commentary; USA	<ul style="list-style-type: none"> <li>- Covid-19 monitoring, tracing and quarantining</li> </ul>	<ul style="list-style-type: none"> <li>- Notified parents about Covid-19 cases (via telephone)</li> <li>- Sent weekly reminder emails asking parents to screen their child(ren) daily</li> </ul>	<ul style="list-style-type: none"> <li>- Identified positive cases among school staff</li> <li>- Enacted quarantines or school closures as appropriate</li> <li>- Supported education staff to devise plans to keep classrooms safe</li> </ul>	<ul style="list-style-type: none"> <li>- Provided professional peer support in the SchoolNurseNet community and on social media</li> </ul>	N/A	N/A	N/A	<ul style="list-style-type: none"> <li>- Covid-19-specific responsibilities impacted on time to do 'traditional' SN role</li> <li>- Navigating different informational sources</li> <li>- Ever-changing standards of care, limited resources, the unknowns about Covid-19 transmission</li> <li>- Unfamiliar work environments for those new to school nursing</li> <li>- Balancing professional practice and judgement with wider guidance</li> <li>- Staffing levels</li> <li>- Workload expectations and increased working hours</li> <li>- The need to travel between schools</li> <li>- "Everyone's need for information at a moment's notice 7 days a week"</li> <li>- Limited PPE supply chain access for schools</li> <li>- Fear of contracting and spreading Covid-19</li> <li>- Stakeholders "forgot" about ongoing non-Covid-19 needs of many students</li> </ul>	
Driscoll, Hutchinson, Lorek & Kiss, June 2021	SAPHNA; Empirical research (modified)	<ul style="list-style-type: none"> <li>- Arranged to see young people in parks and outdoor areas</li> </ul>							<ul style="list-style-type: none"> <li>- Seeing CYP in parks and outdoor areas improved attendance at appointments; one nurse noted that "many of these were children who wouldn't have turned up to appointments in school time pre-lockdown"</li> </ul>	

TABLE 1 (Continued)

Article details		Change in practice					Feedback				
Author(s), publication date	Source, Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice		
Evans, November 2020	Nursing Children and Young People; Commentary; UK	<ul style="list-style-type: none"> <li>- Used other venues such as children's centers</li> <li>- Walk-and-talks</li> <li>- Change in organization of appointments; greater reliance on bookings than drop-in services</li> <li>- Vaccination backlogs; marquees set up in school fields and mobile units (e.g. use of the local football stadium and drive-through clinics)</li> <li>- ChatHealth introduced in April [2020]; most used in times of lockdown, less use as restrictions eased</li> </ul>	<ul style="list-style-type: none"> <li>- Moved to online meetings</li> <li>- Launch of ChatHealth in April [2020], used by parents of primary school children</li> </ul>	<ul style="list-style-type: none"> <li>- Moved to online meetings with teachers</li> </ul>	N/A	N/A	N/A	<ul style="list-style-type: none"> <li>- Feedback on walk and talks was positive: "Being outside in the fresh air, among nature, is very calming" (feedback from CYP and families, SN); "It brought a new dimension to the support we provide. It is a valuable environment to use to engage in a calm manner that we previously may have overlooked, as we traditionally meet pupils indoors" (SN)</li> </ul>	<ul style="list-style-type: none"> <li>- SNs required to wear full PPE while in close proximity to children, and some schools required SNs to wear full PPE "all the time"</li> <li>- PPE created a "barrier to building relationships with pupils".</li> <li>- Lack of ability to see facial expressions and inability to touch arm to show empathy cited as barriers</li> <li>- Workload increase</li> </ul>		
Fauteux, August 2021	American Journal of Nursing; Commentary; USA	<ul style="list-style-type: none"> <li>- When schools closed, SNs resumed carrying out many regular duties remotely; providing basic health education online, connecting families to services for their health and social needs, and doing what they could to help students with chronic conditions stay healthy at home</li> <li>- Outdoor provision of advice and information to students</li> <li>- Outdoor distribution of food and school supplies</li> <li>- Visited skate parks with water, snacks and helmets to connect skaters with mental health support, tutoring, and other resources</li> </ul>	N/A	N/A	<ul style="list-style-type: none"> <li>- Twice weekly support groups held for SN peers</li> </ul>	<ul style="list-style-type: none"> <li>- Assisted public health departments to investigate disease outbreaks in the school community and beyond</li> <li>- SN team used a refurbished vehicle to conduct Covid-19 testing and help at Covid-19 vaccination clinics</li> </ul>	<ul style="list-style-type: none"> <li>- Collaborated with computer services team to modify the districts' document sharing platform to reduce the administrative burden of contact tracing</li> </ul>	<ul style="list-style-type: none"> <li>- Covid-19 collaboration strengthened the relationship between SNs and public health officials</li> </ul>	<ul style="list-style-type: none"> <li>- Increased workloads 'tremendous' (reported 12-14-hour days, seven days a week); 'they're exhausted'</li> </ul>		
Ferrara, February 2021	Massachusetts Report on Nursing; Commentary; Massachusetts, USA	<ul style="list-style-type: none"> <li>- Change in practical physical setup: medical waiting room (where students with Covid-19 symptoms isolated) and triage area (outside SN office for assessing students' symptoms prior to determining whether they could enter the office)</li> <li>- CYP required masks, social distancing and hand sanitiser to enter SN office</li> </ul>	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	

(Continues)



TABLE 1 (Continued)

Article details		Change in practice				Feedback			
Author(s), publication date	Source, Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Flaherty, November 2020	NASN School Nurse; Commentary; Massachusetts, USA	- Taught health lessons virtually	- Met virtually with parents	- Virtual meetings with peers, interdisciplinary staff, and administration (including Section 504 and Individualised Education Plan meetings)	N/A	N/A	N/A	- Partnering with Local Boards of Health around Covid-19 elevated the critical role and profile of SNs	N/A
Gingell & Spencer (no date)	SAPHNA; Service review; Cambridgeshire, England, UK	- Telephone consultations used initially, replacing face-to-face for "non-essential services"	- Telephone consultations used initially for families, replacing face-to-face for "non-essential services"	N/A	N/A	- Microsoft Teams made available - Norfolk Healthy Child Programme used video conferencing for daily sitrep, huddle and wider multi-agency meetings	N/A	- Video conferencing described as beneficial for flexible working; saved time and travel costs; and resulted in increased attendee numbers at meetings - CYP and families reportedly "engaged" positively during video consultations - Virtual visits allowed child welfare checks without needing doorstep visits to shielding families	- Initially contacts were conducted via telephone but these were deemed "insufficient for their completeness"
Hansen, May 2021	NASN School Nurse; Commentary; Lee's Summit, Missouri, USA	N/A	N/A	- Daily interactions between SNs and building administrators - SNs worked closely with school principals in the collection and utilisation of data	N/A	N/A	- Developed a Covid-19-specific hotline (and data sharing process) for schools to report data to the district	- Increased interaction with building administrators increased the visibility and value of SNs and SN data highlighted role of schools in larger public health team and the critical role SNs play in the team	N/A

TABLE 1 (Continued)

Article details	Change in practice				Feedback					
	Author(s), publication date	Source, Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Hoke, Keller, Calo, Sekhar, Lehman, & Kraschewski, February 2021	The Journal of School Nursing: Empirical research (cross-sectional internet survey of Pennsylvania, n = 350 SNs); Pennsylvania, USA	N/A	- In a cross-sectional internet survey, SNs (n = 350) reported that they switched to only electronic communication (in place of paper communication) = 144 or 41.1% - Increased communicate with parents to check in on students' health = 147 or 42.0% - Reduced all forms of parent communication = 71 or 20.3% - Delayed communication regarding school immunisations = 128 or 36.6% - Increased communication regarding Covid-19 = 173 or 49.4%	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Kunz, Manno, Ruffatti, Blohm, Wuergler, Keegan, & Karras, March 2021	NASN School Nurse; Commentary; Illinois, USA	N/A	- Weekly conferences between local department of health and school staff (including SNs) to share Covid-19 guidelines, address questions and present county data - Created School Nurse Task Force (SNTF), which met weekly on Zoom to provide county-wide implementation of Covid-19 protocols for school health offices and classrooms - SNTF created and shared a "COVID-19 toolkit" (20-plus page toolkit containing information on Covid-19 for parents, students and staff) - Created protocols and documentation for contact tracing, isolation and quarantine in the school setting	N/A	N/A	N/A	- Developed worksheets for symptomatic staff/students and close contacts using checklist format - Developed online contact tracing forms to facilitate reporting - Created a visual calendar for patient instruction to track return dates - Developed a release verification letter to ensure requirements were met before returning to the classroom or work - Created vaccine-symptom management guidance	N/A	N/A	N/A

(Continues)

TABLE 1 (Continued)

Article details		Change in practice					Feedback		
Author(s), publication date	Source, Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Lee, West, Tang, Cheng, Chong, Chien, & Chan, June 2021	Nursing Outlook; Empirical research (qualitative study using semi-structured interviews, n = 19 SNs working in Hong Kong); Hong Kong	<ul style="list-style-type: none"> <li>- Communicated with students via telephone</li> <li>- Monitored students' compliance with guidelines</li> <li>- Created an isolation area (no further details provided)</li> <li>- Reinforced the need for 14-day quarantine periods for returned travellers, checked temperatures upon arrival, and monitored student hygiene</li> </ul>	<ul style="list-style-type: none"> <li>- Communicated with parents via telephone</li> <li>- Increased contact to support parents of children from "special school"</li> <li>- Educated parents on the need to check students' temperatures before sending them to school and to keep them home if unwell</li> </ul>	<ul style="list-style-type: none"> <li>- Provided psychological support to school staff</li> <li>- Contacted staff members to provide health advice</li> <li>- Provided staff with education in areas such as proper hand hygiene, cleaning and disinfecting of the school and school buses, wearing of masks, proper cleaning of vomitus, and disposal of PPE</li> </ul>	<ul style="list-style-type: none"> <li>- Formed a WhatsApp group to facilitate informal communication with other SNs, to help overcome professional isolation, information deficit, and uncertainty</li> </ul>	N/A	<ul style="list-style-type: none"> <li>- Developed a triage flowchart</li> </ul>	<ul style="list-style-type: none"> <li>- Telephone contacts were reportedly well received by students</li> <li>- Technology enabled SNs to stay up-to-date with information and allowed ongoing communication with professionals and appreciation and respect for SNs' professional image led to improved relationships with school staff and parents, and improved ability to deliver health education role</li> <li>- SNs "positioned advantageously against budget constraints and possible job cuts"</li> <li>- SNs who reported feeling respected were reportedly more satisfied with their jobs, more grateful for their employers, more resilient, cooperated more with others, performed better, and were more likely to take direction from leaders</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of information and guidelines, and confusing messages from the government caused SNs stress</li> <li>- SNs reportedly received fewer resources and updates than hospital settings</li> <li>- Challenges of obtaining and maintaining appropriate PPE stocks (and knock-on impact of this on stress and uncertainty for SNs)</li> <li>- Challenge of social distancing in small schools</li> <li>- Challenge of maintaining hygiene practices among younger student cohorts as well as issues maintaining PPE practices with students with intellectual disabilities</li> <li>- School teachers refused to wear masks at the beginning of the pandemic, and "bargained" with SNs to relax the rules</li> </ul>
Marrapese, Gormley, & Ceschene, July 2021	NASN School Nurse; Commentary; Greenfield, Massachusetts, USA	<ul style="list-style-type: none"> <li>- Maintained continuity of care by scheduling telehealth assessments in place of scheduled in-person screening visits</li> <li>- Health education for the student (and family) became the primary focus on non-emergency telehealth assessments</li> <li>- Created pre-recorded informational videos (holistic home health and illness prevention)</li> </ul>	<ul style="list-style-type: none"> <li>- Provided health education to families via telehealth assessments and pre-recorded informational videos</li> </ul>	<ul style="list-style-type: none"> <li>- Collaborated with school adjusters to facilitate social groups, to improve "student connectedness"</li> <li>- Provided monthly education to staff on the importance of sharing electronic student information confidentially</li> </ul>	N/A	<ul style="list-style-type: none"> <li>- Collaborated with the Massachusetts Department of Public Health to facilitate contact tracing</li> </ul>	<ul style="list-style-type: none"> <li>- Partnered with the IT department to develop password-secured enrollment portals, electronic consent, and an electronic health record that was independent of the student information system</li> </ul>	<ul style="list-style-type: none"> <li>- Partnered with the IT department to develop password-secured enrollment portals, electronic consent, and an electronic health record that was independent of the student information system</li> </ul>	N/A

TABLE 1 (Continued)

Author(s), publication date	Source, Article type; Location	Change in practice				Feedback			
		Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Marthinsson, Garmy, & Einberg, June 2021	International Journal of Environmental Research and Public Health; Empirical research (qualitative study using semi-structured online focus groups and one interview, n = 17 SNs working in Sweden); Sweden	<ul style="list-style-type: none"> <li>- Held health dialogues via telephone and video calls</li> <li>- Walk-and-talks</li> <li>- Recorded informational videos about health (no detail provided about content)</li> </ul>	<ul style="list-style-type: none"> <li>- Increased health dialogues with parents when offering digital call-in options to participate remotely</li> </ul>	<ul style="list-style-type: none"> <li>- Switched to digital meetings for professionals working in school</li> <li>- Cooperation increased within the school</li> <li>- health service at upper secondary schools during the period of distance learning</li> </ul>	N/A	N/A	<ul style="list-style-type: none"> <li>- Use of virtual methods for consultations cited as "helpful" (with caveat of need to see the student/use video)</li> <li>- SNs reported being able to gain greater insight/understanding into their students' home situations</li> <li>- Easier to reach guardians as many were working from home</li> <li>- More conversations about serious topics when talking to the students</li> <li>- Digital/remote options resulted in time gain</li> <li>- Positive feedback reported on digital school health service meetings</li> <li>- Some SNs reported receiving good support from their managers during the pandemic</li> </ul>	<ul style="list-style-type: none"> <li>- Some SNs felt digital health dialogues make it difficult to transition to discuss sensitive topics</li> <li>- Difficulty of working with students who felt unwell and sought contact via virtual chat platforms</li> <li>- Need to check student was alone when communicating virtually</li> <li>- "so that sensitive topics could be dealt with"</li> <li>- Some SNs cited difficulty communicating with guardians with different linguistic background</li> <li>- when conveying public health recommendations</li> <li>- Some SNs felt information shared digitally was not as detailed</li> <li>- Closer contact with students resulted in increased demands on SNs' time</li> <li>- Some SNs felt they lacked support from managers and colleagues</li> <li>- Inconsistent practices across different schools and management</li> <li>- Ethical challenges, such as saying no to children who wanted a hug</li> </ul>	
Maughan, Johnson, Gryfinski, Lamparelli, Chatham, & Lopez-Carrasco, January 2021	NASN School Nurse; Commentary; USA	N/A	N/A	<ul style="list-style-type: none"> <li>- SNs reported spending much of their summer "learning, preparing, and communicating" with their education leaders to help make decisions before the new school term</li> </ul>	<ul style="list-style-type: none"> <li>- State SN consultants developed materials to help guide SNs, direct them toward latest evidence, and answer questions</li> <li>- Several consultants worked together to draft guidance for healthcare professionals in schools related to PPE, which was reviewed, developed, and finalised with representatives from the NASN</li> </ul>	<ul style="list-style-type: none"> <li>- Weekly calls with state experts who guided SNs through various scenarios</li> <li>- In states with a state SN consultant, this individual often organized calls to share evidence, resources and data</li> <li>- Through networking, some SNs spoke at town halls and at school board meetings</li> </ul>	<ul style="list-style-type: none"> <li>- A state SN consultant collaborated to develop a system to identify and deliver appropriate PPE to all the schools in North Carolina</li> </ul>	<ul style="list-style-type: none"> <li>- SNs' role and communication with educators helped educators to stay informed and increased the SNs' credibility</li> </ul>	<ul style="list-style-type: none"> <li>- Many SNs had to adjust plans and constantly communicate with educators who still asked for decisions to be made that may not have been based on the best evidence</li> </ul>

(Continues)

TABLE 1 (Continued)

Article details		Change in practice				Feedback			
Author(s), publication date	Source: Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Park, Cartmill, Johnson-Gordon, Landes, Mailik, Sinnott, Wallace, & Wallin, May 2021	NASN School Nurse: Commentary; USA	<ul style="list-style-type: none"> <li>- Developed school-located vaccination events (SLVE) for students (and staff)</li> <li>- Produced relevant supporting materials to the development and running of an SLVE, including a template for events and a checklist for future events</li> </ul>	N/A	<ul style="list-style-type: none"> <li>- Developed a SLVE for staff (and students)</li> </ul>	<ul style="list-style-type: none"> <li>- A group of seven SNs assembled and met weekly via Zoom to identify, evaluate and apply research evidence relevant to the SLVE</li> </ul>	<ul style="list-style-type: none"> <li>- Held a virtual meeting with an official from the local department of public health to discuss and implement plans for vaccine clinics in schools</li> <li>- Worked on a general district vaccination plan in consultation with the relevant department of health services</li> <li>- Consulted with school district liability insurer and district attorney prior to finalising plans</li> <li>- A draft plan was forwarded to the health services director; upon amendment it was sent to the superintendent's advisory team for review and approval</li> </ul>	N/A	N/A	N/A
Robarge, April 2021	The Bulletin (official publication of the Indiana State Nurses' Association); Commentary; Indiana, USA	<ul style="list-style-type: none"> <li>- Created videos for students (and families) about public health measures</li> <li>- Social media platforms like TikTok were used for teaching hand washing, mask wearing, social distancing and return to school protocols</li> <li>- Participated in food distribution and other assistance for families with social and health disparities</li> </ul>	<ul style="list-style-type: none"> <li>- Created videos for (students and) families about public health measures</li> </ul>	<ul style="list-style-type: none"> <li>- Involved in the planning, implementing, and evaluating of schools' pandemic and reopening plans</li> </ul>	<ul style="list-style-type: none"> <li>- NASN hosted an annual conference in a virtual environment</li> </ul>	<ul style="list-style-type: none"> <li>- Many tasked with reporting case numbers to state departments of health</li> <li>- Assisted local health departments with contact tracing, including case investigation of positive cases of students and staff while continuing to provide care coordination</li> </ul>	N/A	N/A	N/A
Robinson, February 2021	DNA Reporter (Delaware Nurses' Association); Commentary; Delaware, USA	<ul style="list-style-type: none"> <li>- Conducted daily symptom screenings</li> <li>- Reconstructed office spaces to provide for isolation areas in conjunction with the department of public health</li> <li>- Determined the possibility of quarantine for every report of illness</li> <li>- Relied on ambiguous symptoms to make serious clinical judgments</li> <li>- Educated "everyone" about Covid-19</li> <li>- Provided Chromebooks and ensured internet access for students</li> <li>- Virtual provision of mental health counselling sessions and telemedicine</li> </ul>	N/A	N/A	N/A	<ul style="list-style-type: none"> <li>- Assisted the department of public health in contact tracing and educating communities</li> </ul>	N/A	N/A	<ul style="list-style-type: none"> <li>- Ensuring that families were compliant with medical guidelines was cited as a challenge</li> <li>- SNs took on multiple roles within illness management, with minimal or inadequate PPE, and "little to no additional training"</li> </ul>

TABLE 1 (Continued)

Article details	Change in practice					Feedback			
	Source, Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Schwind, 2020	Texas Nursing Magazine; Commentary; Texas, USA	N/A	N/A	N/A	N/A	- Helped district administrators to develop guidance and plans around school reopening - Helped district administrators to understand new terminology (e.g. PPE, mask fit testing, contact tracing)	N/A	N/A	N/A
Sorg, August 2020	The Conversation (independent source of news analysis and commentary; Commentary; USA	- Undertook daily symptom screening - Assessed illnesses and isolating children as required - Helped to decide whether or not a child should remain at school	N/A	N/A	N/A	N/A	N/A	N/A	- New Covid-19 specific responsibilities added to SNs; "already heavy workloads" - SNs faced "tremendous stress" as they navigated students' return to school - Some SNs felt frustrated with the lack of resources and with school plans that they felt put students and staff at risk - Worked out of small offices with little room for social distancing
Tomkinson (no date)	SAPHNA; Case study; Rugby, England, UK	- Swapped to a telephone consultation	- Used email and post to transfer materials to and from parents/guardians	N/A	N/A	N/A	N/A	- Child preferred telephone conduct of the health assessment rather than face-to-face - Child engaged well and felt listened to in an environment with limited distractions - SN felt that the child "spoke a lot more than they would have done if the [assessment] had been carried out face-to-face within either a clinical setting or school" - SN felt telephone was appropriate for conducting the assessment - SN was able to "hear the positive interaction between the young person and the foster carer" - SN felt able to develop trust and rapport with the child	N/A

(Continues)



TABLE 1 (Continued)

Article details		Change in practice				Feedback			
Author(s), publication date	Source; Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Traut, December 2020	The Nursing Voice (official publication of the Illinois Nurses Foundation); Commentary; Illinois, USA	N/A	- Educated communities on the proper use of PPE	- Educated school staff on the proper use of PPE	N/A	- Participated in school district workgroups to create reopening plans, protocols, and procedures - Worked with local health depts for case monitoring and contact tracing - Provided resources and assistance to administrators regarding Covid-19 cases, school closures and department of health recommendations - Worked with administrators in "creative ways" to source supplies (e.g. PPE) - SNs were "on-call" for phone conversations with administrators regarding ever-changing guidelines from the department of public health and the Illinois State Board of Education	- Reviewed mass temperature scammers - Developed phone apps for tracking and reporting symptoms in students and staff	N/A	- Some SNs felt they were "left out of planning conversations"
Unknown, 2020a	New Hampshire Nursing Association News; Commentary; New Hampshire, USA	- Monitored for Covid-19 symptoms and undertook screening, taking into account child's clinical history - More cautious approach when making clinical decisions	- Monitoring children during Covid-19 required increased communications with parents (via telephone)	N/A	N/A	- Received support from state health experts, including weekly video calls - Took part in a virtual town hall meeting with the New Hampshire Chapter of the American Academy of Pediatrics	N/A	N/A	N/A
Unknown, October 2020b	DNA Reporter (Delaware Nurses' Association); Commentary; Delaware, USA	- Planned, delivered and presented health education for online learning (no further details provided) - Monitored student symptoms	N/A	- Attended online Individual Education Planning meetings for students in special education	N/A	- Liaised with administrators and collaborated with staff members to pre-empt Covid-19 outbreaks - Had frequent conversations with Division of Public Health to review up-to-date guidance from the CDC and WHO - Worked with administrators to plan for staff screening and return to school	N/A	N/A	N/A

TABLE 1 (Continued)

Article details	Change in practice					Feedback			
	Source, Article type, Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Unknown, April 2020c	SAPHNA; Case study; Caldecote, England, UK	- Telephone consultations replaced face-to-face Early Help meeting - Recommended ChatHealth to a child - Sent a list of useful websites to child in the post	- Telephone consultation replaced face-to-face Early Help meeting	N/A	N/A	N/A	N/A	- SN felt they were able to provide the "same level of care and service" to the child and mother	N/A
Unknown, 2020d	SAPHNA; Case study; Nuneaton, England, UK	- Used telephone to conduct annual 'looked after child' health review	- Used telephone call to conduct annual 'looked after child' health review - Used post to send out pre-appointment questionnaire and appointment details	N/A	N/A	N/A	N/A	- SN reported that conducting health assessments over the telephone is "not ideal" but given circumstances, it was the best option to allow the child to share new concerns	N/A
Unknown (no date)	SAPHNA; Case study; Walsall, England, UK	- Engaged with child via virtual technology	- Provided parents with advice and support via virtual technology	N/A	N/A	- Used Microsoft Teams for collaboration with social work managers to review the needs of CYP, and consider how interventions of child protection and child in need plans could be delivered - Conducted virtual case conference, core groups and child in need meetings	N/A	- SN felt that virtual technology capability added a dimension to building relationships, opened new channels of communication, and allowed more in-depth discussions with a focus on the needs of children than before	- Covid-19 resulted in a reduction in services from a specialist provider, resulting in the withdrawal of support for a child and his family
Various, June 2020a	Community Practitioner; Commentary; UK	- Used ChatHealth and telephone contacts	N/A	N/A	N/A	N/A	N/A	N/A	N/A

(Continues)

TABLE 1 (Continued)

Article details	Change in practice				Feedback					
	Author(s), publication date	Source, Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Various, November 2020b	SAPHNA; Collection of case studies; England, UK	<ul style="list-style-type: none"> <li>- Used ChatHealth, telephone and video call consultations</li> <li>- Walk-and-talk sessions</li> <li>- Produced a pre-recorded video about returning to school safely (for students and families)</li> </ul>	<ul style="list-style-type: none"> <li>- Care plans were reviewed virtually</li> <li>- Produced a pre-recorded video - "To spread the message that A&amp;E was safe to visit" (shared on Youtube)</li> <li>- Produced a pre-recorded video about returning to school safely (for students and families)</li> <li>- Telephone calls</li> <li>- Facilitated rollout of a telephone response service that parents could call for advice and support</li> </ul>	<ul style="list-style-type: none"> <li>- SNs involvement in the telephone response service relieved pressure on head teachers who received a high volume of calls</li> <li>- Had regular meetings with head teachers to provide support and advice, and answer questions around Covid-19</li> </ul>	<ul style="list-style-type: none"> <li>- Care plans were reviewed virtually</li> </ul>	N/A	N/A	<ul style="list-style-type: none"> <li>- Parents reported positive feedback on walk-and-talks</li> <li>- Walk-and-talks reportedly filled the gap of missing "physical connection" and allowed SNs to engage with CYP who otherwise struggled</li> <li>- The face-to face contact provided by walk-and-talks allowed for deeper assessments and more personal meetings</li> <li>- Parents reported positive feedback on SNS A&amp;E video, calling it "helpful", "fun to watch" and "reassuring"</li> </ul>	N/A	
Waters, March 2021	Community Practitioner; Commentary; UK	<ul style="list-style-type: none"> <li>- Online consultations</li> </ul>	<ul style="list-style-type: none"> <li>- Online consultations</li> </ul>	N/A	N/A	N/A	N/A	N/A	N/A	N/A
White, July 2020a	British Journal of Child Health; Commentary; UK	<ul style="list-style-type: none"> <li>- Used technology and virtual assessments to support children</li> <li>- Where necessary and after risk assessment, provided face-to-face, walk-and-talk, doorstep and drive-through services</li> </ul>	<ul style="list-style-type: none"> <li>- Used technology and virtual assessments to support families</li> </ul>	<ul style="list-style-type: none"> <li>- Used technology to support schools</li> </ul>	N/A	<ul style="list-style-type: none"> <li>- Used technology to support "partners"</li> </ul>	N/A	N/A	N/A	N/A

TABLE 1 (Continued)

Article details		Change in practice					Feedback		
Author(s), publication date	Source, Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
White, July 2020b	Nursinginpractice.com; Commentary; England, UK	<ul style="list-style-type: none"> <li>- e-Clinics and brief interventions were held via platforms including Microsoft Teams, Facetime and WhatsApp</li> <li>- Provided health education/ promotion lessons, videos and resources covering topics such as hand/ respiratory hygiene to puberty, transition to high school and food poverty</li> </ul>	N/A	<ul style="list-style-type: none"> <li>- Provided digital training for school staff regarding medical conditions in schools, such as asthma, and diabetes</li> <li>- Held safeguarding meetings via a range of digital platforms</li> </ul>	N/A	N/A	N/A	<ul style="list-style-type: none"> <li>- Many CYP reported preferring virtual contact over face-to-face, especially when it offered flexibility in terms of appointment times</li> <li>- Many 'looked after' children reported feeling more able to discuss personal and sensitive matters virtually</li> <li>- Virtual contacts enabled SNs to gain a holistic view of the child and family health needs</li> <li>- Young carers appreciated the time and support they were given virtually</li> </ul>	<ul style="list-style-type: none"> <li>- Virtual contacts with children and families reportedly took up much more of SNs' time</li> </ul>
White, March 2021	British Journal of Child Health; Commentary; UK	<ul style="list-style-type: none"> <li>- Extended childhood vaccine access during evening and weekend hours, via "watch-up" sessions, "drive-thru" sites and at "each and every contact"</li> <li>- One SN delivered immunisations in risk-assessed gardens</li> </ul>	N/A	N/A	N/A	N/A	<ul style="list-style-type: none"> <li>- Introduced and expanded electronic systems, including "e-consent", vaccine notifications, and text support services</li> <li>- Access to e-systems, such as the Child Protection Information System, helped SNs to "target" and thus protect many most vulnerable"</li> </ul>	<ul style="list-style-type: none"> <li>- Digital poverty was a barrier for CYP and families accessing virtual services</li> </ul>	

(Continues)

TABLE 1 (Continued)

Article details	Change in practice					Feedback			
	Source; Article type; Location	Work with children and young people	Work with parents	Work with school-based colleagues	Work with SN colleagues/peers	Partnership working	Innovation	Benefits	Barriers to professional practice
Yip, Yip & Tsui October, 2020	Advances in Nursing and Midwifery; Empirical research (qualitative phenomenological design, n = 9 SNs working in special schools in Hong Kong); Hong Kong	- Prepared online video recordings of the practical demonstration of healthcare techniques, such as hand sanitisation and mask wearing (for students)	- Increased contact with parents	- Communicated with colleagues using Google Meet and Zoom	- Peer support groups formed, mutual mental health support offered	N/A	N/A	- SNs became closer with their school colleagues as a result of using online platforms such as Google Meet	- Infection prevention and control measures "imposed an added burden" on SNs - Hiring of new SNs increased current SNs' workload due to having to teach the role - Increased contact with parents added to workload - Emotional challenges: SNs reported "feelings of helplessness, powerlessness, stress, and frustration when describing how they had felt in this neglected speciality" - Lack of training to undertake expanding role (in relation to infection control duties)

Abbreviations: A&E, Accident & Emergency; CDC, Centers for Disease Control and Prevention; CYP, children and young people; HIPAA, The Health Insurance Portability and Accountability Act; NASN, National Association of School Nurses; PPE, personal protective equipment; SAPHNA, School and Public Health Nurses Association; SN(s), school nurse(s); SNTF, school nurse taskforce; SVLE, school-located vaccination event; WHO, World Health Organization; NB, Terminology included in the table reflects the terminology used in the original articles.

### Liaison with professionals

SNs used technology to facilitate engagement with professional networks, for example, virtually conducting Individual Education Planning, case conferences, core groups, child in need, disability support and safeguarding meetings (Flaherty, 2020; Unknown, n.d.; Unknown, 2020b; White, 2020b). Video conferencing was used for daily handovers, multi-agency meetings (Gingell & Spencer, n.d.) and to connect with social work managers (Unknown, n.d.). Technology platforms were also used to help SNs carry out their roles and responsibilities with school-based colleagues (Barbee-Lee et al., 2021; Evans, 2020; Flaherty, 2020; Martinsson et al., 2021; Unknown, 2020b; Various, 2020b; White, 2020b; Yip et al., 2020). Digitally delivered training for school-based colleagues around medical conditions was offered (White, 2020b).

Specific benefits of using technology for partnership work were reported as follows: the flexibility, time and travel cost savings, and greater attendance at meetings (Gingell & Spencer, n.d.). Virtual communication technology was also credited with providing new dimensions to relationship building and opened new communication channels, increasing the depth of discussions and improving the focus on children's needs (Unknown, n.d.). However, sometimes virtual platforms made it harder to discuss sensitive topics (Martinsson et al., 2021).

SNs offered emotional support to school staff (Lee et al., 2021), and similarly, peer meetings served as a way of providing mutual mental health support (Yip et al., 2020). SNs collaborated with their school-based colleagues to address new challenges, such as working with adjustment counsellors to improve student 'connectedness' (Marrapese et al., 2021), with teaching staff to identify students at risk of chronic absenteeism, and with school counsellors to produce resource lists to meet families' needs (Combe, 2020a). SNs interacted with their peers in new ways such as convening support groups (Fauteux, 2021); in some cases technology was used to facilitate this interaction, including online support groups (Cogan, 2021), providing mutual support (Combe, 2020b), and using apps to communicate informally to help overcome professional isolation (Lee et al., 2021).

A virtual 'town hall' (where points of interest, policy and legislation are discussed) was also used by SN organizations to connect with members (Combe, 2020a), and an annual conference transitioned to a virtual environment (Robarge, 2021). The use of technology was beneficial to communication with other professionals (Lee et al., 2021; Martinsson et al., 2021). Increased technological use and advancement such as the increased use of online systems resulted in services being 'safer, smoother and more efficient' and access to online systems assisted SNs in protecting the most vulnerable (White, 2021, p. 50).

### 4.2.2 | The expanded school health offer

This theme captures the ways in which the SN role expanded beyond its pre-pandemic remit, albeit in keeping with SNs' expertise as public health practitioners. This expanded role included a variety of novel and Covid-19-specific responsibilities.

### Infection prevention and control: CYP and families

SNs took on numerous new Covid-19-specific roles and responsibilities with CYP. These included symptom monitoring and contact tracing (Combe, 2020b; Lee et al., 2021; Robinson, 2021; Sorg, 2020; Unknown, 2020a; Unknown, 2020b). Adaptations were made to existing daily practices, such as wearing personal protective equipment (PPE) for nebulizer administration (Barbee-Lee et al., 2021); physical setups were altered to create isolation areas; and SNs were required to enforce public health isolation and quarantine requirements (Barbee-Lee et al., 2021; Combe, 2020b; Ferrara, 2021; Lee et al., 2021; Robinson, 2021; Sorg, 2020). A telephone response service that parents (and schools) could contact for advice helped to relieve the pressure of calls to schools about Covid-19 (Various, 2020b). Additionally, SNs sent reminder emails to parents encouraging them to screen their children (Combe, 2020b). SNs educated parents and carers on issues relating to Covid-19 (Barbee-Lee et al., 2021; Traut, 2020), and communication with parents often increased for pandemic-related issues (Hoke et al., 2021; Lee et al., 2021; Unknown, 2020a; Yip et al., 2020).

Lesson plans to address Covid-19-related issues were developed (Booher, 2020). SNs produced pre-recorded informational videos predominantly focused on Covid-19 public health messaging (Combe, 2020a; White, 2020b; Yip et al., 2020), and sometimes shared these via social media platforms (Robarge, 2021; Various, 2020b). The videos had the reported benefit of providing advice and reassurance to CYP and parents (Various, 2020b). SNs were also involved in developing infographics to consolidate public health messages (Barbee-Lee et al., 2021).

There were challenges to implementing new infection prevention and control measures, such as having to socially distance from younger children who may experience affectional neglect (Martinsson et al., 2021). Similarly, PPE requirements created barriers to expressing empathy and 'building relationships with pupils' (Evans, 2020, p. 7), while limited space in some schools made social distancing difficult (Lee et al., 2021; Sorg, 2020). SNs were also tasked with ensuring students' compliance with hygiene practices, which was reported to be challenging for example, among younger children and those with intellectual disabilities (Lee et al., 2021). Further, SNs found themselves 'bearing the brunt' of negative social responses to Covid-19 regulations from parents (Cogan, 2021, p. 2) and teachers (Lee et al., 2021). The responsibility of ensuring families complied with guidelines, which carried implications for the wellbeing of the entire school community, was considerable (Robinson, 2021). SNs also faced the challenges of taking on new and extended roles with no additional training (Robinson, 2021; Yip et al., 2020), having to adapt practice in accordance with ever-changing guidelines and a lack of information (Combe, 2020b; Lee et al., 2021), and balancing professional judgement with official guidance (Combe, 2020b) and school requests (Maughan et al., 2021). Some SNs also reported impacts on their ability to carry out their usual (non-Covid-related) duties (Combe, 2020b). Despite these challenges, SNs indicated that their role in preparing for students' return to school and developing/implementing Covid-19 guidelines led to an increased professional visibility (Hansen, 2021; Lee et al., 2021; Maughan et al., 2021).



TABLE 2 Patterning table showing the ways in which school nursing practice changed and evolved during Covid-19

Author and publication year	The continued school health offer			The expanded school health offer		
	Engagement - CYP & families	Education	Liaison with professionals	Infection prevention and control - CYP & families	Infection control - broader role	Innovation
Barbee Lee et al., 2021	x Virtual nurse's office; drive-up clinics; screening questionnaires; empty offices for in-person screening; establishing isolation areas	x Online lessons; virtual Q&A sessions with parents	x Virtual nurse's office	x Social distancing, masks and sanitisation for in-person screening; enforcing school exclusions; infographics	x Supporting custodians with disinfecting processes; serving as a 'professional link' between districts and local health centers	x Development of a standardized student wellness form; development of a staff screening tool
Booher, 2020	x Remote communication			x Lesson plans (Covid-19 and associated issues)		
Bullard et al., 2021			x SN support groups (via Zoom)			x Development of an electronic pass system
Combe, 2020a	x Social media; outdoor distribution of resources; telephone		x Virtual town halls; working with teaching staff to identify students at risk of chronic absenteeism; working with school counsellors to produce resource lists; working with food service partners	x Pre-recorded informational videos		
Combe, 2020b			x Professional peer support (SchoolNurseNet and social media)	x Covid-19 monitoring, tracing and quarantining; telephone calls and emails	x Advising staff on infection prevention and control; monitoring social distancing and Covid-19 cases; actioning quarantines or school closures	
Driscoll et al., 2021	x Meeting CYP in parks and outdoor areas					

TABLE 2 (Continued)

Author and publication year	The continued school health offer			The expanded school health offer		
	Engagement - CYP & families	Education	Liaison with professionals	Infection prevention and control - CYP & families	Infection control - broader role	Innovation
Evans, 2020	x ChatHealth; walk-and-talks; vaccinating in marquees, mobile units and alternative venues; drive-through vaccination clinics; online meetings		x Online meetings			
Fauteux, 2021	x Outdoor distribution of resources, advice and information	x Virtual health education	x SN support groups		x Covid-19 testing, investigation and vaccinations	x Making adaptations to document sharing
Ferrara, 2021				x Change to physical setup; assessing symptoms; masks, social distancing and hand sanitiser required to enter office		
Flaherty, 2020	x Virtual meetings	x Virtual health education	x Virtual meetings			
Gingell and Spencer, n.d.	x Telephone; video interactions for face-to-face digital interventions		x Daily sitrep, huddle and wider multi-agency meetings (via Microsoft Teams)			
Hansen, 2021					x Supporting Covid-19 data collection and use	x Covid-19 data sharing and reporting via hotlines
Hoke et al., 2021	x Switch to only electronic communication			x Communication increased due to Covid-19-related issues		
Kunz et al., 2022				x Vaccination planning; information sharing; resource development and sharing		x Development of screening, monitoring and quarantine release tools (staff and students); creation of 'Covid-19 toolkit'

(Continues)

TABLE 2 (Continued)

Author and publication year	The continued school health offer				The expanded school health offer		
	Engagement - CYP & families	Education	Liaison with professionals	Infection prevention and control - CYP & families	Infection control - broader role	Innovation	
Lee et al., 2021	x Telephone		x WhatsApp for informal peer communication; providing emotional support to school staff	x Preparing procedures; monitoring student compliance with hygiene practices; maintaining PPE stock; creating isolation areas; monitoring quarantine compliance; temperature checks; increased contact to support parents; telephone calls	x Advising staff	x Development of a triage flow-chart	
Marrapese et al., 2021	x Telehealth assessments	x Pre-recorded informational videos	x Working with counsellors to improve student 'connectedness'; educating staff		x Contact tracing	x Development of IT systems (enrollment and e-consent systems, electronic health record)	
Martinsson et al., 2021	x Walk-and-talks; telephone; video calls	x Pre-recorded informational videos	x Digital meetings				
Maughan et al., 2021					x Resource sharing with state experts; collaboration with national SN organization to develop materials; speaking at town hall events; planning for school reopening	x Development of a system to identify and deliver PPE	
Park et al., 2021					x Collaboration for school-based vaccination clinics; general district vaccination planning; virtual peer meetings (via Zoom)		
Robarge, 2021	x Food distribution		x Virtual conference	x Pre-recorded informational videos; social media (via TikTok)	x Case monitoring and contact tracing; planning for school reopening		



TABLE 2 (Continued)

Author and publication year	The continued school health offer			The expanded school health offer			Innovation
	Engagement - CYP & families	Education	Liaison with professionals	Infection prevention and control - CYP & families	Infection control - broader role		
Unknown, n.d.	x Virtual technology		x Virtual (safeguarding meetings); Microsoft Teams				
Various, 2020a	x ChatHealth; telephone						
Various, 2020b	x ChatHealth; video calls; walk-and-talks; telephone		x Virtual (reviewing care plans)	x Telephone response service; pre-recorded informational videos (via YouTube)	x Advising staff		
Waters, 2021	x Online consultations						
White, 2020a	x Walk-and-talks; doorstep and drive-through services; virtual assessments; use of technology generally to support families		x Technology (support to schools)				
White, 2020b	x e-Clinics; consultations/contact via Microsoft Teams, FaceTime and WhatsApp	x Pre-recorded informational videos	x Digital platforms (training and meetings)	x Pre-recorded informational videos			
White, 2021	x Drive-through vaccine clinics; outdoor contacts; extended evening/weekend 'catch-up' sessions						x Implementing vaccine notifications, online text support services and e-consent
Yip et al., October, 2020			x Communications via Zoom and Google Meet; peer mental health support		x Increased contact with parents; pre-recorded informational videos		

Abbreviations: CYP, children and young people; PPE, personal protective equipment; SN, school nurse.  
 NB. Level of detail provided within this table may vary, reflecting the degree of information provided by the articles.

TABLE 3 PAGER table

Patterns	Advances	Gaps	Evidence for practice	Research recommendations
<i>The continued school health offer</i>	There is evidence (anecdotal, informal and empirical) of innovative practices developed and adopted by SNs to deliver routine school nursing services.	There is a paucity of empirical research exploring this topic. There is a lack of geographic representation across the literature.	While there is some evidence of innovative practices being adopted by SNs to deliver routine school nursing services, there is a lack of evaluation or review of these practices (for young people and their families as well as SNs).	Research is needed to explore which innovative aspects of routine school nursing practice could (and should) endure post-pandemic. Geographically focused research is needed due to the diversity of the SN role and healthcare provision globally. To undertake evaluations (from SN and service user perspectives) of practices which may be used more widely and extensively in post-pandemic school nursing practice.
<i>The expanded school health offer</i>	There is evidence (anecdotal, informal and empirical) of SNs taking on various broader public health responsibilities during the pandemic, undertaken alongside their routine duties.	There is a paucity of empirical research exploring this topic. There is a lack of geographic representation across the literature.	While there is some evidence of innovative practices being adopted by SNs to deliver expanded services (i.e. broader public health) it is not clear what aspects (if any) may be maintained in routine school nursing services.	Research is needed to explore what aspects of SNs' expanded role will (and should) endure post-pandemic.

Abbreviation: SN(s), school nurse(s).

*Infection prevention and control: Broader role*

Beyond their daily work with CYP, SNs took on additional responsibilities to mitigate the risk of Covid-19 transmission within the wider school community. These included planning for school reopening (Maughan et al., 2021; Robarge, 2021; Traut, 2020; Unknown, 2020b), providing staff with information and advice (Combe, 2020b; Lee et al., 2021; Traut, 2020; Various, 2020b), supporting management with data collection and usage (Hansen, 2021), supporting disinfection processes (Booher, 2020) and enacting quarantines or school closures (Combe, 2020b). SNs were 'on-call' for conversations regarding evolving state guidelines (Traut, 2020). Lastly, SNs were involved in organizing new school-located Covid-19 vaccination events and required extensive peer and local authority collaboration (Park et al., 2021).

SNs assisted or collaborated with local and state-level partners to pre-empt and manage Covid-19 outbreaks. These efforts focused on case monitoring and contact tracing (Marrapese et al., 2021; Robarge, 2021; Robinson, 2021; Traut, 2020), developing vaccination plans and follow-ups (Kunz et al., 2022; Park et al., 2021), resource development and sharing (Kunz et al., 2022; Maughan et al., 2021; Unknown, 2020b), collaboratively investigating Covid-19 outbreaks in the school community (Fauteux, 2021), acquiring PPE and planning for Covid-related scenarios (Traut, 2020), and assisting in planning and guidance for students' return to school (Schwind, 2020; Traut, 2020). More broadly, SNs served as 'a professional link' between districts and local health centers (Booher, 2020, p. 22). SNs also networked and collaborated through 'town halls' (Maughan et al., 2021) and attended similar virtual events (Unknown, 2020a).

There were positive impacts of these collaborative efforts. A broad increase in cooperation within the school health service was reported (Martinsson et al., 2021). Increased interaction with building administrators led to a greater appreciation of SNs and their role (Hansen, 2021) and partnerships with local health boards elevated their profile (Flaherty, 2020). SNs garnered a 'seat at the Executive Team table' (Combe, 2020a, p. 186) and strengthened relationships with public health officials (Fauteux, 2021). There was variability in support and working practices (i.e working from home) across schools and managers (Martinsson et al., 2021). Similarly, professional conflicts emerged between some SNs and senior decision-makers (Combe, 2020b; Sorg, 2020; Traut, 2020).

*Innovation*

Some SNs were directly involved in the development and implementation of new and innovative processes and tools, including IT systems such as password-secured enrollment portals, electronic health records and e-consent (Marrapese et al., 2021; White, 2021). For CYP, these included an electronic pass system to control the flow of students on campus (Bullard et al., 2021), a triage flow chart (Lee et al., 2021), and a standardized student wellness form (Barbee-Lee et al., 2021). A state SN consultant collaborated to develop a system to identify and deliver PPE (Maughan et al., 2021). Online systems



were also developed to meet specific new needs, including the tracking and reporting of staff and student symptoms and quarantine release procedures (Barbee-Lee et al., 2021; Kunz et al., 2022; Traut, 2020), the provision of vaccine notifications and online text support services (White, 2021).

SNs also delivered regular ethical guidance to school-based colleagues about the confidentiality of student information shared electronically (Marrapese et al., 2021). SNs were also involved in making adaptations to document sharing (Fauteux, 2021), data sharing and the use of hotlines for schools to report to the district (Hansen, 2021).

## 5 | DISCUSSION

This scoping review identified 38 articles that described changes to the way SNs worked during the Covid-19 pandemic. All articles were published in and about developed countries, predominantly the USA, followed by the UK, Hong Kong and Sweden. Analysis yielded two overarching themes: (1) *the continued school health offer*, which described the adaptations SNs made to continue providing their usual services during the pandemic, and (2) *the expanded school health offer*, which encapsulated additional SN roles and responsibilities resulting from Covid-19.

The first theme details the ways SNs adapted their practice to continue working with CYP, families and the wider MDT when government restrictions limited on-site service provision. There is a range of evidence supporting the effectiveness of digital health interventions with CYP, with efficiency and accessibility being notable advantages, though much of this evidence has focused on pharmacological and psychological interventions (see systematic and meta-review by Hollis et al., 2017). Though born out of necessity, numerous articles described the benefits of shifting to virtual platforms for service delivery, with many citing improved communication with and/or access to CYP and families. This ongoing virtual communication also provided SNs with a new insight into CYPs' home environments, which may have facilitated a more holistic assessment of family dynamics and even the detection of abuse. Though our review did not identify articles discussing domestic abuse, the amplification of risk factors during the pandemic increased the vulnerability of many CYP to abuse and neglect at home (World Health Organization [WHO], 2020). SNs play a key role in detecting and responding to child abuse (Harding et al., 2019), and technology was vital for bridging the communication gaps created by the pandemic.

Despite many benefits, some articles highlighted the disadvantages of this increased reliance on technology, including digital poverty and the resulting exacerbation of existing health inequalities. A joint report from The United Nations Children's Fund (UNICEF) and International Telecommunication Union (ITU) (2020) showed that two thirds of school-aged children globally have no internet connection at home. Evidence from a global systematic review indicates that other factors beyond connectivity can affect children's digital skills, including gender and socioeconomic status (O'Connor

et al., 2016). These issues are important to take into account when considering the longevity of SNs' digital health offer. While our findings provide a snapshot of service providers' and users' experiences of using virtual platforms during the pandemic, it is important that these mechanisms for service delivery are thoroughly evaluated before decisions are made regarding their continued implementation (Perakslis & Ginsburg, 2021).

SNs' ongoing communication and working relationships with their school-based colleagues and broader professional partners also changed during the pandemic. During a time where many CYP were increasingly vulnerable to deteriorating mental health (Panchal et al., 2021), exacerbation of existing physical health issues and problems at home (Cohodes et al., 2021), the importance of effective MDT collaboration was vital. Again, SNs' contact with other professionals largely relied on the use of virtual platforms. While much has been written on the effects and outcomes of using virtual platforms with service users, little has been published on the impact of this transition on health providers' interdisciplinary working. Given the likelihood that remote and virtual MDT collaboration will outlast the pandemic, this could be an important avenue for future research.

Beyond the impacts of the pandemic on SNs' traditional (i.e. pre-pandemic) work, this review also identified various ways in which their role expanded. Though SNs around the world have long been key to shaping and delivering public health activities, the pandemic elevated this critical role. Many articles noted that SNs' central role in coordinating the pandemic response helped to strengthen working relationships, many of which arose as a direct result of Covid-19, and provided SNs with new platforms to engage with policymakers. This improved policy-level collaboration and influence is arguably one of the most important outcomes that needs to be sustained post-pandemic. A recent guideline from WHO and the United Nations Educational, Scientific and Cultural Organization (WHO & UNESCO, 2021a) on school health services—the first of its kind—presents 87 specific interventions for improving the equity, quality and consistency of health services for school-aged children globally. This guideline underscores the fundamental relationship between health and educational institutions, while also pointing out the inadequacy of SN coverage across many regions, despite policy calls for minimum staffing levels (WHO & UNESCO, 2021b).

Despite SNs' elevated profile, there is a wealth of evidence suggesting that SNs' rapidly evolving role had a detrimental impact on their ability to carry out routine practice. In a USA bulletin article, Robarge (2021) noted that mitigation efforts—something that would previously have occupied a small portion of SNs' time—suddenly became the predominant focus. Having responsibility for reviewing and implementing new school policies also meant that SNs bore the brunt of many peripheral social repercussions, such as the 'infodemic' (WHO, n.d.) and politicization of mask-wearing and vaccinations (McIntosh et al., 2022). These challenges were compounded by the emotional burden of the pandemic, increased workloads and short staffing (variously exacerbated by SN redeployment). It is concerning to note that global SN numbers continue to fall short of what many authorities consider to be safe (WHO & UNESCO, 2021b).

Maughan and Luehr (2022) have drawn parallels between Covid-19 and the 1918 Spanish Flu pandemic, noting that many of today's SN activities mirror practices from the early 20th century. Yet global development, new technology and nurses' ever-increasing professional autonomy have meant that SNs were able to take on a leading public health role in this most recent global health crisis. Though this undoubtedly brought new challenges to an already stretched workforce, the profession was also strengthened by the increased visibility and reach of their expertise. SNs were quick to embrace new ways of working and proactively adapted their practice to meet new needs, including contributions to the development of numerous innovative solutions that will likely endure post-pandemic. However, without adequate investment in staff and infrastructure, SNs' power to enact the changes envisioned by the WHO and UNESCO (2021b) and other global health authorities (NASN, n.d.; SAPHNA, 2021) will be limited.

## 5.1 | Strengths and limitations

Though we had hoped to capture a range of international literature, the majority ( $n = 23$ ) of our included articles came from the USA, limiting the generalizability of our findings. This will be especially true for low- and middle-income countries where SN practice and coverage are more limited (or even non-existent) (see WHO & UNESCO, 2021a). Our findings are further limited by the nature of the data we retrieved. The fact that the majority of our included articles were opinion and commentary pieces meant that most data were anecdotal, impeding our ability to undertake a systematic review. However, our findings reflect the global attention afforded to SN practice during the pandemic, highlighting a significant literature gap and uncovering important avenues for future research. The authors of this review are currently undertaking follow-on research exploring SNs' experiences in more depth. By including grey literature we were able to capture a wider scope of evidence.

Our review was strengthened by its methodological rigor, including the comprehensive search strategy, screening and data extraction processes. Key expert stakeholders were actively involved throughout the process of developing, conducting and finalizing this review. Multiple researchers were involved in undertaking each of these processes, enhancing the reliability of our findings.

## 6 | CONCLUSION

This scoping review presents global evidence describing how SNs' practices changed over the course of the Covid-19 pandemic. The pandemic accelerated SNs' need and/or ability to devise creative solutions to emerging problems. SN knowledge and skills came to the fore, enabling continued delivery of child-focused services alongside the additional demands of Covid-19. Many of these innovative practices could be useful post-pandemic. However, formal evaluation is needed to identify which practices may merit integration into

routine practice. It is hoped that this review, together with other phases of this project and other research, will contribute to the discussion of innovative SN practices and the vital expert public health role of the SN.

### AUTHORS' CONTRIBUTIONS

GC, JA, SB, TH, JT, DS: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; GC, JA, SB, TH, JT, DS: Involved in drafting the manuscript or revising it critically for important intellectual content; GC, JA, SB, TH, JT, DS: Given final approval of the version to be published. GC, JA, SB, TH, JT, DS: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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### CONFLICT OF INTEREST

The authors declare no conflict of interest.

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### DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the article and/or supplementary material of this article.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# Women's experiences of gestational breast cancer and their interactions with the healthcare system: A scoping review

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## Abstract

**Aim:** To report the evidence of women's experiences following a diagnosis of gestational breast cancer (GBC) and their interactions with the healthcare system.

**Design:** A systematic scoping review.

**Data Sources:** This scoping review systematically searched Medline, CINAHL, Psych INFO, EMBASE and SCOPUS, in addition to six grey literature databases in October 2021. A 2020 PRISMA flow diagram depicting the flow of information.

**Review Methods:** Guided by six steps in Arksey and O'Malley's Framework (2005). One researcher completed the literature review, and four independently screened the titles and abstracts related to the eligibility criteria.

**Results:** Totalling 25 articles, these studies comprise 2 quantitative, 20 qualitative, 1 mixed-method and 2 other documents, a book and debate. Thematic analysis was guided by Braun and Clarke (2006) to identify an overarching theme of *adjustment* that underpinned women's narratives and was reinforced by four major and several minor themes. The four major themes were: *psychological impact*, *motherhood*, *treatment* and *communication*. The relationship between the themes contextualizes the enormous complexity concerning women's experiences with GBC.

**Conclusion:** Cancer management for GBC is complex and multifaceted. At a time of conflicting emotions for women, Multidisciplinary teams are well placed to provide support, normalize the woman's experience of motherhood, demonstrate an understanding of treatment effects, and communicate in a considerate and empathetic manner with information that is timely and relevant. GBC management involves doctors, nurses, midwives and many other healthcare professionals, which can add to the impost of diagnosis.

**Impact:** This scoping review contributes to a better understanding of women's experience of GBC. The results may inform improvements in the support and communication for these women with GBC and their families.

## KEYWORDS

birth, breast cancer, gestation, healthcare professionals, healthcare system, nursing, patient care, patient experiences, patient navigation, pregnancy

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## 1 | INTRODUCTION

Breast cancer diagnosis during pregnancy is uncommon, yet it is the most frequently diagnosed cancer (Peccatori et al., 2018). Gestational breast cancer (GBC) is defined as breast cancer diagnosed during pregnancy or in the first 12 months after the completion of a pregnancy (Kakoulidis et al., 2015; Lee et al., 2012). GBC prevalence ranges from 0.76% to 3.8% of women diagnosed with breast cancer (Ives & Saunders, 2010; Peccatori et al., 2018). It is likely to be underestimated as GBC is restricted to premenopausal women who can conceive; a more accurate prevalence is expected to be more than 7% (Peccatori et al., 2018).

The trend for delayed childbearing associated with an age-related increase in GBC is reported in high-income countries (Islam & Bakheit, 2015; Loibl et al., 2015). In Australia, women under 45 years account for approximately 20% of new cases of breast cancer diagnosed annually (Ives & Saunders, 2010). One in four (25% or 74,657) of the women who gave birth in 2019 were aged 35 years or over (Australian Institute of Health Welfare [AIHW], 2021). Of these, 21% are 35–39 years, and 4.5% are aged 40 years or above (AIHW, 2021). Since 1999 the rate of women giving birth in the older age groups has almost doubled for women aged 40–44 years and quadrupled for those aged 45–49 years (AIHW, 2021). In the United States, the birth rates of women aged 35–39 years and having their first pregnancy have increased for women of all ethnicities (Matthews & Hamilton, 2014). The international relevance of this finding suggests that economic pressures women face in high-income countries increases their risk of GBC.

### 1.1 | Background

In recent years, treatment options for GBC have led to more intensive breast cancer therapies during pregnancy (Durrani et al., 2018; Loibl et al., 2015). However, a standardized approach to treating GBC may not be suitable (Kakoulidis et al., 2015). Additionally, cancer management options for women with GBC are complex and multifaceted.

Women feel confronted dealing with multiple teams of healthcare professionals during early diagnosis, management and surveillance (Ives et al., 2012) at a time when they want to be celebrating a pregnancy or newborn. Multiple teams can lead to conflicting advice, delays and disagreements. One case study outlined how a woman was shocked with contradictory information from several specialists. Three gynaecologists, one surgeon and two oncologists delivered conflicting advice to her. She was confused, angry, suspicious and horrified, resulting in mistrust of the medical profession (Zanetti-Dällenbach et al., 2006).

Understanding women's experiences with GBC requires a woman-centred approach to recognize the needs of the individual during this most challenging time. The purpose of this scoping review was to collate, summarize and report the evidence of women's experiences following their diagnosis of GBC and their interactions with the healthcare system.

## 2 | THE REVIEW

### 2.1 | Aim

This scoping review aims to report the evidence of women's experiences following a diagnosis of GBC and their interactions with the healthcare system.

### 2.2 | Design

A scoping review is a recommended method when not much is known about a topic (Arksey & O'Malley, 2005) such is the case with GBC. Scoping review was used to gain a deeper understanding of an issue and allow for a broad exploration of related literature rather than focusing on answering specific questions (Moher et al., 2015). Scoping reviews inform more about priorities for research, clarifying concepts and identifying knowledge gaps (Arksey & O'Malley, 2005; Pollock et al., 2021). The theoretical framework for scoping reviews developed by Arksey and O'Malley (2005) guided the review with the incorporation of refinements by Levac, Colquhoun and O'Brien (Levac et al., 2010). The systematic review used elements from Joanna Briggs Institute (Peters et al., 2015) to enhance the clarity and rigour of the protocol development and review process. The six steps of Arksey and O'Malley's (2005) framework are to: identify the research question; search for relevant studies, balance the feasibility of the search with comprehensiveness; use an iterative approach to select studies and extract data; chart the data using quantitative summaries and qualitative thematic analysis; report summarized results; and consult with key stakeholders to discuss the findings (Arksey & O'Malley, 2005).

The research question was developed using a modification of PICO: population, intervention, comparator and outcome. The format was then used to create a search strategy to optimize the number of relevant papers identified. The question developed through this process was: "What are women's experiences of gestational breast cancer and their interactions with the healthcare system?"

### 2.3 | Search methods

The databases searched were Medline (hosted by OVID); CINAHL (Complete); Psych INFO, EMBASE; and SCOPUS. Search strategies used keywords and controlled vocabulary for databases where this was required. Terms were combined using Boolean operators "AND" and "OR." The searches were conducted on October 4, 2021. A sample of the search strategy used for the Medline database is presented in Table 1.

Unpublished reports such as dissertations, government documents and healthcare websites were accessed for relevant or emerging research. Alternate grey literature websites, additional papers from reference lists, and databases searched using keywords, including Google Scholar, OATD, Trove, Worldcat and Base.



**TABLE 1** Search strategy for Medline using MeSH terms and key words

Step 1: #1 "Breast cancer\*" OR "breast neoplasm\*" OR "breast carcinoma"

AND

Step 2: #2 Pregnancy\* OR birth\* OR gestation\*

Step 3: #3 "patient experiences\*" OR patient preference OR health behaviour OR "patient navigation" OR "patient care" OR "client Satisfaction" OR "patient participation" OR "consumer participation" OR "client participation" OR "patient satisfaction" OR "client satisfaction" OR "psychosocial" OR "social psychosocial" OR "psychosocial" OR "psychosocial factors" OR "patient-centred care" OR "accountable care organisations" OR "client characteristics" OR "attitude of health personnel" OR "attitude to health" OR "health personnel attitude" OR "decision making" OR attitude\*

AND

Step 4: #4 "Delivery of health care" OR "health care system" OR "health care utilization" OR "health care professionals" OR "health care personnel" OR "health personnel"

Step 5: Combine #1 AND #2 AND #3 AND #4

No restrictions were placed on language, year of publication or study type to identify all relevant articles. Editorials, reviews and letters to the editor were excluded, as were articles where the full text was not discoverable. Full-text screening requires that four terms be met for inclusion to hold. Once collated, duplicates were removed. A summary analysis for the quantitative papers and a thematic analysis was used for the qualitative reports, guided by Braun and Clarke (2006). This review adhered to the PRISMA 2020 statement (Page et al., 2021). The PRISMA flow diagram (Figure 1) depicts the stream of information during the initial screening process.

## 2.4 | Search outcome

In the final analysis (Figure 1), 25 studies were used. The included studies consist of 2 quantitative, 20 qualitative, 1 mixed-method study and 2 other documents, a book and a debate. The total number of participants in these studies was 213.

The published studies included articles from Australia ( $n = 6$ ), United Kingdom (UK) ( $n = 3$ ), Italy ( $n = 3$ ), Switzerland ( $n = 1$ ), Africa ( $n = 1$ ), Singapore ( $n = 1$ ), Japan ( $n = 1$ ), Brazil ( $n = 1$ ) and Canada ( $n = 1$ ). Narrative reports on websites explored the unique journeys of women with GBC who received treatment. These accounts were from the United States of America (USA) ( $n = 1$ ), Australia ( $n = 3$ ), Canada ( $n = 1$ ) and the UK ( $n = 2$ ) (Table 3). Narratives reported the complexities for the women physically, spiritually, emotionally and practically, as well as the impact on their families.

Two quantitative studies observed events that affected women with GBC and non-GBC. One study used a psychological self-administered questionnaire (Henry et al., 2012) to measure subjective distress in women with cancer during pregnancy. The second study used retrospective data to analyse the demographic and

diagnostic variables between the characteristics of women with GBC and non-GBC groups (Dusengimana et al., 2018).

Twenty qualitative studies and narrative reports using various qualitative methods, including grounded theory, were used (Gomes et al., 2021; Rees, 2015), phenomenology (Connell et al., 2006; Facchin et al., 2021; Kirkman et al., 2017; Rodsten, 2017), case studies (Zanetti-Dällenbach et al., 2006), qualitative content analysis (Kozu et al., 2020), narrative reports and a longitudinal qualitative study (Connell et al., 2006). These studies used qualitative techniques and narratives to understand women's perceptions of events concerning GBC. The studies centred on a rich understanding of the woman's experiences with GBC.

Other characteristics of the studies included a mixed-methods study by Ives (2009), which identified specific psychological issues for women diagnosed with GBC and four themes: motherhood, isolation, support and decision-making (Ives, 2009). In a separate book chapter, the same author raised psychosocial issues experienced by women with GBC (Ives et al., 2016).

## 2.5 | Quality appraisal

Scoping reviews aim to provide a descriptive overview of the reviewed material without critically appraising individual studies. It remains unclear as to whether the lack of quality assessment of the studies limits the uptake and relevance of scoping study findings (Levac et al., 2010). Arksey and O'Malley (2005) state that quality assessment does not form part of the scoping review, thus it was not performed as part of this review.

## 2.6 | Data abstraction

Full-text articles were reviewed for eligibility by SH and independent authors (KY, CN, and MM), and reasons for exclusion were documented. The screening tool used identified eligible studies (Table 2). Screening of titles and abstracts assessed by three authors independently (SH, KY, MM) excluded 449 studies. Articles about women's experiences with GBC and their interactions with healthcare were extracted. A matrix charting table involved data extraction, and descriptions of the characteristics and narratives were collated in tabular form (Table 3).

A stakeholders' consultation is the last stage of Arksey and O'Malley's framework (Arksey & O'Malley, 2005). Consultation is an opportunity for exchanging knowledge and providing methodological rigour, perspective, meaning and applicability to the scoping review (Levac et al., 2010). The consultation provided an effective independent review of the findings through the lens of clinicians practicing in a contemporary clinical context. Multiple healthcare professionals were approached but declined to review.

Two clinical stakeholders in the field of cancer (a Medical Oncologist and an Oncology Clinical Trials Nurse) were consulted regarding the findings of this scoping review, reflecting their

FIGURE 1 PRISMA 2020 flow diagram for study selection.

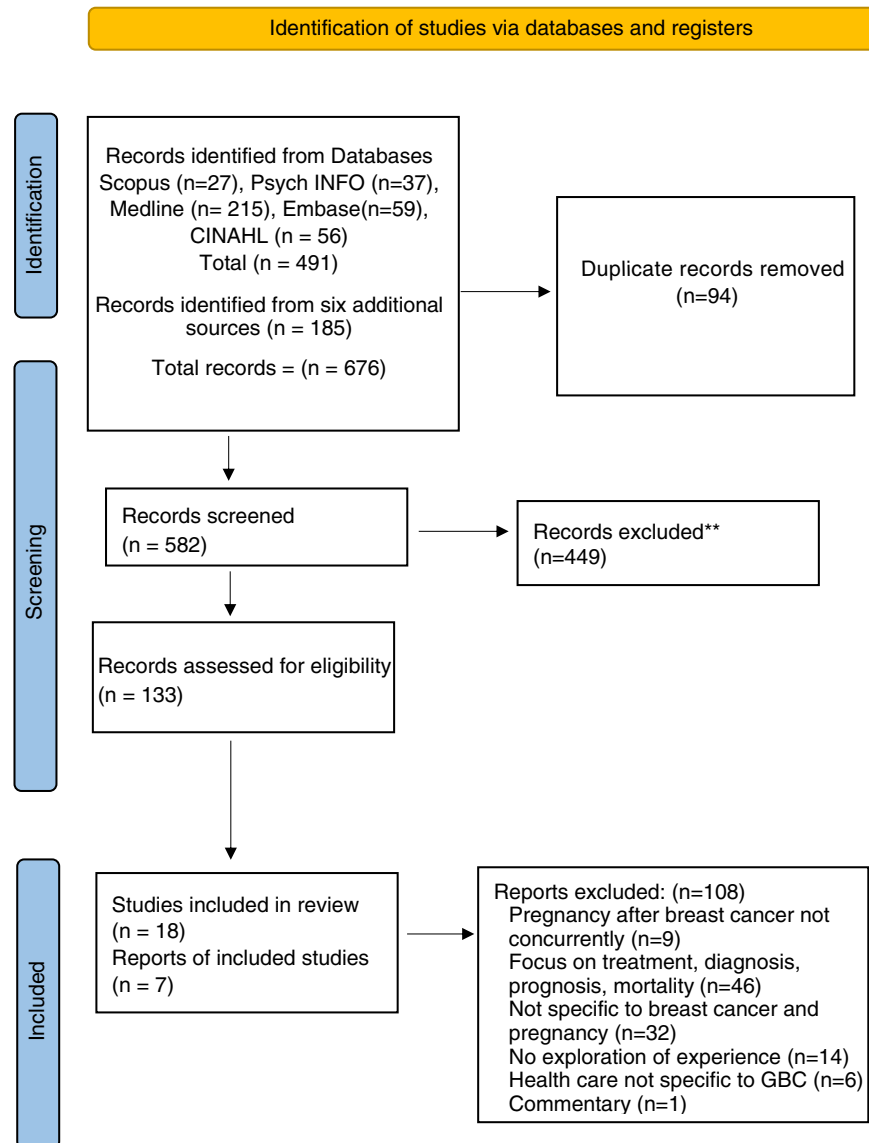


TABLE 2 Screening tool for eligibility of studies to this scoping review

a.	Refers to women who experience breast cancer diagnosis and pregnancy, for example, Gestational breast cancer, other terms breast cancer pregnancy
b.	Is delivering care and understanding of the woman with GBC explored, for example, psychosocial and social issues for the woman?
c.	Is set in a healthcare context that includes all settings, for example, outpatients, inpatients, hospital, community-based or primary care health settings?
d.	It is from the perspectives of doctors, nurses, and other healthcare professionals and patients?

clinical experiences and understandings as per step six of Arksey and O'Malley's (2005) framework. The Medical Oncologist was identified through a specialist referral cancer centre and had experience managing women with GBC. The Medical Oncologist's experiences

resonated with the complexities of issues for women diagnosed with GBC and the difficulty in providing coordinated, simultaneous care between specialities noted in this review. This specialist stated that shared decision-making and management of women among multi-disciplinary teams could be complex as there is no specific team in charge, and each treatment decision must be in consultation with the other teams and the woman.

The clinical trials nurse was identified through professional networks and had previous experience in cancer chemotherapy services caring for women diagnosed with GBC. The Oncology Clinical Trials Nurse stated that the issues identified in her experiences caring for women diagnosed with GBC are genuine. They all experience anxiety, financial stressors and relationship issues; women want to go back to just being a mum. Cancer treatments can affect fertility, preservation options, such as embryo cryopreservation and oocyte (egg) cryopreservation, are expensive and difficult to obtain. The Nurse also identified inconsistency in information and

TABLE 3 Characteristics of included studies

No	Author (year)	Country	Aim	Design	Sample size (n)	Key findings
1	Stafford et al. (2021)	Australia	To identify features and explore the impact of healthcare experiences for women with GBC	Qualitative	23	Identified five themes as relevant to the perceived quality of participant healthcare experiences: control over health care, trust in clinicians, hospitals and systems, coordination of care, an uncommon diagnosis, and holistic, future and oriented care
2	Gomes et al. (2021)	Brazil	To investigate how the diagnosis of cancer during pregnancy occurred and assess its repercussions on the family experience of maternity	Qualitative Grounded Theory	10	10 of the 12 participants were women diagnosed with GBC. Surprised by a GBC diagnosis contains three subcategories, for example, diagnosing cancer during pregnancy, facing illness, and seeking alternatives to deal with the situation
3	Facchin et al. (2021)	Italy	To describe and understand women's subjective experience of being diagnosed with breast cancer during pregnancy	Qualitative Interpretative Phenomenological Analysis	5	Interviewed five women at treatment initiation. Three main themes identified: overwhelming emotions, two, the sense of difference and three: sources of strength
4.	Faccio et al. (2020)	Italy	Explore themes of the developmental process of becoming a mother among three samples: women with breast cancer, women with GBC and women with no history of cancer	Qualitative	4	Four main themes identified fear and worry, the meaning of motherhood, mother foetus relationship and partner support. The psychological aspects of women with GBC to be considered part of care in clinical practice
5.	Kozu et al. (2020)	Japan	To clarify the experience of pregnant women with cancer in decision-making and the role of the nurse	Qualitative	2	Two of the eight women in the study were diagnosed with GBC. The study categorized the decision-making experiences into three phases: interaction between the woman, her foetus, family and medical staff; dilemma and uncertainty; redefinition of the women's own decisions
6.	Liow et al. (2022)	Singapore	To describe the experiences of ethnically diverse Asian women with GBC	Qualitative	7	Three main themes emerged: being a sick woman, juggling between a mother and a patient and seeking normalcy
7.	Chinn (2019)	Canada	To describe the experiences of young women with GBC	Narrative report	1	The accounts of young women and 8 months of pregnancy when diagnosed with GBC, discussed early delivery, genetic testing, treatment, breastfeeding and being positive
8.	Watkins (2019)	Australia	To describe a young woman with a hormone receptor-positive (HER2) breast cancer, pregnancy, chemotherapy and recovery	Narrative report	1	A woman aged 40 was diagnosed with GBC with her second baby. She was undertaking extensive treatment: supportive systems and positive outcomes
9.	Beeston (2019)	Australia	To describe a young woman with GBC who has a hormone receptor-positive (HER2) breast cancer	Narrative report	1	A 36-year-old woman discovers she is 7 weeks pregnant with her second baby, examines her breasts and finds a lump. She describes being diagnosed with HER2

TABLE 3 (Continued)

No	Author (year)	Country	Aim	Design	Sample size (n)	Key findings
10.	Richards (2019)	United Kingdom	To describe four individual accounts and experiences of women diagnosed with GBC	Narrative reports	4	The accounts of these four women with GBC, describe their experiences, psychological impact, emotional distress, difficult decision-making process and treatment effects
11	Ferrari et al. (2018)	Italy	To analyse the psychological issues and construction of the mother-child relationship with cancer during pregnancy	Debate	0	Women raised several issues with GBC concerning psychological management, information, communication and decision-making. Early assessment and evaluation to prevent adverse psychological outcomes
12.	Hammarberg et al. (2018)	Australia	To explore the healthcare experiences of women diagnosed with GBC to inform and improve clinical care of women in this predicament	Qualitative	17	Two overarching themes explored were communication and comprehensive care. The communication theme had two subthemes interdisciplinary and patient communication. Comprehensive care involves the psychosocial consequences of being diagnosed with and treated for GBC. The study also found several subthemes are the spirit, the mind and the body
13.	Dusengimana et al. (2018)	Africa	To evaluate the characteristics, diagnostic delays, and treatment of women with pregnancy-associated breast cancer seeking care at a rural cancer referral facility in Rwanda	Retrospective Cohort Study	12	GBC is an important clinical challenge among patients diagnosed with breast cancer in Rwanda. GBC women did not experience more significant diagnostic delays; most had treatment modifications
14.	Gray (2018)	Australian	To describe how one woman 12 weeks pregnant battled breast cancer and chemotherapy	Narrative report	1	Woman's experiences of the psychological impacts of surgery, radiotherapy, chemotherapy, treatment, physical side effects and new baby concerns. The participant reported being petrified and suffered chronic side effects of severe nausea and inability to breastfeed
15.	Kirkman et al. (2017)	Australia	To understand how women themselves might experience the convergence of abortion and breast cancer	Interpretative Phenomenological	2	Two of the five women's accounts illustrate the different meanings of abortion in women's lives, with the concomitant need for diverse support, advice and information
16.	Rodsten (2017)	United Kingdom	To explore the experiences of women diagnosed with breast cancer while pregnant, including factors that may make these experiences unique to the condition	Qualitative: Interpretative Phenomenological Analysis	11	Chapter 1.3: Pregnancy-associated breast cancer findings include the need to investigate further the emotions and behaviours of the GBC and a real need to ascertain which therapeutic approaches, psychological interventions and types of support will work for whom and in what context. Gestational Breast Cancer is complex and challenging

TABLE 3 (Continued)

No	Author (year)	Country	Aim	Design	Sample size (n)	Key findings
17.	Ives et al. (2016)	Australia	To describe some psychological and social issues for younger women diagnosed with breast cancer. Issues raised by women experiencing GBC	Book	n/a	Chapter 7: Managing cancer during pregnancy highlights the issues raised by women with GBC. Specific issues raised by women who have experienced a cancer diagnosis during pregnancy include, effective communication, motherhood, motivation, fertility, breastfeeding, isolation, support and information, decisions and choices
18.	Rees and Young (2016)	United Kingdom	To explore the experiences and perceptions of women diagnosed with breast cancer during pregnancy	Case Study	3	Breast cancer during pregnancy impacts on young women's lives, assumptions about their pregnancies and new motherhood. They need practical and psychological support in caring for young children
19.	Rees (2015)	United Kingdom	To describe experiences and perceptions of young women with a history of breast cancer in the UK. Chapter 6: Embodies experiences of being diagnosed during pregnancy Chapter 7: diagnoses during pregnancy were biographically disruptive Chapter 9: Diagnosis during pregnancy spanning three key dimensions and perceptions were analysed	Thesis: Qualitative study using grounded theory	3	Chapter 6: Provided evidence that women were at odds with their bodies in several important ways, such as danger, risk, child risk, recurrence, a gap in the treatment expectations between their own and others Chapter 7: Significant accounts of women who during pregnancy described as being biologically disruptive Chapter 9: When combining the three analytical frameworks, several key areas for women identified a diagnosis precluded the opportunity to have in-vitro fertilization (IVF) treatment or embryo preservation, the identity of breastfeeding taken away, given birth prematurely, fear about the impact of this child and others
20.	VanTromp (2015)	United Kingdom	Describes a mother's experience of GBC	Narrative report	1	A woman experiences being 5 weeks pregnant and a diagnosis of GBC. Findings include termination advice, feelings of terror and fear for the unborn child. After the mastectomy, fear of physical reminder. Treatment modalities and 10 years of hormone therapy. Story of hope and encouragement for other women
21.	Pietrangelo (2018)	United States of America	To describe how one woman experienced her family and her health after being diagnosed with GBC	Narrative report	1	After 5 years of infertility and a newly diagnosed gestational breast cancer, a series of life-altering events. These experiences are conflicting emotions, life and death decisions, being terrified, second expert opinion, chemotherapy, lumpectomy, side effects, birth and further chemotherapy, a double mastectomy and evaluating the risks, an individual choice

TABLE 3 (Continued)

No	Author (year)	Country	Aim	Design	Sample size (n)	Key findings
22.	Henry et al. (2012)	Canada	To examine the consequences of maternal cancer diagnosis and treatment during pregnancy on maternal, foetal and neonatal outcomes by measuring the psychological distress	Quantitative	74	Seventy-four women completed the IES and BSI-18 following their cancer diagnosis On average women experienced clinically significant levels of distress up to 51% than 33% of breast cancer patients and higher than 15% found 1 year post-diagnosis. The study suggests the long-standing impact of cancer diagnosis during pregnancy
23.	Ives (2009)	Australia	To identify the specific psychosocial issues for women diagnosed with GBC among three groups of women	Aged, matched case-control study (part of the thesis)	16	The three groups were 1; women with a confirmed diagnosis of GBC, 2; women with an actual diagnosis of breast cancer who subsequently conceived and 3; women with a confirmed diagnosis of breast cancer who did not have GBC and did not subsequently conceive. The findings include no significant difference between the three breast cancer groups in all but two areas, for example, constantly feeling under strain and vaginal dryness. The study identified four main themes motherhood, isolation, support and decision-making
24.	Connell et al. (2006)	Australia	Explores issues about fertility, contraception, pregnancy and breastfeeding after breast cancer	Longitudinal qualitative study Phenomenology	13	Pregnancies occurred during the study. The women experienced mixed responses towards the pregnancy, for example, elated, trepidation, influenced by fears of recurrence, acceleration, metastasis and the debate of termination. Breastfeeding decisions for women who had viable pregnancies during the study changed over time
25.	Zanetti-Dällenbach et al. (2006)	Switzerland	To evaluate the psychological management in pregnant breast cancer patients	Case Study	1	Healthcare professionals raised concerns about understanding the ethical framework, breaking bad news, risk communication, shared decision-making and biopsychosocial care. The case report illustrated the different phases of psychological care and the delicate balance in the decision-making process

Note: IES is a self-administered, 22-item questionnaire measuring subjective distress following a stressful event in three subscales: intrusion, avoidance and hyperarousal. BSI-18 is a self-administered, brief screening inventory measuring levels of distress in three subscales: anxiety, depression and somatization.



advice from multiple healthcare professionals. The women found it hard to trust the information provided because of the differences in each report.

## 2.7 | Synthesis

During the familiarization and description process, searching for themes, reviewing themes, defining and naming themes, the overall compelling extracts produced an overarching theme, four major themes and seven subthemes outlined in Figure 2. Two authors (KY and MM) and a research assistant (PC) independently reviewed the themes. The qualitative studies were analysed in this review using Braun and Clarke's (2006) thematic analysis guide (Braun & Clarke, 2006).

## 3 | RESULTS

### 3.1 | Themes

The overarching theme of adjustment underpinned the narratives of participants. Four significant themes depicted women's experiences of GBC: psychological impact, motherhood, communication and treatment. Seven subthemes identified in the literature (Table 4) describe the in-depth understanding of women. Practical and social aspects, being positive, identity, maternal, breastfeeding, healthcare professionals and physical impact subthemes, will be described following the major themes (Figure 2).

### 3.2 | Overarching theme: Adjustment

Adjustment describes how women use their thoughts and behaviours to regulate their distress and coping mechanisms, a process that changes over time. They emerged with positive well-being as an outcome (Folkman & Greer, 2000). The direct impact on the overall adjustment of women's psychological well-being is related to the

identity associated with motherhood, the treatment choices offered and their relationship with the multidisciplinary team.

### 3.3 | Major theme: Psychological impact

The first major theme, psychological impact, relates to the emotional rollercoaster after the GBC diagnosis. Fear, anxiety and distress were often reported. Fear of imminent death causes great distress for women (Gomes et al., 2021). Words used to describe their fears included shock (Faccio et al., 2020), scared and vulnerable (Facchin et al., 2021), hopelessness (Henry et al., 2012), horrified (Zanetti-Dällenbach et al., 2006), mad panic (Rees & Young, 2016) and a worrying time (Richards, 2019). Many stressors may be resolved in the short term, however, some of the women with GBC experience long-term distress (Henry et al., 2012), altered body image (Facchin et al., 2021) and guilt (Rees & Young, 2016).

The experience of anxiety and distress for women with GBC warrants specific attention by healthcare professionals to generate appropriate support services promptly (Connell et al., 2006; Facchin et al., 2021; Hammarberg et al., 2018). The treatments can also have a psychological impact on relationships with their unborn child, other children, future children and partners (Faccio et al., 2020; Gomes et al., 2021; Hammarberg et al., 2018; Pietrangelo, 2018; VanTromp, 2015). One woman reflected in the study by Liow et al. (2022), "I don't want (another pregnancy) anymore because it happened to me after I gave birth. So, I don't want to have another breast cancer again... it's very traumatizing" (p. 4).

Younger women with breast cancer experienced significantly more anxiety and distress than their older counterparts (Ferrari et al., 2018; Ives et al., 2016). The stressors for all women with breast cancer directly responds to uncertainty (Ives, 2009). In addition to having limited social support (Ives et al., 2016), feelings of uncertainty (Ferrari et al., 2018), low self-esteem (Ives et al., 2016), concerns for future relationships (Ferrari et al., 2018), risk of treatment-related menopause (Rees, 2015) and practical issues (Ives, 2009).

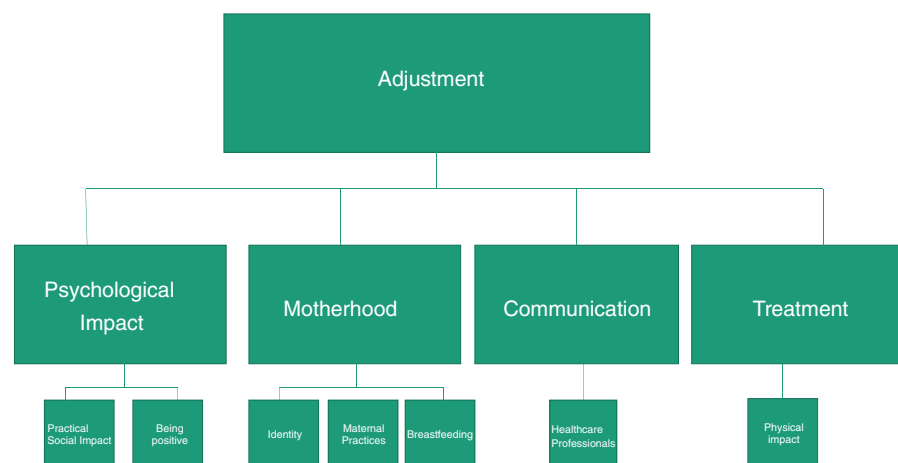


FIGURE 2 GBC themes.

TABLE 4 Subthemes identified

Subthemes	Articles	Extracts	Total
Practical/Social	Kozu et al. (2020), Gray (2018), Richards (2019), Rees and Young (2016), Ferrari et al. (2018), Zanetti-Dällenbach et al. (2006), Facchin et al. (2021), Faccio et al. (2020), Gomes et al. (2021), Hammarberg et al. (2018), Beeston (2019), Rees (2015), Stafford et al. (2021), Ives et al. (2016), Liow et al. (2022), Connell et al. (2006), Rodsten (2017), Dusengimana et al. (2018)	"I didn't know anyone else who had had cancer while pregnant. I didn't even know this could happen. But I talked a lot with other women with breast cancer. It wasn't the same, but it helped" (W4) Gomes et al. (2021)	18
Being Positive	Richards (2019), VanTromp (2015), Ferrari et al. (2018), Faccio et al. (2020), Watkins (2019), Beeston (2019), Gomes et al. (2021), Zanetti-Dällenbach et al. (2006), Rees and Young (2016), Rodsten (2017), Ives et al. (2016)	"I just almost want to stand as a bit of a symbol maybe like to be really strong and that you can do it, and the fact that I did it with a tiny baby which for most people they struggle anyway with that, being a mum for the first time I went through all of that on top you just think I did it, so you can do it? (Lyndsey)" Rees and Young (2016)	11
Identity	Pietrangelo (2018), Ferrari et al. (2018), Facchin et al. (2021), Richards (2019), Liow et al. (2022), Rees & Young, 2016, Rodsten (2017), Ives (2009), Chinn (2019), VanTromp (2015), Beeston (2019)	"Hearing her baby's heartbeat and seeing her moving helped her feel like a pregnant woman and not a cancer mum" (Bromley). Beeston (2019)	11
Maternal practices	Kozu et al. (2020), Gray (2018), Pietrangelo (2018), Richards (2019), VanTromp (2015), Ferrari et al. (2018), Facchin et al. (2021), Faccio et al. (2020), Gomes et al. (2021), Henry et al. (2012), Beeston (2019), Chinn (2019), Stafford et al. (2021), Ives et al. (2016), Kirkman et al. (2017), Liow et al. (2022), Rees and Young (2016), Connell et al. (2006), Rees (2015), Rodsten (2017), Ives (2009)	"When I was diagnosed my initial thoughts were about my children, I was worried at thought of them potentially growing up without me" (Collette) Richards (2019)	21
Breastfeeding	Richards (2019), VanTromp (2015), Ferrari et al. (2018), Faccio et al. (2020), Gomes et al. (2021), Henry et al. (2012), Hammarberg et al. (2018), Watkins (2019), Chinn (2019), Dusengimana et al. (2018), Liow et al. (2022), Rees (2015), Connell et al. (2006), Rees (2015), Rodsten (2017), Gray (2018)	"He breastfeeds beautifully, and I have fallen in love with my one breast again, by seeing how it can nourish and nurture another human being, something I'm so proud I can do even though it will only be for a few more weeks" (Lizzy). VanTromp (2015)	16
Healthcare Professionals	Pietrangelo (2018), Kozu et al. (2020), Ferrari et al. (2018), Faccio et al. (2020), Zanetti-Dällenbach et al. (2006), Facchin et al. (2021), Gomes et al. (2021), Henry et al. (2012), Hammarberg et al. (2018), Stafford et al. (2021), Ives et al. (2016), Kirkman et al. (2017), Connell et al. (2006), Rodsten (2017), Ives (2009), Richards (2019)	"Deciding to continue a pregnancy against medical advice can be a particularly stressful choice, highlighting the importance of shared decision making, patient centred communication and continued physician support" (Henry et al. 2012)	16
Physical Impact	Kozu et al. (2020), Gray (2018), Pietrangelo (2018), Richards (2019), VanTromp (2015), Facchin et al. (2021), Faccio et al. (2020), Gomes et al. (2021), Henry et al. (2012), Hammarberg et al. (2018), Watkins (2019), Beeston (2019), Chinn (2019), Stafford et al. (2021), Dusengimana et al. (2018), Ives et al. (2016), Connell et al. (2006), Liow et al. (2022), Rees and Young (2016), Rees (2015), Rodsten (2017), Ives (2009)	"Because we feel that we are not 100% a woman already, I got a shock why is it (breast) in this kind of form ... like without a nipple" (Lina). Liow et al. (2022)	22

### 3.3.1 | Subtheme: Practical and social aspects

Practical and social aspects for a woman can have psychological implications for herself, family, friends and others. The practical issues for young women include carers' responsibilities (Richards, 2019), physicality changes resulting from treatment (Rees, 2015), career and financial burdens (Ives, 2009), and isolating circumstances like 'feeling different' (Ives et al., 2016, p. 82). Added distress and concerns can be triggered by practical aspects such as the expense of

baby formula (Dusengimana et al., 2018), additional support deficits at home (Ives, 2009), living long distances from family and friends (Ives et al., 2016), limited access to support services and community support groups (Hammarberg et al., 2018).

Assessing the anxiety levels experienced by the woman and her family is essential. Healthcare professionals can provide early psychosocial assessment and services to the women to elicit and address their main concerns (Dusengimana et al., 2018; Facchin et al., 2021; Ives et al., 2016; Rodsten, 2017). Stress and fear can

lead to an inability to cope and bond effectively with the baby (Ives et al., 2016; Rodsten, 2017). Healthcare professionals are pivotal in identifying and recommending resources to ensure that women and their families are well supported. Suggesting a multidisciplinary approach to emotional and social care can link women with GBC with the most appropriate services (Hammarberg et al., 2018; Ives et al., 2016; Rodsten, 2017).

Families play significant roles in the overall well-being and adjustment of women diagnosed with GBC (Gomes et al., 2021; Rodsten, 2017). Psychosocial adjustments are facilitated by a supportive social environment and impede where support is lacking (Rees & Young, 2016). More than half of the studies described how women worried about how their partner would cope with the news of a diagnosis, additional responsibilities and the impact on their family (Facchin et al., 2021; Gomes et al., 2021; Ives et al., 2016; Kirkman et al., 2017; Kozu et al., 2020).

Isolation, distance and disconnection from family or friends contribute to psychological stressors for women (Ferrari et al., 2018; Gomes et al., 2021; Gray, 2018; Rodsten, 2017; Stafford et al., 2021). Women experienced feelings of uncertainty with limited family support or connection (Ferrari et al., 2018; Gray, 2018; Hammarberg et al., 2018; Ives, 2009; Ives et al., 2016; Rees, 2015; Richards, 2019). The significant compounding factors include fear of being unable to manage motherhood duties, cancer treatment and other practical roles (Ives et al., 2016; Liow et al., 2022; Rodsten, 2017). The importance of family and social support is associated with improved recovery and psychosocial adjustments (Gray, 2018; Hammarberg et al., 2018; Liow et al., 2022).

### 3.3.2 | Subtheme: Being positive

Some women explained the importance of being positive when diagnosed with GBC, a sense of pride and wanting to help other women (Ives et al., 2016). One woman's sense of pride was illustrated in her statement that she stated, "I just almost want to stand as a bit of a symbol maybe like to be strong and that you can do it and the fact that I did it with a tiny baby which for most people they struggle anyway with that, being a mum for the first time, I went through all of that on top you just think I did it so you can do it" (Ives et al., 2016, p. 256).

A maternal instinct, such as a 'fighting spirit' to protect her child and her well-being, indicates a positive adjustment (Faccio et al., 2020; Ferrari et al., 2018; Gray, 2018; Zanetti-Dällenbach et al., 2006). The findings of positive adjustment included: experiences of prioritizing care and decisions (Ives et al., 2016); determination to defeat cancer (Beeston, 2019; VanTromp, 2015); maternal instincts to protect the child (Rodsten, 2017); belief in the prospect of their children (Gomes et al., 2021).

## 3.4 | Major theme: Motherhood

Motherhood, the state of being a mother, is viewed differently by women. The maternity experience of women with GBC alters and is

challenging. The challenges are; concerns about the values and beliefs of breastfeeding (Faccio et al., 2020), the fear of transferring the disease or genetic disposition to their newborn (Ives, 2009) and the effect of treatment on the baby (Hammarberg et al., 2018). Could pregnancy cause or accelerate cancer (Connell et al., 2006).

The stage of pregnancy when diagnosed with GBC greatly influenced women's decisions about their cancer management. Each woman's response to these life events and mothering decisions was unique and based on her life's experience, beliefs and values (Connell et al., 2006; Ives et al., 2016; Rees & Young, 2016; Rodsten, 2017).

### 3.4.1 | Subtheme: Identity

Identity is vital for women as it defines them. Women may instinctively question whether their primary identity in this situation is that of a patient, a mother or a new mother (Rodsten, 2017). Motherhood provides identity changes and transformations through having children (Ives, 2009; Rees & Young, 2016; Richards, 2019; Rodsten, 2017). Women with GBC can be conflicted with the motherhood role and femininity (Rees & Young, 2016). Women also acknowledged that surgical treatment decisions and reconstruction often challenged the balance of femininity, preservation and removal (Facchin et al., 2021; Liow et al., 2022). One woman reported that the option of a lumpectomy versus a total mastectomy was a big decision (Chinn, 2019).

### 3.4.2 | Subtheme: Maternal practices

Women with other children often struggle to maintain their parental role due to the side effects of treatment (Ferrari et al., 2018; Gomes et al., 2021; Ives, 2009). Physical engagement with the baby and the family is a desired maternal practice (Gray, 2018; Rees, 2015; Rodsten, 2017; VanTromp, 2015). Life uncertainty can cause women to be overprotective and limit their children's independence just in case they are left without a mother (Henry et al., 2012; Ives et al., 2016; Rodsten, 2017).

These women are confronted with difficult maternal decisions about the life and death of an unborn child (Kirkman et al., 2017). Therapeutic termination of pregnancy might be advised (Gomes et al., 2021; Kirkman et al., 2017). However, one woman stated, "she thinks her husband 'saw the here and now' I was so emotionally overwhelmed at the time." She described repressing her feelings regarding termination until she had finished her cancer treatment (Kirkman et al., 2017, p. 5). The decision for women, either way, comes with internal conflict (Gomes et al., 2021), distress, or "feeling a deep sense of regret" (Kirkman et al., 2017, p. 261).

### 3.4.3 | Subtheme: Breastfeeding

Breastfeeding symbolizes many maternal practices such as protection, growth and development benefits for the baby. For society,

it is economical and environmentally beneficial for the mother. Breastfeeding assists the uterus in returning to the pre-pregnant state. Breastfeeding assists in bonding with their child and is associated with women's concept of what it is to be a 'good mum' (Connell et al., 2006; VanTromp, 2015; Watkins, 2019).

When decisions during diagnosis and treatment change regarding advice to breastfeed or not, women experience significant distress (Connell et al., 2006; Faccio et al., 2020; Hammarberg et al., 2018; Henry et al., 2012; Richards, 2019). Women expressed mourning for the loss of breastfeeding about having the choice taken away (Ferrari et al., 2018; Gray, 2018; Hammarberg et al., 2018; Rees, 2015; Richards, 2019). Conversely, the study by Liow et al. (2022) revealed seven Singaporean women diagnosed with GBC were "largely undisturbed by their inability to breastfeed" (p. 5). The decisions regarding breastfeeding are determined by the different values and priorities of disease or survival (Liow et al., 2022). For Western women, "breastfeeding represents the ultimate contract between mother and baby" (Rodsten, 2017, p. 68).

### 3.5 | Major theme: Communication

The flow of information and communication shared with a woman with GBC is essential, and there must be a continuous dialogue (Zanetti-Dällenbach et al., 2006). Several studies identified that clinical information and the use of nationally or internationally endorsed guidelines such as Breast cancer in pregnancy: recommendations of the international consensus meeting (Amant et al., 2010), and Cancer, pregnancy, and fertility: European Society of Medical Oncology: clinical practice guidelines for diagnosis, treatment and follow-up (Peccatori et al., 2013) are essential for better outcomes. These guidelines provide treating clinicians with evidence-based information, treatment options and outcomes that assist with the clinical decision-making process for women (Connell et al., 2006; Ferrari et al., 2018; Hammarberg et al., 2018; Ives, 2009; Ives et al., 2016; Pietrangelo, 2018; Rees, 2015; Rodsten, 2017; Zanetti-Dällenbach et al., 2006).

#### 3.5.1 | Subtheme: Healthcare professionals

How healthcare professionals communicate affects how women with GBC manage their diagnosis and treatment (Hammarberg et al., 2018). Healthcare professionals require skills, competence, a level of expertise in GBC management, and compassion while speaking to a woman who has been recently diagnosed (Ferrari et al., 2018; Hammarberg et al., 2018; Pietrangelo, 2018; Rodsten, 2017; Zanetti-Dällenbach et al., 2006). Consultation with mothers and family often involves multiple clinicians from different departments and sites (Ives, 2009; Pietrangelo, 2018; Rodsten, 2017; Zanetti-Dällenbach et al., 2006).

Misinformation can cause confusion (Faccio et al., 2020; Pietrangelo, 2018; Rodsten, 2017; Zanetti-Dällenbach et al., 2006),

resulting in women with GBC seeking other professional opinions or abandoning treatment altogether (Pietrangelo, 2018; Rodsten, 2017; Stafford et al., 2021; Zanetti-Dällenbach et al., 2006). Women with GBC must receive timely and relevant information from skilled healthcare professionals (Faccio et al., 2021; Ives et al., 2016; Rodsten, 2017; Stafford et al., 2021; Zanetti-Dällenbach et al., 2006). Accurate information is imperative in assisting women's decision-making (Gomes et al., 2021; Hammarberg et al., 2018; Henry et al., 2012; Ives et al., 2016; Zanetti-Dällenbach et al., 2006).

Delivering clinical information and providing adequate time is essential for women with GBC, as these define the direction of treatment, continuation of pregnancy and decision-making (Connell et al., 2006; Hammarberg et al., 2018; Ives, 2009; Kozu et al., 2020; Rodsten, 2017; Stafford et al., 2021; Zanetti-Dällenbach et al., 2006). Conflicting information among clinicians delivered to these women was evident regarding breastfeeding (Faccio et al., 2020), further children (Connell et al., 2006), cancer treatment (Hammarberg et al., 2018), pregnancy termination (Gomes et al., 2021), fertility (Ives, 2009), early delivery (Kozu et al., 2020), and breast cancer recurrence (Richards, 2019). Some women voiced concerns about several clinicians' limited knowledge of women's reproductive health and GBC (Kirkman et al., 2017). The importance of communicating and explaining complex medical information in layman's terms could prevent misinterpretation. As stated by one woman in Richards (2019), "Nobody explained it was incurable; I wish they had because if I had realised what was at stake, I might have made a different decision" (p. 1).

### 3.6 | Major theme: Treatment

Treatment for GBC involves multidisciplinary teams and subspecialties, which include surgery: lumpectomy or mastectomy; chemotherapy; hormone therapy; endocrine and radiotherapy; diagnostic tests; imaging modalities; termination of pregnancy and induced childbirth (Connell et al., 2006; Gray, 2018; Ives et al., 2016; Kirkman et al., 2017).

The treatment options and decisions were complicated for women as they attributed to changes such as treatment-induced infertility (Stafford et al., 2021). In addition to a mastectomy (VanTromp, 2015), self-esteem issues from altered appearances (Liow et al., 2022), invasive procedures (Watkins, 2019), recovery after caesarean surgery (Henry et al., 2012), fear of not being able to take care of their child due to the course of treatment (Ives et al., 2016) and unexpected side effects (Richards, 2019). Treatment decisions where pregnancy is to continue may cause women to experience anxiety about their child's risk of in-utero exposure or passing chemicals onto the baby via milk (Rees & Young, 2016; Stafford et al., 2021).

The subsequent studies found the treatment to be challenging and traumatic while undergoing surgery, months of chemotherapy, welcoming a baby, recovering from a caesarean section, and undergoing radiation (Beeston, 2019; Connell et al., 2006;

Gray, 2018; Hammarberg et al., 2018; Henry et al., 2012; Ives, 2009; Ives et al., 2016; Liow et al., 2022; Pietrangelo, 2018; Rees, 2015; Richards, 2019; Rodsten, 2017; VanTromp, 2015; Zanetti-Dällenbach et al., 2006).

The women often operated between being mothers and patients (Liow et al., 2022). Treatment modalities can create isolating effects for the women, such as preterm birth (Richards, 2019), physical effects of a mastectomy and lymph node clearance (VanTromp, 2015), breastfeeding difficulties (Rees & Young, 2016), chemotherapy (Gray, 2018) delays in diagnosis (Rodsten, 2017), radiotherapy appointments, interruptions for women wanting to attempt pregnancy through hormone therapy (Ives, 2009) and coping physically overall (Pietrangelo, 2018; VanTromp, 2015).

### 3.6.1 | Subtheme: Physical impact

Women with GBC can experience significant physical effects from their disease and pregnancy (Ives et al., 2016). Some short-term physical changes can include alopecia, skin changes, nausea, tiredness, allergic reactions, weight changes, difficulty lifting or carrying her baby, and procedure recovery (Facchin et al., 2021; Ives et al., 2016). Women often need to adjust to permanent changes in infertility, the impossibility of breastfeeding and partial or total mastectomy (Connell et al., 2006; Gomes et al., 2021; Ives et al., 2016).

For women, the breast signifies their femininity. A breast cancer diagnosis during pregnancy can result in the loss of identity and a sense of inadequacy (Facchin et al., 2021). The physical impact of losing a breast can be very challenging and long-lasting (Facchin et al., 2021). During the treatment phase, surgical options such as breast reconstruction are offered during or after chemotherapy. Breast reconstruction is often selected by young women to quickly regain their feminine appearance and identity (Liow et al., 2022).

## 4 | DISCUSSION

This scoping review provided an in-depth insight into women's experiences of a GBC diagnosis, treatment and their interactions with healthcare system. Synthesis of the selected literature identified an overall theme of adjustment, four major themes and seven subthemes. Adjustments determined from women's narratives described their resilience in adapting to cancer-related changes for their own and child's well-being.

The course of adjustment to a health crisis is a multifaceted process (Alder & Bitzer, 2008). Adjustment to cancer and pregnancy has been identified by Alder and Bitzer (2008) in the literature on the development of theories, models and frameworks. Kübler-Ross (2009) formed a framework for understanding adjustment to their proposed five stages of grief. Gloger-Tippelt (1983) created a model of developmental stages during pregnancy, while Lazarus and Folkman (1984) established a theory of appraisal, stress and coping (Gloger-Tippelt, 1983; Kübler-Ross, 2009; Lazarus & Folkman, 1987). These

all share a similarity in that adjustment is not a normative process, where one stage sequentially follows the next stage.

Kübler-Ross (2009) state the stages of adjustment of denial, anger, bargaining, depression and acceptance are individual responses to loss. These stages support and identify the range of feelings outlined by Lazarus and Folkman (1987). Consideration should be given to these frameworks when situating the overarching theme of adjustment for women responding to a diagnosis of GBC. Should the situation require imminent action, greater emphasis is on problem-focused coping, whereas, if the situation requires accepting or getting used to a case, the emphasis is on emotional-focused coping (Lazarus & Folkman, 1987).

As part of the adjustment process, problem-focused coping strategies are used continuously. Women may feel they have some control over the treatment plans and find problem-focused solutions with their treating team. The subthemes identified as adjustment problem-focused strategies are physical impact, practical and healthcare professionals. Conversely, women can express anger and frustration using emotional-focused coping modes; these are more prominent in the subthemes of identity, maternal practices, breastfeeding and being positive (Carroll, 2020). Coping strategies are not mutually exclusive (Alder & Bitzer, 2008; Carroll, 2020).

Women's experiences of GBC are often overwhelming and more pronounced due to the unexpectedness when combined during pregnancy. Leung et al. (2020) systematically reviewed the psychological aspects of gestational cancer in the literature. The study identified the paucity of literature on the psychological care of women with gestational cancer (Leung et al., 2020). Similar studies by Ives et al. (2016) and Vandenbroucke et al. (2017) support the findings that women with cancer and pregnancy experience high anxiety levels. Kyriakides (2008) described the psychological impact for young women with cancer and pregnancy as a "feeling of being thrown into a world of uncertainty" (p. 250). Zagouri et al. (2016) study of cervical cancer and pregnancy noted that radical surgery and pelvic radiation are the foundations for cervical cancer treatment. Facing possible fetal death and termination of pregnancy requires considerable psychosocial adjustment.

Faccio et al. (2020) found a lack of studies in the literature representing pregnancy and cancer experiences and the transition to motherhood. This scoping review found women diagnosed with GBC to have unique perspectives of motherhood and pregnancy (Ives & Saunders, 2010; Vandenbroucke et al., 2017). Leung et al. (2020) also identified the challenges and complex decisions for women with GBC amounted to experiencing regretful aspects of their pregnancy and motherhood, including birth plans, breastfeeding, genetic counselling and fertility options (Durrani et al., 2018; Leung et al., 2020).

Women often experience conflicting information, inadequate information and difficulties circumventing complex decisions (Leung et al., 2020). The level of explanation provided to women with cancer and pregnancy regarding the risks and available treatments should be accurate, timely, relevant and culturally appropriate (Ives et al., 2012). Women and clinicians' mistaken assumptions of cancer



symptoms include "pregnancy and lactational changes in the breast" (Ives & Saunders, 2010, p. 358).

An explanation for the difficulty in communicating the complex nature of treating GBC is raised in the papers, suggesting the rarity of cases seen by clinicians and the many subspecialties involved. Each has expertise but may not have the necessary knowledge of other clinical areas. For example, an obstetrician and an oncologist may have different views regarding the woman's treatment and delivery time frames (Connell et al., 2006; Hammarberg et al., 2018; Ives, 2009; Zanetti-Dällenbach et al., 2006).

Management guidelines for women with GBC recommend a multidisciplinary team in specialized centres and are supported in other studies for gestational cancers (Padmagirison et al., 2010; Zagouri et al., 2016). This scoping review found the news of a diagnosis and the complex decision-making required of the woman was particularly challenging, primarily when many clinical specialities deliver information.

The scoping review cited four studies from the same author, however, only two were included in the final scoping review. Two of the author's articles used qualitative and quantitative data on women experiencing GBC (a thesis and a book chapter). We did not select the other two author's articles because one duplicated the thesis, and the other was an expert review of GBC management and outcomes.

#### 4.1 | Clinical implications

The implications of this review suggest raising awareness of women's experiences with healthcare professionals through education and training opportunities, leading to changes in providing early identification for psychological support and improved information and communication.

The clinical implications of treating women with GBC require healthcare professionals to provide women-centred care that identifies women as both mothers and patients. This scoping review highlights the limited research investigating the complex issues for women with GBC and their long-term impacts.

#### 4.2 | Limitations and strengths

It is considered a limitation when the quality appraisal of the studies included in scoping reviews is not performed. Scoping reviews aim to provide a descriptive overview of the revised material without critically appraising individual studies. It remains unclear whether the lack of quality analysis limits the uptake and relevance of scoping study findings (Levac et al., 2010).

The literature search conducted during this scoping review also has limitations. Despite trying to capture literature more broadly about women's experiences with GBC, studies from different cultures and other countries were limited. Therefore, our findings may not apply to all populations of women with GBC.

A strength of our review is that we searched five health-related and grey databases for relevant or newly emerging research areas

gaining valuable insights into women's experiences with GBC. The second strength involved the clinician review of women's experiences resonating with the complexities outlined in the literature. A third strength, all six stages of Arksey and O'Malley's (2005) framework have been incorporated into the scoping review.

## 5 | CONCLUSION

This review provided a broad overview of women's experiences with GBC and their interactions with the healthcare system. The review found that women with GBC have difficulty adjusting as they assume the new role of a patient and mother, requiring decisions about treatment and the future, which will affect their relationships with others. Limited studies focused on this interaction between the roles of being a mother and a patient with GBC in the healthcare system. The clinical implications for practice and policy include having knowledgeable and competent healthcare professionals as part of the treating team to ensure accurate, consistent and timely access to information and support. The review suggests recommendations to include early identification of the psychological impact of women diagnosed with GBC and individualized care.

#### AUTHOR CONTRIBUTIONS

SH, CN, KY, MM: Made substantial contributions to conception and design, or acquisition of data or analysis and interpretation of data; SH, CN, KY, MM: Involved in drafting the manuscript or revising it critically for important intellectual content; SH, CN, KY, MM: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; SH, CN, KY, MM: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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#### CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.



## PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15510>.

## DATA AVAILABILITY STATEMENT

Data openly available in a public repository that issues datasets with DOIs. The data that support the findings of this study are openly available in [repository name e.g. "figshare"] at [doi], reference number [reference number].

## PATIENT OR PUBLIC CONTRIBUTION

This is a systematic scoping review of the literature using Arksey and O'Malley's (2005) framework, including stakeholder consultation of two healthcare professionals.

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# Effectiveness of Acceptance and Commitment Therapy for people with advanced cancer: A systematic review and meta-analysis of randomized controlled trials

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## Abstract

**Aims:** To systematically review existing evidence and assess the effectiveness of Acceptance and Commitment Therapy for people with advanced cancer.

**Design:** Systematic review and meta-analysis of randomized controlled trials.

**Data Sources:** Nine databases, including PubMed, Web of Science, Cochrane Library, Embase, CINAHL, PsycINFO, Chinese National Knowledge Infrastructure, VIP Database and Wanfang, were searched. The search covered the period between the inception of the selected databases and August 2022.

**Review Methods:** Two authors independently examined eligible studies and appraised the methodological quality of the included studies by applying the criteria suggested by the Cochrane Effective Practice and Organization of Care followed by data abstraction. The Template for Intervention Description and Replication (TIDieR) checklist was used to identify intervention characteristics. Meta-analysis was performed using RevMan 5.4 software, and the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach was used to evaluate the certainty of evidence.

**Results:** Eight studies, involving 488 people with advanced cancer, were included. The results showed significant effects of Acceptance and Commitment Therapy on the improvement of quality of life and the alleviation of anxiety, depression, psychological distress and fatigue in people with advanced cancer. However, its effects in relieving psychological flexibility and pain were not statistically significant. The certainty of the evidence was low to moderate.

**Conclusion:** People with advanced cancer can benefit from Acceptance and Commitment Therapy, which is conducive to improving their health outcomes.

**Impact:** This review provides evidence about the effectiveness of Acceptance and Commitment Therapy in people with advanced cancer. Further well-designed studies with larger sample sizes are required. This review may help nurses and researchers to design and implement Acceptance and Commitment Therapy in clinical practice, thereby improving health outcomes in this population.

**PROSPERO Registration Number:** CRD42021244568.

## KEYWORDS

Acceptance and Commitment Therapy, advanced cancer, anxiety, depression, meta-analysis, nursing, palliative care, psychological distress, psychological flexibility, systematic review

## 1 | INTRODUCTION

Cancer is a leading cause of death globally, with an estimated 10 million cancer-related deaths worldwide in 2020 (Sung et al., 2021). Advanced cancer refers to cancers that are improbable to be cured or controlled with treatment (American Cancer Society, 2020). The diagnosis of advanced cancer and its complex treatment affect all domains of patients' lives, including physical and psychological aspects. Psychological suffering is a major concern for people with advanced cancer (Wang et al., 2017). Research has shown that 31%–67% of people with advanced cancer experience various psychological problems such as depression, demoralization, anxiety and uncertainty (Huda et al., 2022; Webber et al., 2021). These problems present in combinations and can cause psychological distress, an unpleasant experience of a psychological, social or physical nature that may cripple individuals' abilities to cope effectively with cancer, physical symptoms and treatment (Huda et al., 2022). Untreated psychological symptoms in people with advanced cancer adversely affect physical function, social activities and adherence, leading to aggravated physical symptoms and decreased quality of life (QoL) later (Chen et al., 2017; Rodríguez-Prat et al., 2017). Therefore, management of psychological symptoms is an essential part of palliative care nursing.

Non-pharmacological interventions have been recommended for symptom management in people with advanced cancer (Malakian et al., 2022). Acceptance and Commitment Therapy, a novel form of Cognitive Behavioural Therapy (CBT), has gained popularity worldwide in healthcare research and practice (Du et al., 2021a). Recent studies have touted it as a promising intervention to address the psychological symptoms of people with advanced cancer (Pan et al., 2020; Rost et al., 2012).

Nurses are ideally positioned to implement interventions for people with advanced cancer, as they have the most contact with them and can better identify their psychological problems (Malakian et al., 2022). However, nurses have insufficient experience in Acceptance and Commitment Therapy (Tyrberg et al., 2017). Equipping nurses with evidence-based Acceptance and Commitment Therapy may help them effectively support people with advanced cancer and boost the quality of holistic cancer nursing.

### 1.1 | Background

Acceptance and Commitment Therapy is a third-wave CBT approach (Hayes et al., 2006). Unlike traditional CBT, Acceptance and Commitment Therapy does not try to avoid or eliminate distress. Instead, it is based on a holistic perspective that assists people in

obtaining psychological flexibility—the ability to fully contact the present moment as a conscious human being and to change or persist in behaviour when doing so serves valued ends (Hayes et al., 2006). Specifically, Acceptance and Commitment Therapy includes six core processes: (1) acceptance: actively embracing unwanted thoughts, emotions or experiences rather than controlling them; (2) cognitive defusion: altering the undesirable functions of thoughts rather than an immediate change in their frequency; (3) being present: non-judgmentally contacting the present moment; (4) self as context: reporting one's behaviour from a 'sense of self' perspective; (5) values: chosen qualities of purposive action; and (6) committed actions: committing to actions in the service of their chosen values (Hayes et al., 2006; Zhang et al., 2017).

Psychological flexibility plays an important role in circumstances, such as advanced cancer, over which one can exert little or no control (Davis et al., 2017). It is associated with psychological and physical symptoms and QoL in people with advanced cancer (Mosher et al., 2017, 2021; Novakov, 2021). Thus, given its aim of psychological flexibility, Acceptance and Commitment Therapy may be particularly well-suited for people with advanced cancer as it normalizes their distressing experiences and addresses existential concerns such as the loss of meaning and purpose by encouraging them to live in the present and engage in meaningful activities, thereby alleviating their psychological and physical symptoms (Moreno et al., 2022; Vehling et al., 2019).

In recent years, an increasing number of clinical trials have examined the effects of Acceptance and Commitment Therapy on different health outcomes in people with advanced cancer. Several studies (Li et al., 2022; Rost et al., 2012; Zhang et al., 2021) have shown that this therapy significantly alleviates the psychological symptoms of people with advanced cancer; however, Mosher et al. (2018, 2019) reported inconsistent results. Findings concerning the effect on psychological flexibility among this population are also conflicting (Serfaty et al., 2019; Zhang et al., 2021). A systematic review (Li, Wong, et al., 2021) summarized the relevant studies in this field; however, this review had some limitations. It completed the literature search before October 2019 and only included six studies, involving five randomized controlled trials (RCTs) and one with a single-group pretest–post-test design. The interventions in this review included Acceptance and Commitment Therapy alone or in combination with others, which may influence the evaluation of the true effect of this therapy. Furthermore, no data synthesis was performed. This review provides some insights, but the direct effectiveness of Acceptance and Commitment Therapy for people with advanced cancer remains inconclusive. The rigorously designed RCTs (Li et al., 2022; Mosher et al., 2022; Pan et al., 2020; Zhang et al., 2021) conducted recently in this field



may provide new and stronger evidence. Therefore, we performed a systematic review and meta-analysis of RCTs to specifically explore the effectiveness of Acceptance and Commitment Therapy for people with advanced cancer and to inform clinical nursing interventions.

Additionally, emphasis has been placed lately on better understanding the interventions characteristics in the healthcare context. Identifying intervention characteristics may provide nurses with the knowledge and skills to use this therapy and may guide them in shaping and implementing interventions to promote well-being among people with advanced cancer, thereby enhancing the quality of holistic care. Therefore, we applied the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al., 2014) to provide clear and detailed descriptions of the intervention elements of the included studies.

Overall, this systematic review and meta-analysis aimed to (a) examine the effectiveness of Acceptance and Commitment Therapy on psychological flexibility and psychological symptoms; (b) evaluate the effectiveness of Acceptance and Commitment Therapy on physical symptoms and QoL; and (c) identify the intervention characteristics of Acceptance and Commitment Therapy.

## 2 | THE REVIEW

### 2.1 | Aims

This study aimed to evaluate the effectiveness of Acceptance and Commitment Therapy on health outcomes among people with advanced cancer and to identify the intervention characteristics.

### 2.2 | Design

This systematic review and meta-analysis were performed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021). The study protocol was registered in PROSPERO (CRD42021244568) before any analysis was conducted. The eligibility criteria for this review were modified after the protocol registration. The original target population was people with terminal illness, which may include different diseases, thus resulting in a potential bias in the meta-analysis. Since our literature screening results showed that 90% of the included studies focused on people with advanced cancer, we specifically defined the study population as people with advanced cancer. The original criterion for the intervention was to adopt at least three processes of Acceptance and Commitment Therapy. Since it was irrational and lacked sufficient scientific basis, we modified it into Acceptance and Commitment Therapy involving all six core processes, based on relevant reviews (Du et al., 2021b; Zhao et al., 2021). All other processes were conducted in line with the protocol registration.

### 2.3 | Search methods

A comprehensive literature search was performed in nine databases from their inception to August 2022: PubMed, Web of Science, Cochrane Library, Embase, CINAHL, PsycINFO, Chinese National Knowledge Infrastructure (CNKI), VIP Database and Wanfang. We adopted a search strategy combining indexed terms with free-text terms: (neoplasms OR cancer\* OR neoplasm\* OR tumor\* OR tumour\* OR carcinoma\* OR malignan\* OR oncology) AND ('terminally ill' OR advanced OR terminal\* OR metastat\* OR palliative OR hospice\* OR incurable OR dying OR 'late stage' OR 'end stage' OR 'end of life') AND ('acceptance and commitment therapy' OR 'acceptance and commitment' OR 'acceptance therap\*' OR 'commitment therap\*' OR acceptance-based). The search terms were modified and adapted across different databases. Appendix S1 presents the search strategies for the databases. Reference lists, Google Scholar and Clinical Trials.gov were also manually searched to retrieve potential studies.

### 2.4 | Search outcomes

Literature screening was performed by two authors independently according to the inclusion and exclusion criteria (Box 1), and any divergence was resolved through negotiation with the third author. Figure 1 depicts the literature search and selection process. We identified 269 records via database search and Google Scholar; of these, 30 were retained after duplicate removal and screening of titles and abstracts. After full-text assessment, 22 studies were excluded. We finally included eight RCTs (six in English and two in Chinese) in the meta-analysis (Li et al., 2022; Mosher et al., 2018, 2019, 2022; Pan et al., 2020; Rost et al., 2012; Serfaty et al., 2019; Zhang et al., 2021).

### 2.5 | Quality appraisal

The risk of bias (RoB) tool comprising nine aspects (Cochrane Effective Practice and Organisation of Care, 2017) was adopted to assess the methodological quality of the included RCTs. Each criterion was ranked as having a low, high or unclear risk of bias. We also evaluated the potential for research fraud, misreporting or selective reporting in the included studies. The Retraction Watch Database was searched to check the integrity of the included RCTs. Prospective clinical trial registrations or protocols of the included studies were also checked. The certainty of the pooled evidence was rated using Grading of Recommendations Assessment, Development and Evaluation (GRADE) covering five domains: limitations in design, inconsistency, imprecision, indirectness and publication bias (Ryan & Hill, 2016). Evidence can be categorized into four levels: high, moderate, low and very low. GRADEpro GDT (<https://gradepro.org/>) was used to generate the GRADE evidence



**BOX 1 Review inclusion and exclusion criteria****Studies**

Included: Randomized controlled trials (RCTs).

Excluded: Studies that were repeatedly published or with full-text unavailable.

**Participants**

Included: Adults (≥18 years old) diagnosed with advanced cancer (stage III or IV).

Excluded: Studies involving mixed samples (people with cancer in stage I and II or non-cancer advanced illness) lacking independent data.

**Interventions**

Included: Acceptance and Commitment Therapy involving all six core processes.

Excluded: Studies involving intervention that combined Acceptance and Commitment Therapy with other interventions or components.

**Comparison**

Included: Usual care, wait-list or other treatments.

Excluded: Studies involving control that contained Acceptance and Commitment Therapy components.

**Outcomes**

The studies should include at least one of the primary outcomes or secondary outcomes.

**Primary outcomes**

Included: Psychological flexibility and psychological symptoms (e.g. anxiety, depression and psychological distress).

Excluded: Studies lacking relevant outcome data.

**Secondary outcomes**

Included: Physical symptoms (e.g. pain and fatigue) and QoL.

Excluded: Studies lacking relevant outcome data.

table. Two authors independently evaluated the methodological quality of the included studies and the certainty of evidence; disputes were resolved through discussion with a third author.

**2.6 | Data abstraction**

A self-designed form was used to extract the following information from the included studies: (a) basic information, including authors, country and publication year; (b) participant characteristics, including type of advanced cancer, mean age and sample size of each group; and (c) outcome indicators, measurement tools, evaluation time points and statistical data. The TIDieR checklist (Hoffmann et al., 2014) was used to extract intervention characteristics such as duration, delivery format and adherence rate. Data were extracted

by two authors independently, with the third author serving any disagreements (Table 1).

**2.7 | Synthesis**

Review Manager (RevMan) 5.4 was used for data synthesis. Since all outcomes were presented as continuous variables, mean differences (MDs) or standardized mean differences (SMDs) with 95% confidence intervals (CIs) were calculated as effect sizes, based on whether the same outcome was measured by the same scale. Pooled effect sizes were measured using changes in the mean and standard deviation (SD) from baseline to post-intervention outcomes for both groups. SD change values were calculated using the following equation (Higgins & Green, 2011):

$$SD_{\text{change}} = \sqrt{SD_{\text{baseline}}^2 + SD_{\text{post}}^2 - (2 \times r \times SD_{\text{baseline}} \times SD_{\text{post}})}$$

A correlation coefficient ( $r$ ) value of 0.5 was employed and unavailable SDs at baseline and post-intervention were calculated based on standard errors (Higgins & Green, 2011; Saragih et al., 2021). When the study reported data at multiple time points after the intervention, the data at the latest time point were selected for analysis. Heterogeneity between studies was investigated using Higgins  $I^2$  statistic and Chi-square ( $\chi^2$ ) test (Higgins et al., 2003). In the absence of marked heterogeneity ( $p > .1$  and  $I^2 < 50\%$ ) among studies, the fixed-effects model was used. Otherwise, a random-effects model was adopted to pool data, and subgroup analysis was performed to determine potential sources of heterogeneity. Based on relevant reviews (Du et al., 2021a; Li, Wu, et al., 2021) and characteristics of the included studies, we tabulated possible factors for subgrouping, such as different cultural contexts and intervention delivery formats. Sensitivity analysis was performed by removing studies unavailable in English to check whether the pooled results still hold. For data that could not be merged, a descriptive synthesis was performed. The funnel plot for assessing publication bias was not drawn, considering the limited number of included studies for each outcome.

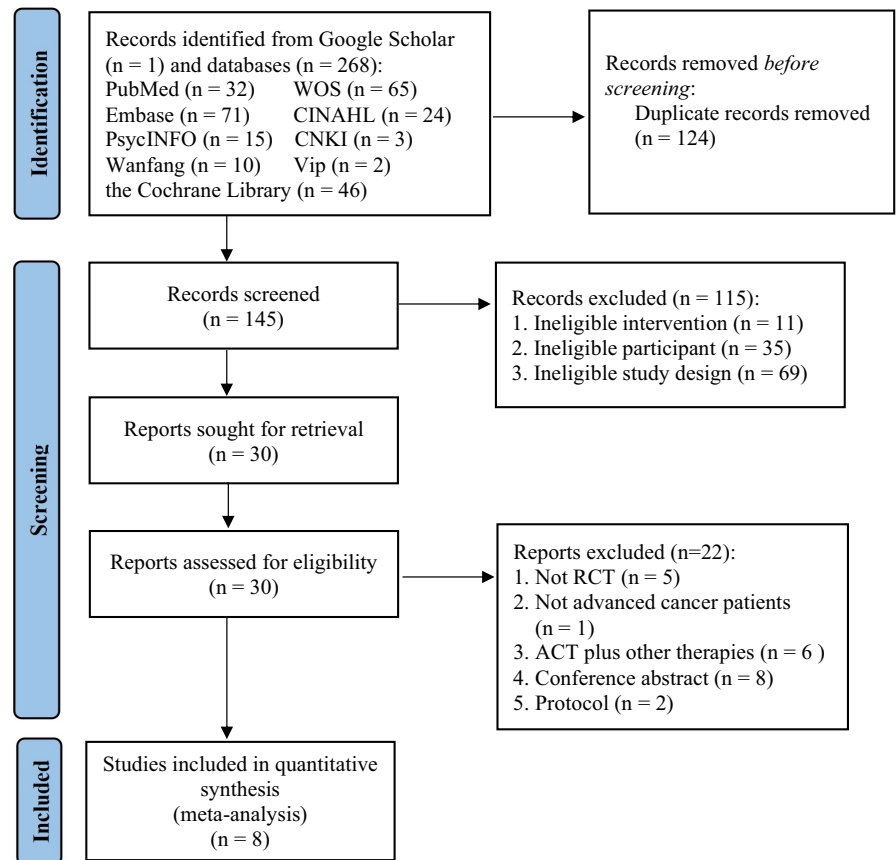
**3 | RESULTS****3.1 | Study characteristics**

In total, eight RCTs published between 2012 and 2022 were included. These studies were conducted in the United States (Mosher et al., 2018, 2019, 2022; Rost et al., 2012), China (Li et al., 2022; Pan et al., 2020; Zhang et al., 2021), and United Kingdom (Serfaty et al., 2019).

**3.2 | Participant characteristics**

A total of 488 people with advanced cancer were included in eight RCTs, with sample sizes varying from 40 to 122. Two studies

**FIGURE 1** Flow chart of study identification.



(Mosher et al., 2019; Zhang et al., 2021) focused on mixed cancer types, and five targeted a single type of cancer, including ovarian (Rost et al., 2012), breast (Mosher et al., 2018), lung (Li et al., 2022; Mosher et al., 2019), pancreatic (Pan et al., 2020) and gastrointestinal (Mosher et al., 2022) cancers. Participants' mean age varied from 40.2 to 62.6 years.

### 3.3 | Intervention characteristics

All studies included the six core processes of Acceptance and Commitment Therapy. The interventions were performed by psychologists (Mosher et al., 2022; Rost et al., 2012), nurses (Pan et al., 2020; Zhang et al., 2021), a PhD candidate in nursing (Li et al., 2022) and social workers with experience in using Acceptance and Commitment Therapy (Mosher et al., 2018, 2019; Serfaty et al., 2019). The interventions lasted between 6 weeks and 4 months, with the most common length being 6 or 8 weeks, delivering 4–12 sessions in total. The sessions were often delivered once a week, and the duration of each session varied from 50 to 90 min. The delivery formats included face-to-face (Pan et al., 2020; Rost et al., 2012; Serfaty et al., 2019; Zhang et al., 2021), telephone-based (Mosher et al., 2018, 2019, 2022) and face-to-face combined with video conferencing (Li et al., 2022). Seven studies (Li et al., 2022; Mosher et al., 2018, 2019, 2022; Pan et al., 2020; Rost et al., 2012; Serfaty et al., 2019) assessed participants' adherence, which ranged from 62.0% to 87.5%. Six studies (Li et al., 2022; Mosher et al., 2018,

2019, 2022; Pan et al., 2020; Rost et al., 2012) assessed intervention fidelity. Three of these six studies (Mosher et al., 2018, 2019, 2022) reported a fidelity rate ranging from 96% to 99%, and Li et al. (2022) reported the average fidelity rating scores per session, ranging from 5.90 to 6.60 (rating scale: 1–7). Table 2 reports the complete intervention components of each study, based on the TIDieR checklist.

### 3.4 | Quality of included studies

Figures 2 and 3 depict the methodological quality of individual studies and the risk of bias summary respectively. All studies were rated as having a 'low risk' of random sequence generation bias, and four studies (Li et al., 2022; Mosher et al., 2022; Pan et al., 2020; Serfaty et al., 2019) adequately described the allocation concealment methods. Studies by Serfaty et al. (2019) and Zhang et al. (2021) were rated as exhibiting 'high risk' and 'unclear risk' of bias arising from similar baseline characteristics. All studies were judged to have a 'low risk' of bias for similar baseline outcome measurements, incomplete outcome data and selective outcome reporting. It was unclear whether knowledge of allocation was adequately prevented in two studies (Pan et al., 2020; Rost et al., 2012). Moreover, Li et al. (2022) and Rost et al. (2012) were rated as having a 'low risk' of bias arising from protection against contamination, while the bias for the other six studies was uncertain. No study was retracted as per the Retraction Watch Database. Five studies (Li et al., 2022; Mosher et al., 2018, 2019, 2022; Serfaty et al., 2019) were prospectively

TABLE 1 Characteristics of included studies

Author, Year	Country	Population	Sample size (E/C)	Mean age (SD)	Experimental group	Control group	Time-point of measures	Outcomes (measures)
Rost et al. (2012)	United States	Advanced ovarian cancer	47 (25/22)	56 (-)	ACT	Usual care	Baseline, end of the 4th, 8th and 12th sessions	Anxiety: BAI Depression: BDI-II Psychological distress: POMS Quality of life: FACT-G
Mosher et al. (2018)	United States	Metastatic breast cancer	47 (23/24)	56.23 (11.72)	ACT	Education/ Support care	Baseline, 8-week, and 12-week post-baseline	Anxiety: PROMIS Depression: PROMIS Pain: PROMIS Fatigue: FSI-I
Mosher et al. (2019)	United States	Advanced lung cancer	50 (25/25)	62.60 (12.13)	ACT	Education/ Support care	Baseline, 2-week, and 6-week post-intervention	Anxiety: PROMIS Depression: PROMIS Psychological distress: DT Pain: PROMIS Fatigue: FSI-I
Serfaty et al. (2019)	United Kingdom	Advanced cancer	42 (20/22)	62.0 (11.5)	ACT	Talking control	Baseline, 1.5-month, 3-month, 4.5-month and 6-month post-intervention	Psychological flexibility: AAQ-II Psychological distress: K10 Quality of life: EQ-5D-5L
Pan et al. (2020)	China	Advanced pancreatic cancer	122 (61/61)	40.23 (11.67)	ACT	Usual care	Baseline, 8-week, and 20-week post-intervention	Anxiety: DASS-21 Depression: DASS-21
Zhang et al. (2021)	China	Advanced cancer	100 (50/50)	49.07 (2.13)	ACT	Usual care	Baseline and post-intervention	Psychological flexibility: AAQ-II Anxiety: SAS Depression: SDS
Li et al. (2022)	China	Advanced lung cancer	40 (20/20)	56.90 (7.05)	ACT	Usual care	Baseline and 1-week post-intervention	Anxiety: GAD-7 Depression: PHQ-9 Fatigue: FSI-I Quality of life: FACT-L
Mosher et al. (2022)	United States	Advanced gastrointestinal cancer	40 (20/20)	58.55 (13.00)	ACT	Education/ Support care	Baseline, 2-week, and 3-month post-intervention	Psychological flexibility: AAQ-II Fatigue: FSI-I Quality of life: MQOL-R

Abbreviations: E, experimental; C, control; SD, Standard deviation; ACT, Acceptance and Commitment Therapy; BAI, Beck Anxiety Inventory; BDI-II, Beck Depression Inventory-II; POMS, Profile of Mood States; FACT-G, Functional Assessment of Cancer Therapy-General; PROMIS, Patient-Reported Outcomes Measurement Information System; FSI-I, Fatigue Symptom Inventory-Interference; DT, Distress thermometer; AAQ-II, Acceptance and Action Questionnaire II; K10, Kessler Psychological Distress Scale; EQ-5D-5L, European Quality of Life-5 Dimension-5 Level; DASS-21, Depression Anxiety Stress Scales; SAS, Self-Rating Anxiety Scale; SDS, Self-Rating Depression Scale; GAD-7, Generalized Anxiety Disorder Scale; PHQ-9, Patient Health Questionnaire; FACT-L, Functional Assessment of Cancer Therapy-Lung; MQOL-R, McGill Quality of Life Questionnaire-Revised.

TABLE 2 Characteristics of included interventions according to TIDieR checklist

Author, Year	Brief name	Why	What (materials and procedures)	Who provided, how and where	When and how much	Tailoring and modification	How well	
							Adherence <sup>a</sup>	Fidelity <sup>b</sup>
Rost et al. (2012)	ACT	Yes	Incorporating key psychological processes typically targeted by ACT, such as mindfulness, acceptance and values. Metaphors and therapeutic strategies, such as creative hopelessness and control as the problem, were included to set up the treatment rationale.	<ul style="list-style-type: none"> <li>A psychologist</li> <li>Face-to-face; Individually</li> <li>Facilitator's office, chemotherapy treatment room, inpatient ward and physician exam rooms</li> </ul>	<ul style="list-style-type: none"> <li>Length of intervention: 4 months</li> <li>Number of sessions: 12</li> <li>Duration per session 60min</li> </ul>	<ul style="list-style-type: none"> <li>NR</li> <li>NR</li> </ul>	<ul style="list-style-type: none"> <li>Strategies: minimize travel and time requirements by scheduling appointments in line with clinic visits and/or chemotherapy treatments; patients of ten completed the questionnaires when waiting for their appointment.</li> <li>Adherence rate: 68.0% (32/47)</li> </ul>	<ul style="list-style-type: none"> <li>Assessment and strategies: A checklist for per session was completed by the therapist to ensure compliance with the protocols. Any deviation was noted and revised at the next session with the patient. Additional supervision was provided by the second author.</li> <li>Fidelity rate: NR</li> </ul>
Mosher et al. (2018)	ACT	Yes	<p>Session 1: discuss patient coping strategies for managing symptoms and distress; Session 2: practice mindfulness exercise; Session 3: practice cognitive defusion; Session 4: practice acceptance; Session 5: identify personal values; Session 6: plan and practice values-consistent actions.</p>	<ul style="list-style-type: none"> <li>A master's level social worker with experience using ACT</li> <li>Telephone; Individually and dyadic</li> <li>N/A</li> </ul>	<ul style="list-style-type: none"> <li>Length of intervention: 6 weeks</li> <li>Number of sessions: 6</li> <li>Duration per session 50–60 min</li> </ul>	<ul style="list-style-type: none"> <li>Patients learned the same skills, while in-session and home practices were tailored to their cancer-related experiences and other challenges.</li> <li>NR</li> </ul>	<ul style="list-style-type: none"> <li>Strategies: NR</li> <li>Adherence rate: 83.0% (39/47)</li> </ul>	<ul style="list-style-type: none"> <li>Assessment and strategies: The therapists were trained with didactics and role plays of treatment sessions in manuals and supervised weekly by two psychologists. One of the psychologists randomly selected 18% of audio recordings to review for adherence to the manuals based on a fidelity checklist. Both psychologists provided feedback on treatment adherence and quality.</li> <li>Fidelity rate: 99%</li> </ul>

(Continues)

TABLE 2 (Continued)

Author, Year	Brief name	Why	What (materials and procedures)	Who provided, how and where	When and how much		Tailoring and modification	How well	
					Length of intervention:	Number of sessions:		Adherence <sup>a</sup>	Fidelity <sup>b</sup>
Mosher et al. (2019)	ACT	Yes	Session 1: discuss current coping strategies for managing symptoms and distress; Session 2: practice mindfulness exercise; Session 3: practice cognitive defusion; Session 4: practice self as context; Session 5: identify core values; Session 6: practice value-based actions.	<ul style="list-style-type: none"> <li>A master's level social worker with experience using ACT</li> <li>Telephone; Individually</li> <li>N/A</li> </ul>	<ul style="list-style-type: none"> <li>Length of intervention: 6 weeks</li> <li>Number of sessions: 6</li> <li>Duration per session 50 min</li> </ul>	<ul style="list-style-type: none"> <li>Participants learned the same skills, in-session and home practices were tailored to their cancer-related or care-related experiences and other challenges.</li> <li>NR</li> </ul>	<ul style="list-style-type: none"> <li>Strategies: NR</li> <li>Adherence rate: 76.0% (38/50)</li> </ul>	<ul style="list-style-type: none"> <li>Assessment and strategies: The therapists were trained with didactics and role plays of treatment sessions in manuals and supervised weekly by two psychologists. One of the psychologists randomly selected 18% of audio recordings to review for adherence to the manuals based on a fidelity checklist. Both psychologists provided feedback on treatment adherence and quality.</li> <li>Fidelity rate: 96%</li> </ul>	
Serfaty et al. (2019)	ACT	Yes	The first four sessions involved helping the participant understand the concept and the core elements of ACT. The last four sessions aimed at helping patients practice them.	<ul style="list-style-type: none"> <li>A therapist with at least 2 years of experience using ACT</li> <li>Face-to-face; Individually</li> <li>Hospice day-therapy unit, patients' home or therapist's clinic</li> </ul>	<ul style="list-style-type: none"> <li>Length of intervention: 3 months</li> <li>Number of sessions: 8</li> <li>Duration per session: 60 min</li> </ul>	<ul style="list-style-type: none"> <li>NR</li> <li>NR</li> </ul>	<ul style="list-style-type: none"> <li>Strategies: provide 3 months to complete eight sessions to allow for missed sessions due to reasons such as illness.</li> <li>Adherence rate: 62.0% (26/42)</li> </ul>	<ul style="list-style-type: none"> <li>Assessment and strategies: NR</li> <li>Fidelity rate: NR</li> </ul>	

TABLE 2 (Continued)

Author, Year	Brief name	Why	What (materials and procedures)	Who provided, how and where	When and how much	Tailoring and modification	How well	
							Adherence <sup>a</sup>	Fidelity <sup>b</sup>
Pan et al. (2020)	ACT	Yes	<p>Session 1: distinguish between reality and spiritual experience;</p> <p>Session 2: focus on finding insights into the validity of thought and action; Session 3: focus on the present moment rather than mental distress;</p> <p>Session 4: oral aikido exercises to accept unwanted feelings; Session 5: learn self-compassion and self-respect;</p> <p>Session 6: provide guidance on how to exercise self-control to prevent future conflicts.</p>	<ul style="list-style-type: none"> <li>Nurses trained by an experienced psychologist</li> <li>Face-to-face; Individually</li> <li>Inpatient ward</li> </ul>	<ul style="list-style-type: none"> <li>Length of intervention: 8 weeks</li> <li>Number of sessions: 6</li> <li>Duration per session: 90 min</li> </ul>	<ul style="list-style-type: none"> <li>NR</li> <li>NR</li> </ul>	<ul style="list-style-type: none"> <li>Strategies: NR</li> <li>Adherence rate: 65.0% (79/122)</li> </ul>	<ul style="list-style-type: none"> <li>Assessment and strategies: Each session was observed and evaluated by a psychologist to assess the investigator's adherence to the treatment protocol.</li> <li>Fidelity rate: NR</li> </ul>
Zhang et al. (2021)	ACT	Yes	<p>Help patients master six core skills of ACT, respectively, including acceptance, cognitive defusion, being present, self as context, values and committed actions.</p>	<ul style="list-style-type: none"> <li>A primary nurse and a nurse with psychological consultant qualification</li> <li>Face-to-face; Individually</li> <li>Inpatient ward</li> </ul>	<ul style="list-style-type: none"> <li>Length of intervention: NR</li> <li>Number of sessions: 6</li> <li>Duration per session: NR</li> </ul>	<ul style="list-style-type: none"> <li>NR</li> <li>NR</li> </ul>	<ul style="list-style-type: none"> <li>Strategies: NR</li> <li>Adherence rate: NR</li> </ul>	<ul style="list-style-type: none"> <li>Assessment and strategies: NR</li> <li>Fidelity rate: NR</li> </ul>

(Continues)



TABLE 2 (Continued)

Author, Year	Brief name	Why	What (materials and procedures)	Who provided, how and where	When and how much	Tailoring and modification	How well	
							Adherence <sup>a</sup>	Fidelity <sup>b</sup>
Li et al. (2022)	ACT	Yes	<p>Session 1: review experiences on the struggles with cancer-related fatigue and realize the consequence of controlling fatigue and cancer experiences, thus introducing acceptance as an alternative;</p> <p>Session 2: separate thoughts or feelings related to the experience of fatigue and lung cancer with literal truth and view them objectively and transcendently;</p> <p>Session 3: clarify personal values and present the smallest value-guided goal; Session 4: emphasize the ongoing value-based goals and committed to actions for a meaningful cancer life.</p>	<ul style="list-style-type: none"> <li>A PhD candidate in nursing with experience in oncological psychological care</li> <li>Face-to-face and video conferencing; Individually</li> <li>An independent meeting room of the respiratory department</li> </ul>	<ul style="list-style-type: none"> <li>Length of intervention: 4 weeks</li> <li>Number of sessions: 4</li> <li>Duration per session: 60–90 min</li> </ul>	<ul style="list-style-type: none"> <li>NR</li> <li>NR</li> </ul>	<p><b>Adherence<sup>a</sup></b></p> <ul style="list-style-type: none"> <li>Strategies: the participants received a reminder of appointments via WeChat in advance.</li> <li>Adherence rate: 87.5 (35/40)</li> </ul>	<p><b>Fidelity<sup>b</sup></b></p> <ul style="list-style-type: none"> <li>Assessment and Strategies: The interventionist received ACT trainings for 15 days and online group supervision every 2 weeks. The interventionist conducted self-evaluation with a day-to-day diary and a 60-item ACT fidelity checklist to assess whether each point occurred in the session recording.</li> <li>Semi-monthly meeting with supervisor was held to ensure adherence to the protocol. Randomly selected 20% of the intervention audiotapes were reviewed by ACT practitioners to provide feedback to adjust the interventionist's skills.</li> <li>Fidelity: 5.90 to 6.60 (rating scale: 1–7)</li> </ul>

TABLE 2 (Continued)

Author, Year	Brief name	Why	What (materials and procedures)	Who provided, how and where	When and how much	Tailoring and modification	How well	
							Adherence <sup>a</sup>	Fidelity <sup>b</sup>
Mosher et al. (2022)	ACT	Yes	During the first session, the therapist asked about the patients' background and strategies for coping with fatigue and introduced the practice of mindfulness. During the next six sessions, patients practiced mindfulness, learned adaptive coping skills, clarified their values and set SMART goals (specific, measurable, achievable, relevant and time-bound) based on their values.	<ul style="list-style-type: none"> <li>A master's level mental health clinician and a doctoral level psychologist with experience using ACT</li> <li>Telephone; Individually and dyadic</li> <li>N/A</li> </ul>	<ul style="list-style-type: none"> <li>Length of intervention: 6 weeks</li> <li>Number of sessions: 6</li> <li>Duration per session: 50 min</li> </ul>	<ul style="list-style-type: none"> <li>The ACT was adapted to the dyad by including joint mindfulness practices and leveraging the relationship during discussions.</li> <li>NR</li> </ul>	<ul style="list-style-type: none"> <li>Strategies: NR</li> <li>Adherence rate: 80.0% (32/40)</li> </ul>	<ul style="list-style-type: none"> <li>Assessment and Strategies: The therapists were trained and supervised weekly by two psychologists. A master's level clinician, two psychologists and two doctoral students in clinical psychology randomly reviewed 40% of recordings for adherence to the manuals using checklists. Psychologists provided feedback on treatment fidelity and quality, and role plays were conducted to improve fidelity.</li> <li>Fidelity rate: 98%</li> </ul>

Abbreviations: TIDieR, Template for Intervention Description and Replication; ACT, Acceptance and Commitment Therapy; NR, Not reported; N/A, Not applicable.

<sup>a</sup>Adherence rate refers to the number of patients attending all sessions in ACT and control groups/total number of patients completing the baseline assessment.

<sup>b</sup>Fidelity rate refers to the number of required topics and exercises covered in each session/total number of fidelity criteria.

	Random sequence generation	Allocation concealment	Baseline outcome measurements similar	Baseline characteristics similar	Incomplete outcome data	Knowledge of the allocated interventions adequately prevented during the study	Protection against contamination	Selective outcome reporting	Other risks of bias
Li et al. 2022	+	+	+	+	+	+	+	+	+
Mosher et al. 2018	+	?	+	+	+	+	?	+	+
Mosher et al. 2019	+	?	+	+	+	+	?	+	+
Mosher et al. 2022	+	+	+	+	+	+	?	+	+
Pan et al. 2020	+	+	+	+	+	?	?	+	+
Rost et al. 2012	+	?	+	+	+	?	+	+	+
Serfaty et al. 2019	+	+	+	-	+	+	?	+	+
Zhang et al. 2021	+	?	+	?	+	+	?	+	+

FIGURE 2 Risk of bias summary for each study.

registered at Clinical [Trials.gov](https://www.clinicaltrials.gov), whereas the other three studies were unregistered. Although prospective trial registration is a transparent mechanism to identify publication or reporting bias, it does not prevent low-quality trials, data manipulation or fraud, because a change or deletion of registration information could be reasonable and important problems also existed in the quality of information in trial registries (Tovey et al., 2015). Statistical checks were not performed

as they cannot detect fraudulent trials (Tovey et al., 2015), and there were no reasonable grounds for suspicion about the included studies (Roberts et al., 2015). In addition to database searches, Google Scholar and Clinical [Trials.gov](https://www.clinicaltrials.gov) registry websites were searched to retrieve unpublished data. Therefore, we conclude that no specific problems of research integrity were detected in the included studies and incorporated these studies into the meta-analysis.

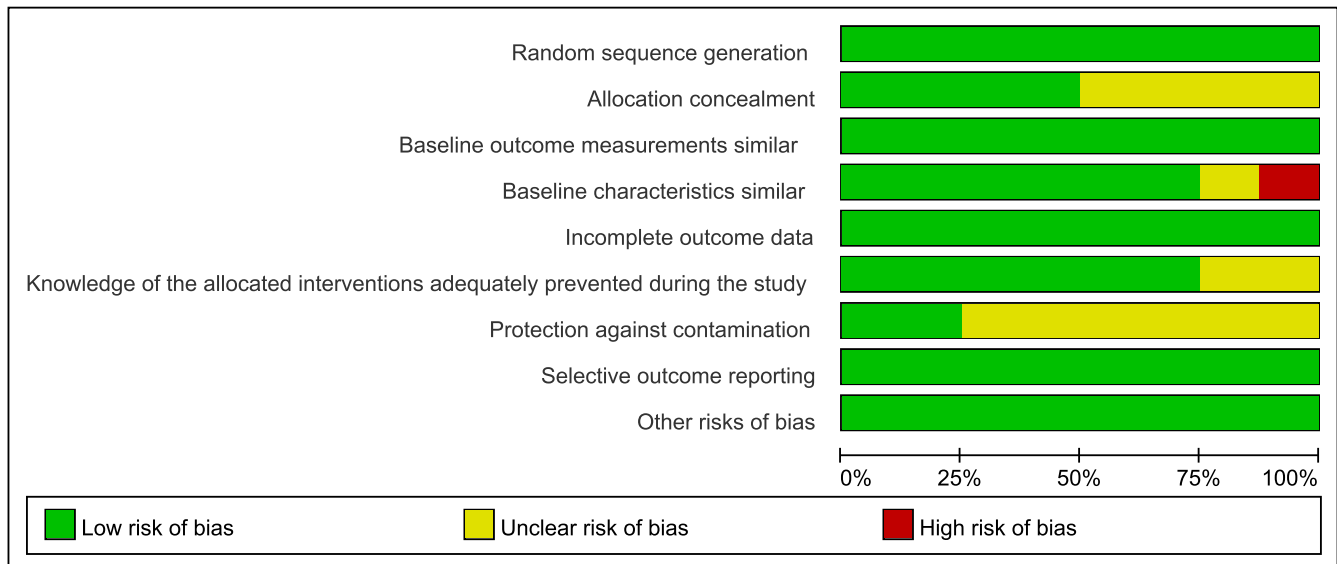


FIGURE 3 Risk of bias graph for all included studies.

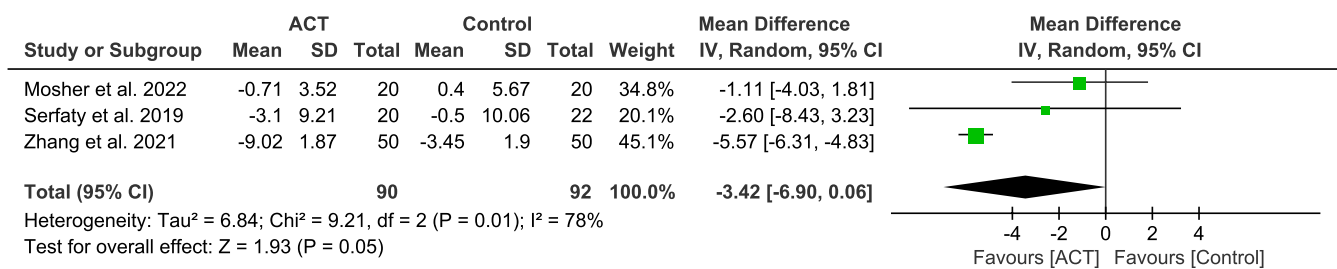


FIGURE 4 Forest plot of the effect of Acceptance and Commitment Therapy on psychological flexibility of people with advanced cancer.

### 3.5 | Effects of acceptance and commitment therapy

#### 3.5.1 | Primary outcomes

##### Psychological flexibility

Three studies (Mosher et al., 2022; Serfaty et al., 2019; Zhang et al., 2021), involving 182 participants, measured psychological flexibility. The meta-analysis using the random-effects model suggested that Acceptance and Commitment Therapy had a non-significant effect on psychological flexibility among people with advanced cancer (MD = -3.42, 95% CI: -6.90 to 0.06,  $p = .05$ ) (Figure 4). High heterogeneity was noted across these studies ( $I^2 = 78%$ ,  $p = .01$ ).

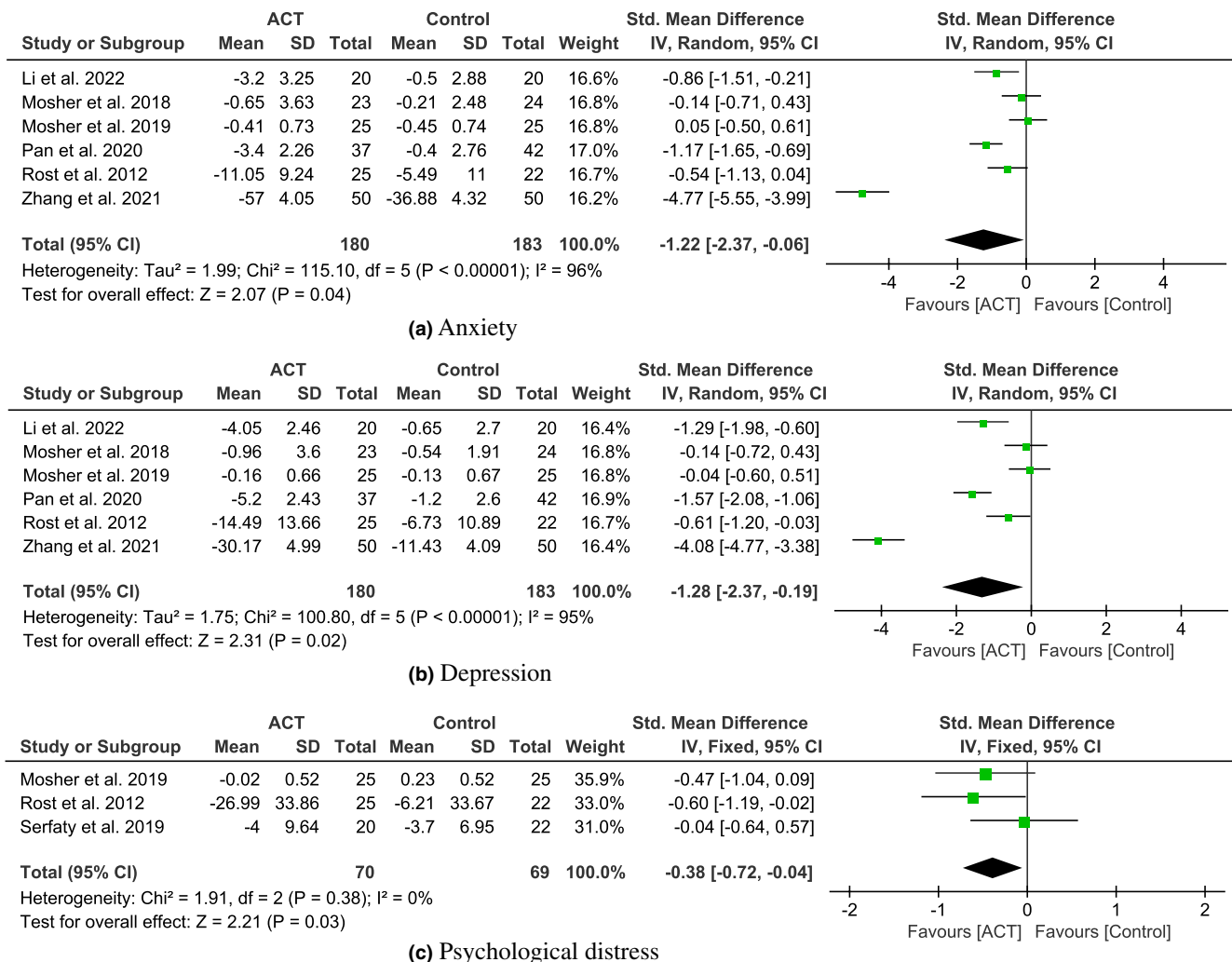
##### Psychological symptoms

Six studies (Li et al., 2022; Mosher et al., 2018, 2019; Pan et al., 2020; Rost et al., 2012; Zhang et al., 2021), involving 363 participants, measured anxiety. The meta-analysis showed a significant difference in anxiety between the Acceptance and Commitment Therapy and control groups (SMD = -1.22, 95% CI: -2.37 to -0.06,  $p = .04$ ) (Figure 5a). High heterogeneity was noted among these studies

( $I^2 = 96%$ ,  $p < .001$ ). Subgroup analysis based on possible grouping factors suggested that heterogeneity remained high in the subgroups (Appendix S2). A 'low' GRADE rating was assigned to the alleviation of anxiety using Acceptance and Commitment Therapy due to inconsistency (Table 3).

Six studies (Li et al., 2022; Mosher et al., 2018, 2019; Pan et al., 2020; Rost et al., 2012; Zhang et al., 2021), involving 363 participants, measured depression. The meta-analysis showed a significant difference in depression between the Acceptance and Commitment Therapy and control groups (SMD = -1.28, 95% CI: -2.37 to -0.19,  $p = .02$ ) (Figure 5b). High heterogeneity was noted among these studies ( $I^2 = 95%$ ,  $p < .001$ ). Subgroup analysis based on possible grouping factors suggested that heterogeneity remained high in the subgroups (Appendix S2). A 'low' GRADE rating was assigned to the alleviation of depression using Acceptance and Commitment Therapy due to inconsistency (Table 3).

Three studies (Mosher et al., 2019; Rost et al., 2012; Serfaty et al., 2019), involving 139 participants, measured psychological distress. The meta-analysis suggested that Acceptance and Commitment Therapy significantly alleviated psychological distress in people with advanced cancer (SMD = -0.38, 95% CI: -0.72 to



**FIGURE 5** Forest plot of the effects of Acceptance and Commitment Therapy on anxiety, depression and psychological distress of people with advanced cancer.

-0.04,  $p = .03$ ) (Figure 5c). Low heterogeneity was observed across these studies ( $I^2 = 0\%$ ,  $p = .38$ ). A 'moderate' GRADE rating was assigned to the alleviation of psychological distress using Acceptance and Commitment Therapy due to imprecision (Table 3).

### 3.5.2 | Secondary outcomes

#### Physical symptoms

Two studies (Mosher et al., 2018, 2019), involving 97 participants, measured pain. Both studies showed non-significant differences between the Acceptance and Commitment Therapy and control groups. Meta-analysis was not conducted considering the limited number of RCTs.

Four studies (Li et al., 2022; Mosher et al., 2018, 2019, 2022), involving 177 participants, measured fatigue. The meta-analysis showed that Acceptance and Commitment Therapy significantly alleviated fatigue in people with advanced cancer (MD = -0.69, 95% CI: -1.35 to -0.04,  $p = .04$ ). Low heterogeneity was observed across these studies ( $I^2 = 11\%$ ,  $p = .34$ ) (Figure 6). A 'moderate' GRADE

rating was assigned to the alleviation of fatigue using Acceptance and Commitment Therapy due to imprecision (Table 3).

#### QoL

Four studies (Li et al., 2022; Mosher et al., 2022; Rost et al., 2012; Serfaty et al., 2019), involving 169 participants, measured QoL. The meta-analysis suggested that Acceptance and Commitment Therapy significantly improved QoL of people with advanced cancer (SMD = 0.74, 95% CI: 0.43 to 1.05,  $p < .001$ ) (Figure 7). Low heterogeneity was found across these studies ( $I^2 = 0\%$ ,  $p = .91$ ). A 'moderate' GRADE rating was assigned to the improvement of QoL using Acceptance and Commitment Therapy due to imprecision (Table 3).

### 3.6 | Sensitivity analysis

This review included two studies (Pan et al., 2020; Zhang et al., 2021) that were not available in English; these assessed three of the seven outcomes, including psychological flexibility, anxiety and depression. Sensitivity analysis was conducted by omitting these two

TABLE 3 Summary of quality of evidence (GRADE)

Outcomes	Effect estimate MD/ SMD (95% CI)	No. of studies	No. of participants		Certainty of evidence
			ACT	Control	
Anxiety	-1.22 (-2.37, -0.06)	6 RCTs	180	183	⊕⊕○○ (b↓↓) Low
Depression	-1.28 (-2.37, -0.19)	6 RCTs	180	183	⊕⊕○○ (b↓↓) Low
Psychological distress	-0.38 (-0.72, -0.04)	3 RCTs	70	69	⊕⊕⊕⊕ (c↓) Moderate
Fatigue	-0.69 (-1.35, -0.04)	4 RCTs	88	89	⊕⊕⊕⊕ (c↓) Moderate
Quality of life	0.74 (0.43, 1.05)	4 RCTs	85	84	⊕⊕⊕⊕ (c↓) Moderate

Note: Reasons for certainty downgrading. (a) Risk of bias in design. (b) Inconsistency. (c) Imprecision. (d) Indirectness. (e) Publication bias.

Abbreviations: MD, mean difference; SMD, standardized mean difference; CI, confidence interval; RCTs, randomized controlled trials; ACT, Acceptance and Commitment Therapy; GRADE, Grading of Recommendations Assessment, Development and Evaluation.

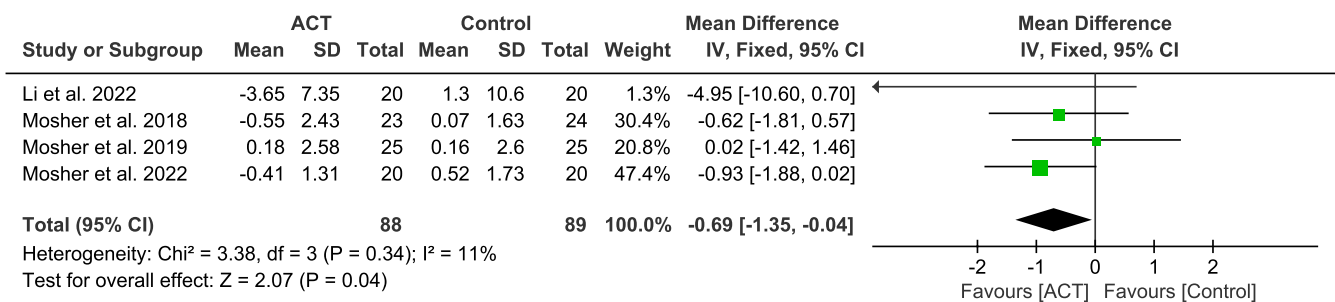


FIGURE 6 Forest plot of the effect of Acceptance and Commitment Therapy on fatigue of people with advanced cancer.

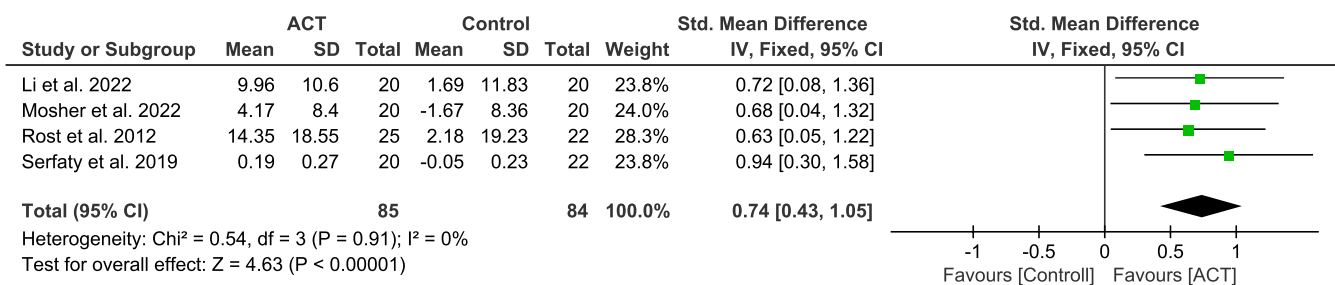


FIGURE 7 Forest plot of the effect of Acceptance and Commitment Therapy on quality of life (QoL) of people with advanced cancer.

studies, and the results for psychological flexibility and anxiety did not change significantly. However, the results for depression were altered, suggesting that the results were relatively unstable. Appendix S3 reports the detailed results of the sensitivity analysis.

#### 4 | DISCUSSION

This review of eight RCTs found that Acceptance and Commitment Therapy had significant effects on anxiety, depression,

psychological distress, fatigue and QoL but non-significant effects on psychological flexibility and pain in people with advanced cancer. Effective improvement in fatigue was observed in this meta-analysis. This was a new finding, as it was inconsistent with a previous review finding (Li, Wong, et al., 2021) that Acceptance and Commitment Therapy failed to alleviate fatigue in people with advanced cancer. Furthermore, our review provides new evidence on the effect of the intervention on psychological flexibility. Compared with the previous review (Li, Wong, et al., 2021), the current meta-analysis provided stronger evidence by including four



more RCTs (Li et al., 2022; Mosher et al., 2022; Pan et al., 2020; Zhang et al., 2021).

Psychological flexibility, as the general goal of Acceptance and Commitment Therapy, is the direct causal factor of this therapy (Li, Wu, et al., 2021). Contrary to our expectations, the results showed that Acceptance and Commitment Therapy had no significant effect on psychological flexibility. This finding contradicts a previous meta-analysis (Zhao et al., 2021) that involved 10 studies with 883 people with cancer and found a moderate effect of Acceptance and Commitment Therapy on psychological flexibility. Among the three studies included in our meta-analysis, Zhang et al. (2021) (involving 100 participants) found that psychological flexibility was greatly improved in the intervention group, while the remaining two studies by Mosher et al. (2022) and Serfaty et al. (2019) (involving 40 participants) showed weak and non-significant improvement in psychological flexibility. In other words, small sample sizes may have limited the measure's sensitivity to change. Considering the limited number of studies analysing this outcome and the high heterogeneity across the three studies, we cannot draw definite conclusions. Thus, further studies with larger sample sizes are warranted to determine the effectiveness of Acceptance and Commitment Therapy on the psychological flexibility of people with advanced cancer.

Negative emotions are common in patients approaching the end of life (Lee & Ramaswamy, 2020). This review indicated that Acceptance and Commitment Therapy had significant effects on anxiety, depression and psychological distress in people with advanced cancer. These results are supported by multiple meta-analyses targeting different populations (Bai et al., 2020; Hughes et al., 2017; Zhao et al., 2021). This is probably because Acceptance and Commitment Therapy increases physical activities and social interactions among people with advanced cancer, making them focus on the present life instead of losing themselves in negative feelings (Zhao et al., 2021). However, there was high heterogeneity across the studies on anxiety and depression, which may be due to the diversity of outcome measurement tools, therapists and intervention delivery formats. Therefore, these results should be cautiously interpreted. Future studies need to carefully consider the intervener and the format and adopt validated and preferably consistent instruments to measure the same outcomes. It is also necessary to investigate whether the aforementioned factors affect the magnitude of the intervention effect.

With the deterioration of the disease, people with advanced cancer often suffer from physical distress, commonly manifesting as pain, fatigue and other treatment-related symptoms (Henson et al., 2020). Our results showed that Acceptance and Commitment Therapy significantly alleviated fatigue in people with advanced cancer. This finding coincides with that of a systematic review involving people with fibromyalgia (Hegarty et al., 2020) and a trial involving people with chronic fatigue (Jacobsen et al., 2017). However, this finding contradicts a previous review finding (Li, Wong, et al., 2021). Differences in findings could be due to the narrative nature of the previous review and the additional inclusion in this meta-analysis of two RCTs (Li et al., 2022; Mosher et al., 2022) measuring fatigue,

compared with the previous. Only two studies (Mosher et al., 2018, 2019) measured pain in people with advanced cancer, and the results were not statistically significant; meanwhile, inconsistent conclusions were found in previous reviews of people with chronic pain (Du et al., 2021b; Hughes et al., 2017). As we included limited studies with small samples, data synthesis was not conducted; thus, the findings should be interpreted with caution. Future studies should include pain measurements to better clarify the effectiveness of Acceptance and Commitment Therapy for pain.

A good QoL for people with advanced diseases is the ultimate goal of palliative care (Chang et al., 2021). Our results revealed that Acceptance and Commitment Therapy remarkably improved QoL of people with advanced cancer, which coincides with the results of a meta-analysis involving people with cancer (Zhao et al., 2021). Notably, each of the four studies (Li et al., 2022; Mosher et al., 2022; Rost et al., 2012; Serfaty et al., 2019) included in this meta-analysis consistently presented significant improvement of QoL, and low heterogeneity was found across these studies. This is possibly because people with advanced cancer who receive Acceptance and Commitment Therapy may attempt to normalize their distressing thoughts and live in the moment. More importantly, they may re-examine their lives based on an overall perspective, identify personal values and take activities to improve their conditions and consequently their QoL (Zhao et al., 2021).

The delivery format, intervener and intensity of Acceptance and Commitment Therapy were diverse. Due to the limited number of studies, we failed to draw definite conclusions about the optimal intervention components. It is worthwhile to discuss intervention characteristics to inform future research and practice. In the included studies, approximately 75% of the interventions did not exceed six sessions. This should be considered especially for people with advanced cancer, as they have a limited life expectancy. A further consideration is that shorter interventions with fewer sessions may facilitate participants to remember and consolidate what they have learned. Face-to-face delivery was the most adopted format in clinical settings. Three of the included studies (Mosher et al., 2018, 2019, 2022) attempted a telephone-based format and showed a higher adherence rate (76%–83%) than face-to-face format (62%–68%), possibly because telephone-based delivery is not affected by limitations of time and distance. However, face-to-face interventions in this review tended to be effective in alleviating psychological symptoms, whereas telephone-based interventions were not. Telephone-based formats may hinder interveners from understanding participants accurately and provide targeted programmes, adversely affecting patients' access to knowledge and skills. Thus, further studies are needed to explore interventions with different delivery formats and dosages to determine the optimal Acceptance and Commitment Therapy model.

With regard to intervention providers, two of the included studies (Pan et al., 2020; Zhang et al., 2021) incorporated nurses. A qualitative study from the nurses' perspective found that Acceptance and Commitment Therapy was useful for nurses in helping patients cope with struggles, enriching typical ward duties and dealing with

personal stress (Tyrberg et al., 2017). Nurses are the main force in caring for people with advanced cancer and can better understand their distress, as nurses have more access to them than other health-care professionals. They may be excellent candidates for implementing interventions. Therefore, future research and practice should consider more involvement of nurses.

#### 4.1 | Limitations

This review had some limitations. First, we only included eligible studies in English and Chinese, thereby omitting potential studies in other languages. Second, there were inconsistencies and imprecision across the studies, which caused low or moderate certainty of evidence. Third, the same parameters were measured using multiple instruments, which may cause measurement bias and effect deviation. Fourth, different control conditions may have mitigated the intervention effects. Finally, the relatively small sample sizes for most of the included RCTs could affect the accuracy of the results due to a lack of sufficient statistical power to detect the intervention effects.

#### 4.2 | Implications for future research and practice

This meta-analysis showed the application value of Acceptance and Commitment Therapy for clinical decision-making. Given the limited number of included RCTs, more high-quality RCTs with powered sample sizes are required. Future RCTs should consider using the TIDieR checklist to ensure sufficient description of intervention characteristics, along with the CONSORT checklist, to optimize the reporting quality of RCTs. Validated and consistent instruments are recommended when measuring the effectiveness of the same outcome, and appropriate controls should be chosen to improve the internal validity of the results. Furthermore, future studies are warranted to explore an optimal intervention design. Conducting more RCTs with different intervention components is a desirable way.

Palliative care nursing emphasizes the provision of holistic care. This study showed significant improvements attributable to Acceptance and Commitment Therapy in psychological symptoms among people with advanced cancer, along with fatigue and QoL. These findings can inform clinical nursing interventions. Nurses play a critical role in providing holistic care to people with advanced cancer. Compared with other healthcare professionals, nurses usually spend most time with patients and can better identify their unmet psychological needs, which may contribute to building a therapeutic alliance. Therefore, training for nurses is necessary to help them provide evidence-based Acceptance and Commitment Therapy to support people with advanced cancer. Given patients' limited life expectancies and the time limitations of nurses, concise and targeted intervention programmes may be feasibly integrated in daily nursing practice. This integration will allow nurses to effectively manage the psychological and physical symptoms of people with advanced cancer and promote their QoL and the quality of holistic care.

## 5 | CONCLUSIONS

Acceptance and Commitment Therapy is effective in improving anxiety, depression, psychological distress, fatigue and QoL in people with advanced cancer. This review highlights the need for more rigorously designed RCTs to ascertain these findings, and for further research to determine the optimal intervention model to maximize the intervention effect. Nurses play a pivotal role in caring for people with advanced cancer and are more aware of the symptom burdens experienced by patients; thus, they are better placed to implement evidence-based Acceptance and Commitment Therapy to improve patients' well-being and promote the efficiency of palliative care nursing. Healthcare policymakers should support nurses in integrating Acceptance and Commitment Therapy in daily nursing practice, which presents an opportunity to extend this intervention to more people with advanced cancer.

#### AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE\*): (1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content.

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Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# Registered nurse–patient communication research: An integrative review for future directions in nursing research

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## Abstract

**Aim:** To explore communication research in nursing by investigating the theoretical approaches, methods, content and perspectives in research on real-time registered nurse (RN)–patient communication.

**Design:** An integrative review of real-time communication between RNs and patients.

**Data Sources:** Empirical research papers were searched in PubMed, CINAHL Plus and Medline. The results from the database searches were supplemented with results from manual searches in reference lists.

**Review Methods:** A total of 1369 articles published between January 1996 and December 2021 were screened, which resulted in the inclusion of 52 articles.

**Results:** The integration of various theories, such as nursing or communication theories, is weak in most of the included studies. RN–patient communication appears to influence relationship building. Even when nurses strive to meet patients' needs, they often focus primarily on nursing routines and physical care. The topic of the communication varies depending on the situation and different communication styles are used. When a patient-centred approach is adopted, the interpersonal communication becomes quite symmetrical, with complementary roles of nurses and patients. Within a more asymmetric communication context, nurses dominate communication, choose topics and function as instructors. How the nurses communicated subsequently influenced the patients' communication styles and strategies.

**Conclusion:** Communication is multifaceted, contains different strategies and is important for building trust and facilitating patient-centred care. The importance of RNs' communication for interaction and relationship-building seems to be well established within research, but few studies focused on patients' communication with RNs.

**Impact:** This integrative review gives an overview of the width and depth of observational studies on RN–patient communication research. The variety of studies indicates that this area is a less well-grounded field of research. Future research is warranted to support nurses in their communication, especially regarding the exploration of patients' communication and desired communication skills in nurse–patient interactions.

**Patient or Public Contribution:** No patient or public contribution was included in this integrative review.

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## KEYWORDS

communication, integrative review, interaction, patient, registered nurse

## 1 | INTRODUCTION

Communication is considered a core principle of nursing practice (Casey & Wallis, 2011). The importance of communication and a well-functioning nurse–patient relationship to provide high-quality care is well known (Caris-Verhallen et al., 1997; Fleischer et al., 2009; Shattell, 2004; Street et al., 2009). The ability to provide effective communication is also emphasized as central for assuring high-quality care and patient safety, as well as detecting important needs, providing support and information and enhancing patient learning (Kwame & Petrucka, 2022). There has also been a strong trend for patient- or person-centred care, which highlights patients' rights to autonomy, information and shared decision-making, in which communication is a key element (Håkansson Eklund et al., 2019). Furthermore, Sundler et al. (2020) have stressed the importance of acknowledging communication skills that can facilitate person-centred care. However, less is known about the actual communication, hereafter called real-time communication, between registered nurses (RNs) and patients. To the best of the authors' knowledge, there is no recent review on the real-time RN–patient communication, and how such studies are guided by theory.

## 2 | BACKGROUND

Communication and interaction are complex processes that are central to the exploration and understanding of patients' health conditions (Parker et al., 2020). The terms communication and interaction are often used interchangeably in nursing research and are seldom clearly described or explained (Fleischer et al., 2009). Both interaction and communication are processes and situations involving behaviours that are communicative and convey messages. However, interaction can be seen as a superior term characterized by a mutual and dynamic process, while communication can be seen as a special type of interaction linked to the exchange of information and experiences with the aim of reaching understanding and building a relationship. Communication includes both verbal and non-verbal expressions and is described as something that always happens when people meet, making it a prerequisite for constructive interactions (Fleischer et al., 2009; Watzlawick et al., 1967/2014). Communication is a core element of nursing care used as a promoter or tool for interaction and relationship-building, and nursing communication also influences patients' health and well-being (Fleischer et al., 2009). For instance, communication can instil trust, support well-being or self-care actions and strengthen the patient's autonomy.

Interaction and communication are critical for assessing the needs and outcomes of patients, such as increased knowledge,

self-care skills, adherence to treatment, trust, high-quality medical decisions, social support and empowerment (Street et al., 2009). Until now, the number of RN–patient communication studies and reviews in this field is sparse, compared to the number of studies and reviews on physician–patient communication, see, for instance, Beck et al. (2002), Laidsaar-Powell et al. (2013), Zill et al. (2014), Cohen et al. (2017) and Ghosh et al. (2020). There are some previous reviews in nursing, but no recent literature review with a focus on studies using observations (in person, or by audio or video recording) of communication between RNs and patients. Previous reviews have focused on theoretical nursing models and care for older people (Caris-Verhallen et al., 1997); additionally, reviews have observed a unidirectional focus in nurses' communication (Shattell, 2004) or have noted that the concepts of interaction and communication were used interchangeably (Fleischer et al., 2009). In addition, a theoretical perspective was often lacking, except for the use of the cognitive model of social information processing (Sheldon & Ellington, 2008).

Nurses' communication with patients is commonly embedded in everyday activities (Macdonald, 2016; Sundler et al., 2016) and can occur while performing nursing tasks (Fleischer et al., 2009; Shattell, 2004). Nursing care requires an understanding and sensitivity to patients' experiences and emotional concerns. Nurses' relationship-building and communication with patients include the confirmation of emotions (McCabe, 2004). The communication is also important for addressing patients' needs and worries (Högländer et al., 2017; Sundler et al., 2016). Thus, communication and interaction are imperative and can reflect humanistic values of respect, self-determination and empathy (McCormack et al., 2011).

The present review focuses on studies of real-time RN–patient communication. Methods and approaches used to investigate real-time communication vary. To date, observational methods seem to have been less frequently used than other methods when describing or investigating communication. Most studies used retrospective qualitative interviews of nurses and/or patients concerning their communication (Amoah et al., 2019; Chan et al., 2019; Fleischer et al., 2009). It has been suggested that further research using real-time observations in nursing research is needed (Liu et al., 2021; Williams et al., 2017). However, research using real-time observations like audio or video recordings for data collection may be challenging. For instance, data collection involving nurses tends to invade the normal workflow more compared to doctors, while nurses tend to walk around much more, doctors most often meet patients while sitting down. Thus, nursing encounters are more complicated to record with an unmanned camera during ordinary nursing care. There may also be difficulties to manage data collection when the researcher must engage nurses in the recruitment of patients (Sundler et al., 2017). As stressed by Liu et al. (2021) recordings may influence the actual situation as participants being aware of the

recording may act in a different way when being recorded. Although no huge differences are being observed (Arborelius & Timpka, 1990; Penner et al. 2007; Pringle & Stewart-Evans, 1990). There may also be challenges to obtain access to the field when recruiting participants, and when obtaining ethical approval concerning the intrusiveness of using recordings in, for instance, home care services when data are collected in a person's own home and with respect to their integrity (Sundler et al., 2017).

RN–patient communication is a hallmark of professional competence in nursing that is sometimes undervalued. There is a need for a current assessment of the state-of-the-art research on real-time communication between RNs and patients to identify what is known in this area and what has not yet been researched. More knowledge is needed on real-time communication and on how to apply the best communication practices.

### 3 | THE REVIEW

#### 3.1 | Aim

The aim of this review was to explore communication research in nursing by investigating the theoretical approaches, methods, content and perspectives in research on real-time RN–patient communication.

#### 3.2 | Design

An integrative review was conducted to assess nursing research on real-time communication between RNs and patients. An integrative review is a broad research review that allows the researcher to combine both theoretical and empirical literature and to include a variety of data types and diverse methodologies (Whittemore & Knaf, 2005). The present review followed the process described by Whittemore and Knaf (2005), encompassing problem identification, a literature search, data evaluation, data analysis and the presentation of results. The sources of data were empirical research papers, and no theoretical literature was used.

#### 3.3 | Search methods

A systematic literature search strategy was undertaken to identify relevant studies. Article retrieval was performed via database searches and manual searching. The latter involved searching for articles in the reference lists. First, we conducted computerized database searches in PubMed, CINAHL Plus, and Medline with assistance from a librarian. Keywords (based on MeSH terms) of “nurse” and “patient” or “person” and “communication” or “observation” were used in the searches. When scanning the search results, the following inclusion criteria were used: (1) observational studies of real-time RN–patient communication, (2) peer-reviewed studies, (3)

studies that were written in English and (4) studies that were published between January 1996 and December 2021. The limitation in the years was based on a previously published literature review that covered articles published before 1996 (Caris-Verhallen et al., 1997). Articles not available in full text ( $n = 6$ ) were excluded.

Unpublished manuscripts, abstracts, and dissertations were excluded, as well as studies involving participants younger than 18 years of age. Furthermore, we excluded studies with participants from different professions when it was impossible to distinguish the results on RN–patient communication from other healthcare professional–patient communication. This exclusion ensured that the focus on RN–patient communication was maintained. Articles were excluded if they lacked descriptions of methods (e.g. data collection, analysis or participants) or the study did not include real-time communication; for example, studies with indirect methods used to assess communication, such as interviews.

#### 3.4 | Search outcome

An initial broad search of the literature yielded a total of 1369 references. All the references from the search were screened for duplicates. The references were screened by title, after which they were screened by abstract. A second screening of the methods section was performed to verify whether the articles complied with the inclusion criteria. A total of 128 references were read in their entirety by four of the authors. Each author screened a fourth of the references, and joint discussions were enacted to resolve any doubts and to maintain compliance with the inclusion and exclusion criteria. The second screening was comprehensive, with multiple checks to verify the accuracy of the screenings and to validate that all the inclusion and exclusion criteria were met. After the second screening, additional articles were included through an additional hand search and from the screening of the reference lists ( $n = 16$ ), which finally resulted in the inclusion of 52 references. The literature search was documented as a Prisma flow diagram, see [Figure 1](#).

#### 3.5 | Quality appraisal

For the quality appraisal, we used the Mixed Methods Appraisal Tool (MMAT) version 2018. The MMAT was designed to appraise the quality of empirical studies and permits for appraisal of qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies and mixed methods studies. The MMAT checklist contains two screening questions, and five questions for each of the five different study designs included in the appraisal (Hong et al., 2018). Each study was screened and rated in accordance with MMAT. To ensure consistency among the researchers we discussed our appraisal based on the methodological quality criteria. All the included articles demonstrated high quality (based on the MMAT) and met 75%–100% of the evaluated criteria in the MMAT checklist.

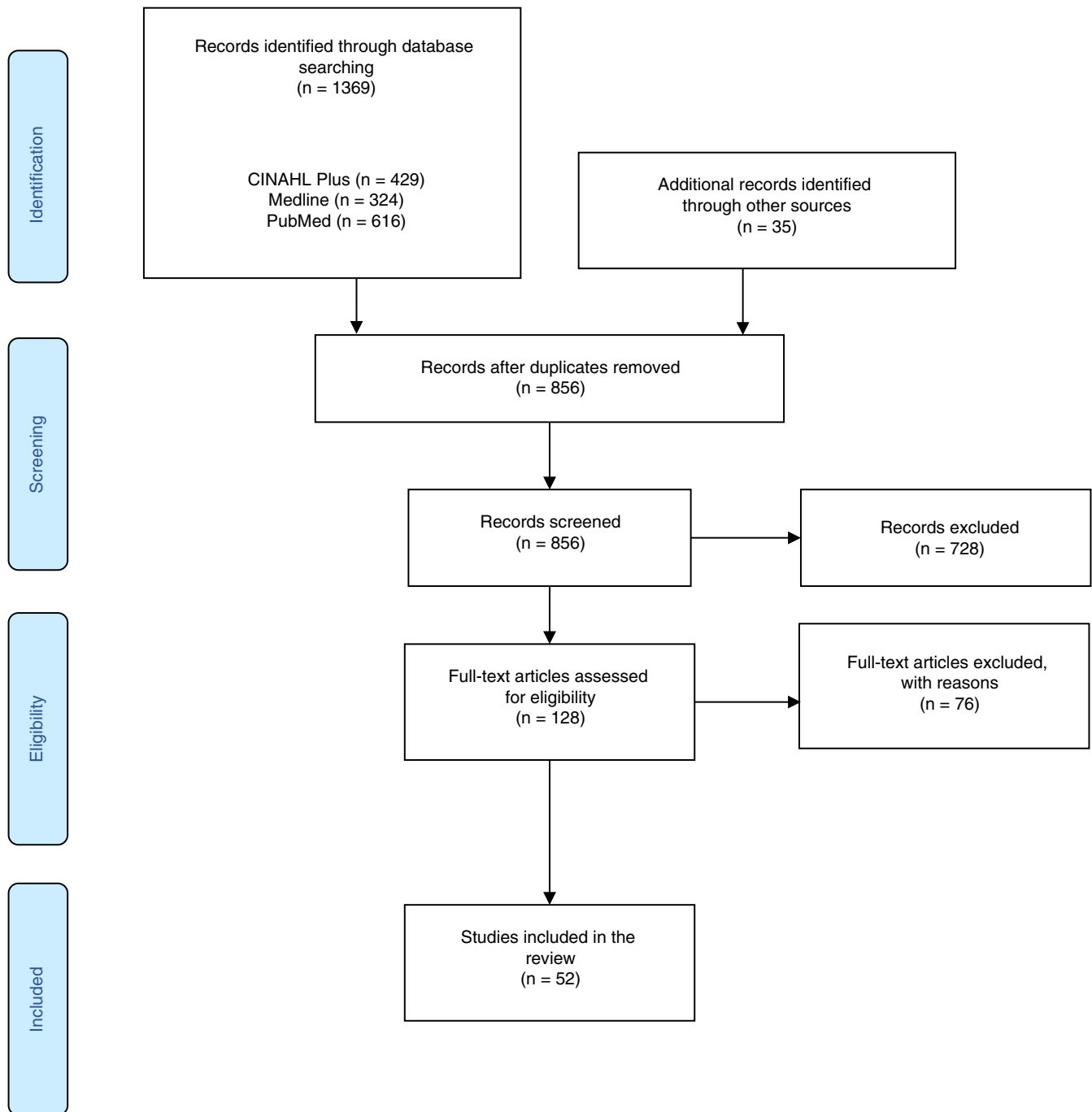


FIGURE 1 Flow diagram of the literature search.

### 3.6 | Data abstraction and synthesis

The following data were extracted from the studies and organized as follows: theoretical approach, aim, methods and design, setting, participants, data collection, analysis and results. The extracted data were compared and analysed for differences and similarities, and similar data were grouped. The analysis followed a constant comparison method, as suggested by Whittemore and Knafel (2005). With constant comparison patterns, variations and similarities are established. This method is preferable when using a variety of data

that are obtained with different methodologies (Whittemore & Knafel, 2005), as was done in the present study.

## 4 | RESULTS

The results are presented in three main sections: theoretical approaches used in studies on real-time RN–patient communication, methods, and approaches used for examining RN–patient communication, and the meaning and nature of RN–patient communication.

## 4.1 | Theoretical approaches used in studies on real-time RN–patient communication

In general, the theoretical perspectives related to RN–patient communication were implicit. None of the studies used a nursing theory or theorist, and most of the studies had no clear theoretical underpinnings for communication. In some studies, a patient- or person-centred perspective was described as a conceptual framework underlying RN–patient communication and interaction, thus demonstrating an interactional and relationship-based view on communication (Bolster & Manias, 2010; de Leeuw et al., 2014; Ellington et al., 2018; Ernesäter et al., 2016; Hakimnia et al., 2014; James et al., 2020; Sundler et al., 2020). There were also theoretical views on empathy described in relation to RN–patient communication (de Leeuw et al., 2014; Eide, Sibbern, Egeland, et al., 2011; Eide, Sibbern, & Johannessen, 2011) and a social constructionist perspective (Barrere, 2007; Gordon et al., 2009).

## 4.2 | Methods and approaches used for examining RN–patient communication

The characteristics of the 52 included studies are summarized in Table 1. Altogether, these included 739 RNs and 3317 patients. Data collection of real-time RN–patient communication was mainly conducted through audio or video recordings ( $n = 43$ ) or participatory observations ( $n = 9$ ). The most commonly used methods for coding data were the Verona coding definition of emotional sequences [VR-CoDES] ( $n = 8$ ), the Roter interaction analysis system [RIAS] ( $n = 6$ ) and conversational analysis [CA] ( $n = 4$ ).

Most papers originated from Nordic countries (e.g. Sweden, Norway, Finland and Denmark,  $n = 22$ ), and some papers were from the United States ( $n = 8$ ), the Netherlands ( $n = 5$ ), England/UK ( $n = 5$ ), Australia ( $n = 5$ ), and Canada ( $n = 2$ ). Single papers were from Iran, Indonesia, New Zealand, China and Switzerland. Hospitals and primary care settings were the prevailing settings, followed by home care, hospice and telenursing settings. In most studies, participants were commonly and solely comprised of RNs and patients ( $n = 41$ ).

## 4.3 | The meaning and nature of RN–patient communication

The meaning and nature of RN–patient communication were categorized as (1) the focus and impact of communication, (2) various, more or less person-centred communication styles and (3) the content of patient communication, further described below.

### 4.3.1 | The focus and impact of communication

The focus of communication was found to influence the relationship-building and interaction between RNs and patients. The focus of the

communication could both point to and result from a power imbalance between RNs and patients.

The interaction between RNs and patients changes during encounters and might signify both symmetry and asymmetry (Barrere, 2007). When building a relationship, the roles of RNs and patients could be complementary and facilitate symmetry through a social exchange in the communication such as humour and trust (Lotzkar & Bottorff, 2001) or by including the patient's family members (Reblin et al., 2016). However, psychosocial issues, positive emotions and partner statements usually receive much less attention than physical care information (Ellington et al., 2018). RNs were found to dominate the communication and interaction when they initiated the contact, decided on the topic, or had an instructor role (Duxbury et al., 2010; Ellington et al., 2018, 2012; Högländer et al., 2017; Kettunen et al., 2000; Pettersson et al., 2018). RNs' dominance was also observed in consultations in which they talked more than their patients (Ellington et al., 2018, 2012). RNs' contributions to the interaction and communication with patients were sometimes minor compared to other professionals such as physicians (Weber et al., 2007).

A dominant discourse of communication was also described as nonpatient centred (Siouta et al., 2019). The dominant role could increase or decrease, depending on the RN's interaction with the patient (Barrere, 2007; Ellington et al., 2018, 2012). If the RNs instead invited the patient to participate in his or her care, it could decrease the asymmetry in the relationship (Bolster & Manias, 2010).

Even if the RNs strived to meet patients' needs, they often focused on nursing routines, for example, tasks regarding nutrition, hygiene, physical examinations or medication administration (Gordon et al., 2009; Macdonald et al., 2013; Prip et al., 2019) as well as on patients' medical conditions and questions (Johnsson, Wagman, et al., 2018; Prip et al., 2019). RNs were often the ones who initiated the gathering of patient information (Duxbury et al., 2010), and the communication became characterized by a focus on treatment, which seldom explored patients' existential and psychosocial concerns (Prip et al., 2019). RNs were reported to be more confident and efficient in communication on medical or physical aspects, rather than in communication on emotional aspects (O'Baugh et al., 2009). Some studies reported that RNs exhibit poor skills in answering patients' questions (Carlsson & Pettersson, 2018; Collins, 2005; Roche & Jones, 2021), clarifying their doubts or exploring their comments (de Leeuw et al., 2014; Duxbury et al., 2010; Eide, Sibbern, Egeland, et al., 2011; Eide, Sibbern, & Johannessen, 2011; Ernesäter et al., 2014; Ernesäter et al., 2016; O'Baugh et al., 2009).

### 4.3.2 | Various, more or less person-centred communication styles

RNs' communication with patients was multifaceted. In some situations, communication became more focused on the RNs' agenda; compared to when RNs used a more patient-centred approach. RNs also used different communication styles and strategies. There were

TABLE 1 Characteristics and summary of included studies

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Barrere (2007), USA Discourse analysis of nurse–patient communication in a hospital setting: implications for staff development	To examine nurse–patient communication and identify interactions of symmetry and asymmetry	Qualitative ethnographic study with a cross-sectional design using discourse analysis	Hospital Data gathered from 140 audio-taped nurse–patient conversations Participants: 20 nurses (10 females/10 males) 20 patients (10 females/10 males)	The nurse–patient interactions demonstrated both symmetry and asymmetry, and this changed during conversations. The nurses were found to be dominant and had an instructor role; they initiated the interaction and introduced new topics; they instructed patients about medications, procedures and test results. Patient education occurred and nurses provided reassurances in every interaction. The instructor role was found to increase the asymmetry and the nurse's dominant role. When the nurses provided time for the patient to talk and were not rushed, the symmetry increased. The nurses were reported to listen to the patients, even if they sometimes overlooked the patient's cues
Berry (2009), USA Nurse practitioner/patient communication styles in clinical practice	To investigate nurse practitioner–patient communication styles in clinical practice	Quantitative cross-sectional design using quantitative manifest content analysis guided by Roter and Hall's communication styles	Nurse practitioner (NP) office visits Data were gathered from 53 audio-taped interactions. Participants: 53 NP (43 females/10 males) 53 patients (29 females/24 males)	The findings suggest that approximately one third of NPs (30.2%) used a patient-centred communication, versus NPs who used a provider-centred communication (69.8%). The nurses frequently used information-giving and information-seeking styles. Less frequently the nurses used social conversations, positive talk and partnership building. Negative talk was the least used
Bolter and Manias (2010), Australia Person-centred interactions between nurses and patients during medication activities in an acute hospital setting: qualitative observation and interview study	To examine the nature of interactions between nurses and patients during medication activities in an acute care setting with an underlying philosophy of person-centred care	Qualitative study using a naturalistic observational research design	Hospital, acute care ward Data gathered from observations (n = 11) and interviews (n = 27) Participants: 11 nurses (9 females/2 males) 25 patients (6 females/19 males)	Some nurse–patient interactions during medication activities were found to be consistent with a person-centred care. The nurses commonly initiated and dominated the interactions and provided patients with information. They sometimes missed opportunities for patient participation. The nurses were described to stand beside the patient's bed, making little eye contact with their patient. Only a few nurses sat down during the medication activities. Nurses appeared to be rushed with limited time for the patients and the environment was hectic and demanding for the nurses. Barriers to person-centred care were observed when the care was centred on routines or the nurses' views rather than the individual patient
Carlsson and Pettefsson (2018), Sweden Communicative and pedagogical strategies in nurses' and surgeons' discharge consultations with patients undergoing surgery for colorectal cancer.	To describe the structure, content and the communicative and pedagogic strategies in discharge consultations between patients and professionals after colorectal cancer surgery	Explorative study using both quantitative and qualitative design	Hospital, surgical care Data gathered from 13 audio-taped nurse–patient and surgeon–patient consultations Participants: 7 nurses (all females) 7 patients (3 females/4 males) 4 surgeons (all males)	The communication and length of time varied among the consultations with nurses and surgeons. There were more questions in the consultations with surgeons than with nurses. Medical terminology was used by both nurses and surgeons during conversations and information-giving. In relation to medications, nurses seemed vaguer in their instructions. Both nurses and surgeons gave clear as well as unclear responses to patients' questions. Patients asked more questions if responses from the professionals were unclear. Clear communication was deemed important to help patients manage their recovery and regain control

TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Collins (2005), USA Explanations in consultations: the combined effectiveness of doctors' and nurses' communication with patients	To consider how explanations are deployed in patients' communication with doctors and nurses	Qualitative. Comparative design Conversation analysis	Primary healthcare Data gathered from 38 video- and audio-recorded consultations <i>Participants:</i> 5 Nurses (all females) 6 Doctors (1 female/5 males) 23 Patients (Sex NS)	During consultations, nurses used a language that was more everyday-like, compared to doctors who used a more technical and medical language. The nurses provided space and responded to patients' views to a larger extent than the doctors did. In consultations with nurses, the patients' problems and concerns seemed to be given more space, while doctors tended to have a more medical point of view. The study concludes that these differences are complementary in their contribution to the individual care of patients
de Leeuw et al. (2014), the Netherlands Nurse-patient communication in follow-up consultations after head and neck cancer treatment	To explore the content and form of nurse-patient communication in follow-up consultations with HNC patients with or without a partner present	Descriptive observational study using quantitative methods Data coded with the Medical Interview Aural Rating Scale	Hospital, Oncology outpatient clinic Data gathered from 17 video-recorded nurse-patient consultations <i>Participants:</i> 3 Nurses (all females) 10 Patients (5 females/5 males) 6 Partners (3 females/3 males)	The findings describe that patient cues were found to consist of more vague expressions rather than clear expressions of emotions. Nurses most frequently responded with distancing behaviours to patients' and partners' cues, hence reducing rather than providing space in the communication, however, most informational questions were adequately addressed. Most nurses' conversations contained small talk to keep the conversation going, without further exploration of patients' utterances. The study concludes that adequate cue and question responses remain challenging for nurses.
Drevenhorn et al. (2001), Sweden Counselling Hypertensive patients: an observational study of 21 public health nurses	To observe what kind of nonpharmacological treatment was given by the nurses during visits for blood pressure measurement and to measure the nurse's and the patient's activity level using the Nurse Practitioner Rating Form (NPRF) instrument	Quantitative observational study	Primary healthcare Data gathered from 63 observations of blood pressure assessments <i>Participants:</i> 21 Nurses (sex NS) Patients (numbers and sex NS)	Nurses' conversations with patients were found to mostly contain somatic or medical issues. Almost all patients were found to ask questions about medications. Non-pharmacological information was mainly related to diet and physical activity. In 15 out of 63 observations, psychosocial content was observed during non-pharmacological conversations
Duxbury et al. (2010), England A structured observation of the interaction between nurses and patients during the administration of medication in an acute mental health unit	To describe current practice in the administration of medication in an acute psychiatric unit and explore factors that influence nurses' decisions regarding the administration of medication during rounds	Quantitative observational study	Hospital, acute mental health ward Data gathered from 20 observations of nurse-patient interactions during medication administration <i>Participants:</i> 24 Nurses (12 females/12 males) 57 patients (sex NS)	During interactions nurses often demonstrated warmth, empathy and a diplomatic interpersonal style. In most of the observations, the nurses checked that they had understood the patients' perspectives. The nurses demonstrated active listening skills. This was often shown through affirming nods, eye contact, or expressing caring and concern. There was a good balance of verbal communication in most observations (93% between nurses and patients). Information giving was initiated more by the nurses than by patients. Solutions to problems initiated by patients were commonly explored. There were situations when the patients' views were not explored, and the nurses did not always ask for patients' views or acceptance of medication

(Continues)



TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Efrainsson et al. (2015), Sweden Nurses' and patients' communication in smoking cessation at nurse-led COPD clinics in primary health care	To describe smoking cessation communication between patients and registered nurses trained in MI in COPD nurse-led clinics in Swedish primary health care	A prospective observational study using quantitative methods	Primary health care Data gathered from 26 video-recorded nurse-patient non-smoking consultations Participants: 6 Nurses (all females) 13 Patients (11 females/2 males)	During the non-smoking consultations, the nurses asked closed-ended questions, made reflections, and provided information, and they did not adhere to the principles of a motivational interview in the interactions with patients. Patients were mainly neutral or adhered to what nurses said, but there was a limited focus on how the patient could stop smoking
Eide, Sibbern, Egeland, et al. (2011); Eide, Sibbern, & Johannessen, 2011, Norway Fibromyalgia patients' communication of cues and concerns: interaction analysis of pain clinic consultations	To explore the types of concerns and cues patients expressed in an initial consultation with a nurse at a pain clinic, how and who initiated these cues and concerns, and predictors of these expressions	A cross-sectional exploratory design. Quantitative analysis of data coded with VR-CoDES	Pain clinic Data gathered from 58 video-recorded nurse-patient consultations Participants: 5 Nurses (4 females/1 male) 58 Patients (49 females/9 males)	The consultations in this study had a mean duration time of 36.14 min (range 14.25–52.30). In these, the patients expressed 801 cues and concerns, mostly about pain. The patients expressed more explicit concerns when nurses to a higher extent responded emphatically. When lacking empathic responding there was an association with patients expressing more implicit cues. The study concludes that the patients with fibromyalgia in the study expressed many expressions contained emotional distress. They more often expressed implicit emotional cues ( $n = 591$ ) rather than explicit concerns ( $n = 210$ ). The study suggests that education and skills training may be needed to help professionals to detect expressions of emotional distress and to respond in an empathic manner
Eide, Sibbern, Egeland, et al. (2011), Eide, Sibbern, and Johannessen (2011), Norway Empathic accuracy of nurses' immediate responses to fibromyalgia patients' expressions of negative emotions: an evaluation using interaction analysis	To describe and evaluate nurses' immediate responses to fibromyalgia patients' expressions of negative emotion in first consultation at a pain clinic	Descriptive observational study using quantitative analysis of data coded with VR-CoDES	Pain clinic Data gathered from 58 video-recorded nurse-patient consultations Participants: 5 Nurses (4 females/1 male) 58 Patients (49 females/9 males)	In this study, 801 responses by nurses to patients' expressions of emotional cues and concerns were coded. The nurses most frequently (75%) responded by using minimal encouragement to patients' emotional expressions, with explicit recognition to 13% of expressions and the rest (12%) were responses not within the perspective of the patient. The study suggests that further explorations are needed on the effects of empathic accurate responses of nurses
Elington et al. (2012), USA Hospice nurse communication with patients with cancer and their family caregivers	To provide insight into in-home visits. Specifically, the pilot project aims were to: (1) test the feasibility of in-home audio-recording of interactions among hospice nurses, patients and families, (2) study the nature and content of communication during in-home hospice nurse visits and (3) assess the fit of a widely used communication coding system RIAS to hospice encounters	Descriptive pilot study using qualitative methods to analyse data coded with RIAS	Hospice Data gathered from 32 audio-recorded nurse-patient/family caregiver interactions Participants: 5 Nurses (5 females/0 male) 7 Patients (2 females/5 males)	In general, the nurses talked more during the recordings than patients and family caregivers. Nurses used questions in 8% of their talks and provided information advice mainly related to physical care. Their talk was also coded as partnership building (17%) and devoted to emotional responses (8%) and 4% of their statements reflected humour. A large proportion of lifestyle statements were found (23%). The patients were silent in 11 of the 32 visits. When they spoke, most talks concerned physical care information (31%) or lifestyle statements (19%). Some statements were about psychosocial information (6%), while few questions were asked by the patients (2%). The study concludes that audio-recorded home hospice nurse visits were feasible, and RIAS was suited to code content of the encounters. The findings showed a wide range of topics and emotions during nurse-patient/family caregiver conversations

TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Ellington et al. (2018), USA Communication among cancer patients, caregivers, and hospice nurses: Content, process and change over time	To describe communication of home hospice nurse visits to cancer patient-caregiver dyads, and to assess change in communication related to domains of care over the course of visits	Multi-site prospective observational longitudinal study using quantitative methods to analyse data coded with RIAS	Hospice Data gathered from 537 audio-recorded home hospice visits <i>Participants:</i> 58 Nurses (51 females/5 males/2 missing data) 101 Patients (40 females/60 males/1 missing)	In the conversations, 54% of the utterances were made by the nurses, 29% by the caregivers, and 17 by patients. The conversations predominantly focused on physical care. Home hospice conversations were predominantly focused on physical care, maintaining a relatively stable focus for the domains of physical and psychosocial/daily life care. A small decrease in emotional expressions was observed over time. Nurses often fail to recognize the critical role of caregivers and to address their concerns about patient care. The study suggests that nurses' communication strategies used could be developed to better support the family
Ernesäter et al. (2014), Sweden A comparison of calls subjected to a malpractice claim versus 'normal calls' within the Swedish healthcare direct: a case-control study	To compare communication patterns in calls subjected to a malpractice claim with matched controls	Case-control design using quantitative methods to analyse data coded with RIAS	Tele telenursing Data gathered from 52 audio-recorded telenursing calls (26 cases +26 matched controls) <i>Participants:</i> Nurses (numbers and sex NS) 52 Patients (20 females/32 males)	In all cases and controls the communication was slightly provider-driven, with a ratio of tele nurse/caller talk of 1.31 (SD 0.24) in the cases, versus a ratio of 1.28 (SD 0.30) in the controls ( $p = 0.424$ ). Statistically significant differences were found between the cases and controls: tele nurses used fewer open-ended medical questions in the cases compared with controls; callers provided tele nurses with more medical information in the controls compared with the cases and tele nurses used more facilitation and patient activation activities in controls, e.g. back-channel responses. In the malpractice-claimed calls, the nurses used closed-ended questioning to a larger extent than in control calls, where more open-ended questions and back-channel responses were used. Such responses, e.g. open-ended questions of back-channelling allowed for richer medical descriptions and more information from callers. The study concludes that these communicative techniques are important
Ernesäter et al. (2016), Sweden Telephone nurses' communication and response to callers' concern—a mixed methods study	To describe telephone nurses' and callers' communication, investigate relationships within the dyad and explore telephone nurses' direct response to callers' expressions of concern	An exploratory, descriptive and correlational design with a mixed-methods approach, data coded with RIAS and content analysis	Tele telenursing Data gathered from 25 audio-recorded telenursing calls <i>Participants:</i> 21 Nurses (21 females/0 male) 25 Patients (14 females/11 males)	Tables and text The analysis of the 25 calls found that the telephone nurses made more utterances than the callers, 1439 compared with 1209. During the calls, the nurses mainly asked closed-ended medical questions, and they mainly responded to concern with closed-ended medical questions while exploration of callers' reasons for concern was sparse. The study concludes that the nurses' reluctance to use open-ended questions and to follow up on callers' understanding might be a threat to concordance and a potential threat to patient safety
Fakhr-Movahedi et al. (2011), Iran A qualitative content analysis of nurse-patient communication in Iranian nursing	To explore cultural and contextual factors influencing nurse-patient communication according to lived experiences of Iranian nurses and patients	Qualitative study using grounded theory	Hospital Data gathered from interviews and observations <i>Participants:</i> 8 Nurses (all females) 9 Patients (4 females/5 males)	All nurses believed that communication with patients was important. They strived to support and meet the patients' needs. The Nurse-patient communication was influenced by factors such as physician orders and administrative demands, and the nurses communicated with patients unsystematically, according to patients' requests and needs. The present study findings implied that despite the nurses' beliefs in the importance of nurse-patient communication, in practice the role was not running well because of structural and socio-cultural factors

(Continues)

TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Finset et al. (2013), Norway	To investigate how patient, clinician and relationship characteristics may predict how oncologists and nurses respond to patients' emotional expressions	Observational study data coded with the VR-CoDES	Cancer care Data gathered from audio-recorded nurse/physician-patient consultations <b>Participants:</b> 19 Nurses (17 females/2 males) 5 oncologists (1 female/4 males) Patients (numbers and sex NS)	During the consultations, the patients expressed 471 cues and 109 concerns. The nurses were five times more likely to provide space for further disclosure of cues and concerns (according to VR-CoDES definitions) than oncologists in outpatient follow-up consultations were. Nurses gave room for further disclosure to explicit concerns and nurse-initiated cues/concerns, but the effects were smaller than for oncologists
Gordon et al. (2009), UK	To explore how nursing staff and patients with aphasia or dysarthria communicate with each other in natural interactions on a specialist stroke ward	Observational study using conversation analysis	Stroke unit Data gathered from 35.5 h of video recordings and field notes <b>Participants:</b> 14 Nurses (sex NS) 5 Patients (2 females/3 males)	In this study, the nursing staff started 88% ( $n = 20$ ) of the opening sequences analysed and 44% of the interactions were related to a nursing task. Five openings (19%) appeared to be 'social' in nature, and not task oriented. Overall, the interactions were asymmetric, with very limited patient contributions. The nursing staff controlled the conversations by choosing the topic and flow of conversations, and patient participation was limited. This study concludes that overall, the nursing staff controlled the conversations around nursing tasks
Hafskjold et al. (2017), Norway	To describe nursing staff's responses to older people's emotional distress, and identify factors that encourage further emotional disclosure	Observational study coding data with the VR-CoDES	Home care visits Data gathered from 196 nurse-patient home care visits <b>Participants:</b> 16 Nurses (12 females/4 males) 17 Nurse assistants (15 females/2 males) 48 Patients (37 females/11 males)	During audio-recorded home care visits, 635 expressions of emotional distress among older people were coded. In 48% of nursing staff responses, the content was emotion focused. Expressions with explicit reference to emotion most frequently received emotion-focused responses (60%), whereas more implicit emotions mostly received non-emotion-focused responses (59%). The study concludes that emotion-focused responses by nurses were promoted when nursing staff elicited the emotional expression, and when the patient expression referred to an explicit emotion
Hakimnia et al. (2014), Sweden	To explore the communication between telenurses and callers in authentic calls to SHD 1177	Descriptive qualitative study	Tele nursing Data gathered from 20 audio-recorded calls <b>Participants:</b> 11 Nurses (10 females/1 male) 20 Patients (13 females/7 males)	The analysis revealed five types of calls: a gatekeeping call, a gendered call, a call marked by impersonal traits, a call with voices of the life world and a counter-discourse call. The dominating patterns in the calls were of gatekeeping and biomedical character. The study concludes that awareness of gender biases and knowledge about callers' different resources to be heard, can improve the inequality in the communication between telenurse and callers
Heyn (2013), Norway	To examine the impact of an interactive tailored patient assessment (Choice) on communication of emotional cues and concerns expressed by cancer patients in terms of source of initiation of cues/concern, explicitness, timing during the consultation and consultation type (inpatient/outpatient)	Quasi-experimental quantitative	Hospital, Cancer care Data gathered from 196 audio-recorded cancer consultation <b>Participants:</b> 196 Patients (63 females/133 males) 24 clinicians: 19 Nurses (17 females/2 males)	A total of 471 cues and 109 concerns in clinician-patient consultations ( $n = 196$ ), with a majority of patient-elicited utterances. Almost half of the utterances of cues and concerns were categorized as hints, and there were more often descriptive cues in the intervention group than in the control group, especially if elicited by the patients. Nurse and patient communication: Cues (78.9%) and concerns (21.1%) were common in consultations with nurses. Patients expressed more descriptive cues and concerns to nurses than to physicians. More utterances were initiated by patients (61.3%) than by nurses (38.7%). Nurses were often provided with explicit responses to patients' cues/concerns and provided space for further disclosure

TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Heyn et al. (2011), Norway	To test the effect of Choice, an interactive tailored patient assessment tool (ITPA), on cancer patients' expressed cues and concerns (C&Cs) and clinicians' physicians and nurses	Quasi-experimental Quantitative	Hospital, Cancer care Data gathered from 196 audio-recorded cancer consultation Participants: 196 patients (63 females/133 males) 24 clinicians: 19 Nurses (17 females/2 males)	A total of 473 cues and 109 concerns were coded with more utterances of cues/concerns in the intervention compared with the control group and in consultations with nurses. Significant differences in the type of response were found between clinicians, where nurses significantly more often provided responses that produced space for further disclosure of patients' cues/concerns compared with physicians.
Högländer et al. (2017), Sweden Registered Nurses' and nurse assistants' responses to older persons' expressions of emotional needs in home care	To explore nurse assistants' and registered nurses' responses to older persons' expressions of emotional needs during home care visits	Descriptive, cross-sectional study Data coded with VR-CoDES	Home care visits Data gathered from 188 nurse/nurse assistant-patients home care visits Participants: 11 Nurses (8 females/3 males) 20 Nurse assistants (12 females/8 males) 44 Patients (29 females/15 males)	NAs' and RNs' responses to older persons' emotional concerns, coded with the VR-CoDES. A total of 121 responses by RNs were found. Most of the RN responses were non-explicit ( $n = 92.2\%$ ) and provided space (78.5%) for further disclosure. Responses less frequently reduced space (21.5%). Examples of such responses are given in the text. RN responses were mainly non-explicit responses providing space for older persons to talk more about their emotional concerns
James et al. (2020), Australia Nonverbal communication between registered nurses and patients during chronic disease management consultations: Observations from general practice	To explore nonverbal communication behaviours between general practice nurses and patients during chronic disease consultations	Observational study	Video recordings of 36 nurse-patient consultations at general practices. 14 GPN (general practitioner nurses, all females) 36 patients (20 females/16 males)	Joint convergence of nurse-patient behaviours and non-verbal communication was found. The most common was laughing, smiling and eye contact. The findings point to nurses supporting patients through non-verbal communication. Symmetrical and asymmetrical communication was present in the consultations
Jansen et al. (2009), the Netherlands Emotional and informational patient cues: The impact of nurses' responses on recall	To investigate older cancer patients' informational and emotional cues, how nurses respond to these cues and the effect of cues and responses on patients' information recall	Quantitative, Cross-sectional and explorative MIARS	10 Hospitals, cancer care. Video-recorded consultations and questionnaires. 105 patients (34 females/71 males) Nurses (NS)	Patients gave more informational than emotional cues. The most frequent response to emotional cues was distancing followed by acknowledgement. Nurses gave appropriate information in response to most informational cues. Patients' expressions of emotional or informational cues did not influence recall; neither did nurses' responses to informational cues. Responses to emotional cues did affect recall. The more nurses responded by giving 'minimal' encouragements (e.g. 'Hmmm'), the more patients recalled, while distancing responses (e.g. switching focus) were associated with lower recall scores. A common response to emotional cues was distancing (35.8%) followed by acknowledgement (29.5%). How the nurses responded to emotional cues influenced patient recall (remembering information) whereas distancing responses negatively influenced the recall (remembering less)

(Continues)



TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Johnsson, Boman, et al. (2018), Sweden Voices used by nurses when communicating with patients and relatives in a department of medicine for older people—An ethnographic study	To describe how nurses communicate with older patients and their relatives in a department of medicine for older people in western Sweden	Ethnographic and qualitative design informed by the sociocultural perspective	Department of medicine for older persons Data gathered from 135 h of observed nurse–patient relative interaction Field notes 40 informal field conversations with nurses Participants: 24 Nurses (sex NS) 40 Patients (sex NS)	The results describe how nurses communicated with four different voices: a medical voice; a nursing voice; a pedagogical voice and a power voice. The voices were context dependent, and the nurses switched between different voices when changing focus. When nurses can combine their voices in a successful way, and by limiting the power voice, the communication could become more positive for all involved. A successful combination of voices was described to facilitate good nurse–patient–relative communication. To improve patient care and health outcomes the communication used is important for relationship building
Johnsson, Wagman, et al. (2018), Sweden What are they talking about? Content of the communication exchanges between nurses, patients and relatives in a department of medicine for older people—An ethnographic study	To explore and describe the content of the communication exchanges between nurses, patients and their relatives in a department of medicine for older people in western Sweden	Ethnographic and qualitative design informed by the sociocultural perspective	Department of medicine for older persons Data gathered from 135 h of observed nurse–patient relative interaction Field notes 40 informal field conversations with nurses Participants: 24 Nurses (sex NS) 40 Patients (sex NS)	Three categories of the content of the communication were described, that was: medical with focus on the patient's medical condition, personal content with focus on the individual patient's life situation and explanatory content related to patient's health and needs. The study concludes that nurses need to be aware of the importance of the communication content and the importance of asking questions. The content used by the nurses in the communication could help enable a more holistic view and facilitate person-centred care
Kettunen et al. (2000), Finland Communicator styles of hospital patients during nurse–patient counselling	To answer the question of what kind of communicator the Finnish patient is during counselling sessions with a nurse in a hospital	Descriptive qualitative	Hospital Data were gathered from 38 videotaped and transcribed health counselling sessions and interviews with nurses and patients. Participants: 19 Nurses (18 females/1 male) 38 Patients (24 females/14 males)	The study describes seven communicator styles used by patients: Quietly Assenting, Emotionally Expressive, Storyteller, Stoic Observer, Inquisitive of Detail, Dominant and Critical Self-observer. The communicator styles indicated the ways in which patients participated. Even though the nurses were flexible, a strong tendency was observed that the nurses directed the conversation in a stereotypical manner that restricted the speech of the patient

TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Kettunen et al. (2003), Finland Speech practices that facilitate patient participation in health counselling—A way to empowerment?	Aimed at a description of nurses' speech practices that facilitated the inclusion of patients' perspectives and preferences and encouraged patients to express themselves	Qualitative CA	Hospital Data were gathered from 38 video recordings of health counselling at 7 wards.  Participants: 19 nurses (18 females/1 male) 38 patients (24 females/14 males)	Affective questions and tentative speech, together with continuers, facilitated active participation by patients. Thus, patients were free to discuss their ideas, concerns, experiences and knowledge with nurses. The findings indicated that nurses were able to establish collaboration and involve patients in their frame of reference. Nurses' affective questions were something that manifested empowering acts from the nurses. Affective questions related to patients' perspectives and views, deal with feelings, experiences, and concerns, participation, options to choose topics and providing space for their wishes, hence empowering the patient.  Patient participation was facilitated when the nurses used affective questions, tentative speech and continuers. In conversations where the nurses allowed patients to freely discuss their experiences, concerns, and views, they were able to establish collaboration and involve patients. The study concludes that conversations that emphasized partnership and social and emotional talk were important, and the study advances professional understanding of the patient-centred empowering practice
Kettunen et al. (2006), Finland Lifestyle counselling in type 2 diabetes prevention: A case study of a nurse's communication activity to produce change talk	To investigate the construction of change talk: how a nurse initiated change talk, how it was received by a patient, and what communication activity produced change talk	Qualitative Case study Influences by CA	Primary health Data were gathered from 8 video recordings of counselling sessions with the same dyad (nurse and patient).  Participants: 1 nurse (female) 1 patient (female)	Change talk was described based on three categories: rejected, restrictive and expansive change talk. Overall, the nurse's communication was interpreted as patient-centred, when not using change talk that interrupted our inhabited patient's talk. Maintaining professional authority at the same time as having a patient perspective could be a dilemma. Change talk could be demanding and was best produced when the nurses focused on the patient's view
Kim et al. (2001), Indonesia Client communication behaviors with health care providers in Indonesia	To analyse determinants of active communication in Indonesia to devise client education and provider training interventions to encourage active client communication	Descriptive, cross-sectional study. Data coded with RIAS	Family planning consultations Data gathered from 1203 audiotaped consultations  Participants: 201 service providers (all females) 18 Nurses 183 midwives 1203 Parents (1201 females/2 males)	Results describe culturally acceptable ways for the clients' communication during family planning consultations. These included asking questions, requesting clarification, stating opinions and expressing concerns.  In this study, client active communication was found to be associated with the providers' information giving, providers' facilitative communication, providers' expressions of negative emotion, client educational level and province
Lam et al. (2020), China Factors affecting the levels of satisfaction with nurse–patient communication among oncology patients	To investigate the factors influencing the level of satisfaction with nurse–patient communication among oncology patients during their daily routine procedures	Observational design	Oncology Data were gathered from observations (n = 110) from two wards 25 RN (21 females/4 males) 94 patients (47 females/47 males)	The most common positive nonverbal cues used by nurses during routine care were visual contact (80.2%) and proximity (75.2%), and for patients visual contact (82.2%) and maintaining attention (63.4%) were common. Negative nonverbal cues, such as ignoring, were rarely seen in nurses

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TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Linn et al. (2020), the Netherlands Talking about Dr. Google: Communication strategies used by nurse practitioners and patients with inflammatory bowel disease in the Netherlands to discuss online health information	To explore how patients with Inflammatory Bowel Disease (IBD) and nurse practitioners (NPs) in the Netherlands communicate about online health information-seeking	Descriptive design using a qualitative Grounded theory method	Discussion about online health information-seeking Data gathered from 58 consultations, including 87 relevant sequences/segments Participants: 8 Nurse Practitioners (8 females/0 male)	The discussion about online health seeking was equally initiated by patients and nurses. The results indicate that the internet is becoming integrated in communication during consultations with patients. In these conversations, the nurses used a patient-centred approach and responded by taking patients' online health information-seeking seriously or affirming their beliefs
Lotzkar and Botorff (2001), Canada An observational study of the development of a nurse-patient relationship	To identify features of nurse-patient interactions (NPI) in the development of a nurse-patient relationship (NPR)	Descriptive study using qualitative ethnological methods	Cancer treatment unit Data gathered from 60 videotaped nurse-patient interactions sequences from 8 patients being continuously videotaped for 72 h Participants: Nurses (numbers and sex NS) 8 Patients (sex NS)	The findings describe the active and complementary roles of nurses and patients when developing a nurse-patient relationship. Moreover, the results highlight the contribution of social exchange, trust and humour in the relationship. Continuity of nursing care is reported as important for relationship building
Macdonald et al. (2013), New Zealand Nurse-patient communication in primary care diabetes management: an exploratory study	To examine the actual talk and perspectives of nurses and patients who were newly diagnosed with diabetes to describe the features of effective interaction and to identify areas for reflection and possible improvements to practice	Descriptive case study using qualitative content analysis	Diabetes care Data gathered from 35 videotaped nurse-patient interactions Participants: 10 Nurses (sex NS) 18 Patients (10 females/8 males)	In this study, the consultations with nurses commonly involved the completion of checklists, physical examination, referral to other health professionals and distribution of written material. The nurses' consultations were commonly longer than consultations with other professionals. The consultations were based on the nurses' clinical agenda more than the patient's perspective. The protocols and checklists used by the nurses both help and hinder communication
Mallett and AHern (1996), England Comparative distribution and use of humour within nurse-patient communication	To describe the frequency, distribution and use of humorous instances occurring within haemodialysis sessions	Ethnomethodological ethnography using conversation analysis	Haemodialysis care Data gathered from video recordings Participants: Nurses (numbers and sex NS) 5 Patients (2 females/3 males)	Findings describe that the amount and proportion of humour from the patients varied. The findings indicate that humour may be an important facilitator for nurse-patient communication
Manias and Williams (2007), Australia Communication between patients with chronic kidney disease and nurses about managing pain in the acute hospital setting	To examine communication between patients with chronic kidney disease and nurses about managing pain in the acute hospital setting	A single group, non-comparative design using qualitative data analysis	Acute hospital settings involving patients with chronic kidney disease Data gathered from observations for 52 h involving 103 incidents of pain communication and interviews Participants: 14 Nurses (12 females/2 males) 53 Patients (19 females/34 males)	The findings describe three themes: complexity of pain, knowledge about pain management, and contextual characteristics of the renal units. The complexity of pain involved the nature of pain and the effects of analgesics on the body. Difficulties to manage pain were related to various causes of the pain. The context involved a perceived urgency of pain communication and environmental stressors

TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Mulder et al. (2014), the Netherlands Quality assessment of practice nurse communication with type 2 diabetes patients	To assess if, and how, nurses applied the five key elements of self-management support in standard care	An observational study	Primary care Data gathered from tape-recorded nurse-patient consultations <i>Participants:</i> 7 Nurses (6 females/1 male) 66 Patients (28 females/38 males)	Nurses usually used assessed current health behaviours and follow-up consultations. The care contained discussions on health behaviours and in less than half of the consultations, the patients got advice to change dietary or physical activity behaviours. Conclusions were that nurses' communication can benefit from using standardized assessments of health behaviours and beliefs as a foundation to support and give advice
O'Baugh et al. (2009), Australia Investigation into the communication that takes place between nurses and patients during chemotherapy	To explore the verbal and nonverbal communication that occurs between cancer patients and nurses during chemotherapy administration	Qualitative, descriptive approach	Cancer patients during chemotherapy Data gathered from 8 video-recorded nurse-patient conversations <i>Participants:</i> 6 Nurses (5 females/1 male) 8 Patients (3 females/5 males)	It was common to first provide an overview of the steps that they would follow in the communication. A major amount of the nurses' communication is concerned with conveying information to support patients practically and psychologically. The conversations had the main focus on procedure focused and they rarely clarified patients' doubts. Nonverbal communication involved looking, touching, movements and emotions. The nurses were efficient in their communication regarding physical and medical areas but could hesitate to address and discuss emotional issues
Oguchi et al. (2011), Australia Measuring the impact of nurse cue-response behaviour on cancer patients' emotional cues	To explore the impact of nurse responses to patients' and family members' emotional cues and concerns during the chemotherapy education consultation	Quantitative, Explorative and cross-sectional VR-CoDES	Hospitals Data gathered from audio-recorded education sessions in chemotherapy <i>Participants:</i> 51 patients (30 females/21 males) 13 nurses (7 females/6 males) Family members	Both patients and family members were reported to express cues and concerns during consultations, even if most cues and concerns were expressed by patients. In a third of the answers, 35%, the nurses responded by providing space. Responses from the nurses that provided space for further disclosure were significantly associated with a decrease in patient expressions of cues and concerns
Oliver et al. (2019), USA Behind the doors of home hospice patients: A secondary qualitative analysis of hospice nurse communication with patients and families	To examine the use of validation communication techniques by hospice nurses during home visits to patients and their family caregivers	Qualitative content analysis	Home hospice visits by nurses Data gathered from 65 hospice nurse visits <i>Participants:</i> 65 Nurses (59 females/6 males) 8 Patients (3 females/5 males)	The nurses used validation communication techniques. For example, paying attention, reflecting back, reading minds, understanding the context, recognizing the valid and showing equality. This occurred at least once during each visit. Findings suggest that nurses use validation techniques in their communication with patients and family caregivers. The use of basic techniques is common and the use of more complex forms of validation is rare
Pettersson et al. (2018), Sweden Prepared for surgery—Communication in nurses' preoperative consultations with patients undergoing surgery for colorectal cancer after a person-centred intervention	To describe preoperative communication after a person-centred intervention in nurses' consultations with patients undergoing surgery for CRC	An explorative quantitative and qualitative design	Surgery Data gathered from audio-taped nurse-patient consultations <i>Participants:</i> 10 Nurses (9 females/1 male) 18 Patients (6 females/12 males)	During the consultations, the nurses talked and introduced new topics: Preparation before surgery, Discovery, Tumour, Operation, Recovery after surgery, and Thrombo-prophylaxis. They used two different approaches to communicating: Talking to and talking with the patient, the latter could be seen as person-centred communication. Talking with patients instead of talking to them, may contribute to increasing the patient's understanding. The use of an open question can contribute to patients' participation and a dialogue between nurses and patients

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TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Prip et al. (2019), Denmark Observations of the communication practices between nurses and patients in an oncology outpatient clinic. Annica	To explore communication between nurses and patients undergoing chemotherapy in an outpatient clinic to gain insight into how patients are supported	Qualitative inductive approach using thematic analysis	Oncology outpatient clinic Data gathered from 70 h of participant observations Participants: Nurses (numbers and sex NS) Patients (numbers and sex NS)	Three main themes were identified: treatment-centred communication, efficient communication and spatially bound communication. The communication was characterized by the content that was focused on the treatment. The aspects of existential, psychosocial and sexual concerns were rarely explored
Roche and Jones (2021), UK A qualitative study of nurse–patient communication and information provision during surgical pre-admission clinics	To explore patient and nursing perspectives of information provision in the pre-admission element of an Enhanced Recovery After Surgery programme, an evidence-based approach implemented to improve the quality of surgical care	Qualitative	Outpatient clinics and hospital wards for surgery Data were gathered from a total of 18 h of recorded observations of pre-admissions at 11 outpatient clinics and 42 semi-structured interviews at three hospital wards. 21 patients (10 females/11 males) 21 Registered nurses (17 females/4 males)	Patients' information needs were not satisfied when RNs sometimes were unwilling or unable to answer questions and provide information. Sometimes the patients were not receptive to the information and had difficulty understanding it
Reblin et al. (2016), USA Caregiver, patient and nurse visit communication patterns in cancer home hospice	To identify common patterns of communication in home hospice nurse–patient caregiver home hospice visits and to identify nurse, caregiver–patient dyad and visit characteristics that predict visit communication patterns	Qualitative, data coded with RIAS	Hospice Data gathered from audio-recorded nurse–patient visits Participants: 58 Nurses (51 females/5 males/2 missing) 101 Patients (40 females/60 males/1 missing)	Six communication patterns occurred in two perspectives: (1) who interacts most with the nurse (patient, caregiver, or dyad) and (2) the relatively high or low expressions of distress during the visit. The result contributes to how to organize triadic communication patterns in cancer home hospice visits
Sandhu et al. (2009), UK Emergency nurse practitioners and doctors consulting with patients in an emergency department: a comparison of communication skills and satisfaction	To compare the content of, and satisfaction with, consultations made with patients presenting with problems of low acuity to an ED	Qualitative and quantitative	Emergency department Data gathered from video-recorded consultations (n = 296) Participants: 6 Nurses (4 females/2 males) 46 Patients (24 females/22 males)	The nurses focused on patient education and counselling medical condition, or therapeutic regimen compared with the doctors. There were no significant differences in consultation length. The nurses had higher levels of overall self-satisfaction regarding the consultations than doctors. Patient satisfaction was significantly related to building a relationship in their talks
Sayah et al. (2014), Canada Health Literacy and Nurses' Communication with Type 2 Diabetes Patients in Primary Care Settings	To examine the application of interactive communication loops, use of jargon and the impact of health literacy (HL) when nurses provide education and counselling to patients with type 2 diabetes in the primary care setting in Alberta, Canada	Exploratory, Qualitative study with a cross-sectional design using discourse analysis	Primary care, diabetes. Data gathered from audio recordings and a survey Participants: 6 nurses—all females 36 patients (21 females/15 males)	The complete communication loop could be noted in 11% of the talks. Most common were to clarifying health information (58%) and repeating health information (33%). 81% never used to check understanding and 42% never asked for understanding. 17% used medical jargon and mismatched language and 25% used respectively. Patients' HL did not affect patterns of communication regarding the use of communication loops. Nurses used less jargon and mismatched words with patients with inadequate HL

TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Stouta et al. (2019), UK Communicative constructions of person-centred and non-person-centred caring in nurse-led consultations	To examine whether and how person-centred caring is constructed verbally in the ongoing communication in consultations between patients with cancer and nurses at nurse-led chemotherapy outpatient clinics	Qualitative	Cancer care Data gathered from 45 audio-recorded nurse-patient consultations and interviews  Participants: 13 Nurses (13 females/0 male) 45 Patients (25 females/20 males)	The major discourse was non-person-centred oriented. The alternative discourse person-oriented related to the patient's personal and sociocultural context was identified and showed that nurses could develop a person-centred approach to consultation. They also replicated a traditional biomedical model. The result showed 5 themes: Discursive approaches to the start of the consultation, Discursive approaches to talking about side-effects, Discursive approaches to patient education, Discursive approaches to feelings, worries and concerns, and Discursive approaches to decision making. It's important to give the person the chance to learn and become the one that's competent to make his/her own decisions
Sundler et al. (2020), Sweden Attributes of person-centred communication: A qualitative exploration of communication with older persons in home health care	To explore attributes of person-centred communication between nurses and older persons being cared for in their home	A descriptive study with a qualitative approach	Home health care Data gathered from 77 audio recordings of nurse-patient communication  Participants: 11 Nurses (8 females/3 males) 37 Patients (29 females/8 males)	Person-centred communication was related to approaches that recognize, invite and involve the person. The RNs facilitated mutual interaction and a deep relationship with the person. Attentive communication is important to facilitate person-centred care. The care requires communication skills that make it possible to recognize, invite and involve the person
Uitterhoeve et al. (2009), the Netherlands Nurse-patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication	To investigate the relationship between nurses' cue-responding behaviour and patient satisfaction	Quantitative, Explorative (cross-sectional) MIARS	Hospital Data were gathered from 100 video-recorded conversations.  Participants: 34 nurses (28 females/6 males) 100 patients (45 females/55 males)	Nurses' cue responding was independently related to patient satisfaction. Patients with palliative treatment had higher satisfaction regarding communication than the patients that were curatively treated.  70% of cues signalled worry or concern, 24% of cues mentioned worry or concern, and 6% expressed unpleasant emotion. Nurses explored 21% of the cues per conversation. 24% were acknowledged and 55% had a response using distancing behaviour.
Wakefield et al. (2008), USA Nurse and patient communication profiles in a home-based telehealth intervention for heart failure management	To compare differences in nurse and patient communication profiles between two telehealth modes: telephone and videophone, and evaluated longitudinal changes in communication, nurse perceptions and patient satisfaction	Randomized controlled clinical trial, data coded with RIAS	Home-based heart failure care Data gathered from recordings of two telehealth modes: telephone and videophone  Participants: 3 Nurses (3 females/0 male) 28 Patients (0 female/28 males)	There were no significant demographic differences between the telephone and videophone groups. The nurses have a high degree of utterances related to the categories of Data gathering, Building a relationship and Activating and partnership building. The highest number of utterances appeared in the Building a relationship category.  Nurses commonly used open-ended questions, back-channel responses, friendly jokes and checks to try to increase their understanding on the telephone than on the videophone. To give compliments and build partnerships were less frequently used by the nurses compared with the videophone. On the telephone they more often gave lifestyle information and approval comments, and, on the videophone, it was more common to use closed-ended questions

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TABLE 1 (Continued)

Author/year/country	Aim	Methods/study design	Setting and sample	Findings/Conclusion
Weber et al. (2007), Schweiz Communication during ward rounds in Internal Medicine: an analysis of patient–nurse–physician interactions using RIAS	To describe the content and mode of patient–physician–nurse interactions during ward rounds in Internal Medicine	Randomized study, quantitative, data coded with RIAS	Hospital—Ward rounds on Internal Medicine units Data gathered from tape- recorded ward rounds <i>Participants:</i> 13 Nurses (12 females/1 male) 59 Patients (33 females/26 males) 8 physicians (3 females/5 males)	Less than 5% of the nurses and physicians used utterances that focused on lifestyle information or psychosocial topics. All participants used closed questions more often than open questions. Nurses asked 1 open question concerning lifestyle and they did not use questions regarding psychosocial content or patients' feelings

Abbreviations: MIARS, the Medical Interview Aural Rating Scale; NS, not state; RIAS, Roter Interaction Analysis System; VR-CoDES, the Verona Coding Definitions of Emotional Sequences.

also differences in how communication was expressed, that is, verbal or non-verbal communication.

The topic for the communication varied, often depending on the situation or context of care. RNs' communication could also be influenced by structural and sociocultural factors (Fakhr-Movahedi et al., 2011). The communication could have a wide range of topics, for instance, related to information regarding illnesses or procedures (Efraimsson et al., 2015; O'Baugh et al., 2009; Pettersson et al., 2018; Roche & Jones, 2021), medical or therapeutic regimens (Carlsson & Pettersson, 2018; Drevenhorn et al., 2001; Duxbury et al., 2010; Hakimnia et al., 2014; Johnsson, Boman, et al., 2018; Kim et al., 2001; Manias & Williams, 2007; Mulder et al., 2014; Pettersson et al., 2018; Sandhu et al., 2009; Sayah et al., 2014) or non-pharmacological topics, such as diet and physical activity (Drevenhorn et al., 2001; Mulder et al., 2014; Sayah et al., 2014) and health behaviours (Mulder et al., 2014). Psychosocial or socioemotional content was also common (Drevenhorn et al., 2001; Pettersson et al., 2018) involving small talk (de Leeuw et al., 2014; Sundler et al., 2020) and building relationships with the patients (Sandhu et al., 2009).

Different communication styles were used when talking with patients, such as medical, nursing, pedagogical or power styles (Johnsson, Boman, et al., 2018). RNs also used attentive and conforming communication, with active listening and open-ended questions (Oliver et al., 2019; Pettersson et al., 2018; Sundler et al., 2020). When asking open-ended questions, RNs received more detailed descriptions and information from patients (Ernesäter et al., 2014). In addition, communication loops were used as a strategy for clarifying and repeating information while checking for understanding (Sayah et al., 2014). Giving more space for further exploration was another strategy to explore the specific patient's needs and problems (Collins, 2005; Duxbury et al., 2010; Finset et al., 2013; Heyn et al., 2013, 2011; Högländer et al., 2017; Oguchi et al., 2011). Other communication strategies involved the use of back channelling, friendly jokes, checks for understanding, compliments and partnership building (Johnsson, Boman, et al., 2018; Kim et al., 2001; Oliver et al., 2019; Wakefield et al., 2008). RNs also validated the patient's expression by showing understanding (Eide, Sibbern, Egeland, et al., 2011; Eide, Sibbern, & Johannessen, 2011; Kettunen et al., 2003; Oliver et al., 2019).

Non-verbal communication, such as eye contact, touching, movements, affirming nods, attitude and showing emotions, were often used (Duxbury et al., 2010; Eide, Sibbern, Egeland, et al., 2011; Eide, Sibbern, & Johannessen, 2011; James et al., 2020; Johnsson, Boman, et al., 2018; Lam et al., 2020; O'Baugh et al., 2009). RNs' non-verbal communication with patients can aid in communicating care and concern, such as demonstrating friendship (Johnsson, Boman, et al., 2018; O'Baugh et al., 2009; Sundler et al., 2020), warmth and empathy (Duxbury et al., 2010; Eide, Sibbern, Egeland, et al., 2011; Eide, Sibbern, & Johannessen, 2011).

Patient-centred communication strategies were also reported (Berry, 2009; Pettersson et al., 2018; Sundler et al., 2020), with RNs

inviting, involving and recognizing patients during communication, and encouraging them to narrate their experiences (Pettersson et al., 2018; Sundler et al., 2020), focusing on their emotions (Hafskjold et al., 2017) and facilitating a mutual interaction (Sundler et al., 2020). Patient-centred communication was more personal and focused on the individual patient's perspective of their situation and everyday life (Johnsson, Wagman, et al., 2018; Collins, 2005). However, social conversation and partnership building were sometimes less frequently used (Berry, 2009).

There were examples of communication that did not include active listening or confirming the patient (Kettunen et al., 2006; Pettersson et al., 2018), with these examples focusing on closed-ended questions and providing information (Duxbury et al., 2010; Efraimsson et al., 2015; Ernesäter et al., 2014, 2016; Pettersson et al., 2018), or RNs not asking for the patient's view or acceptance (Duxbury et al., 2010). Sometimes, RNs also ignored topics posed by the patient (Eide, Sibbern, Egeland, et al., 2011; Eide, Sibbern, & Johannessen, 2011; Johnsson, Boman, et al., 2018) or distanced themselves during communication (de Leeuw et al., 2014; Jansen et al., 2009; Johnsson, Boman, et al., 2018; Uitterhoeve et al., 2009). RNs sometimes used one-way communication and provided instructions, often based on themselves as experts on the topic (Carlsson & Pettersson, 2018) and restricted the speech of the patient (Kettunen et al., 2006, 2000). Sometimes RNs used medical jargon with the risk that RN-patient communication became unclear (Sayah et al., 2014).

#### 4.3.3 | The content of patient communication

Fewer studies were reporting on patients' communication, with a focus on patients' expressions of concerns and the content of the patient communication. Patients used different communication styles and their communication were affected by the RNs' communication.

Studies showed that the content of patients' communication with RNs included questions regarding medical issues, such as medications, medical examinations or symptoms (Drevenhorn et al., 2001; Kim et al., 2001), lifestyle issues (Wakefield et al., 2008), social talk (Kim et al., 2001), emotional cues (Eide, Sibbern, Egeland, et al., 2011; Finset et al., 2013; Heyn et al., 2011, 2013; Kettunen et al., 2000; Oguchi et al., 2011) or informational cues (Jansen et al., 2009).

Similar to RNs, the patients also used different communication styles, such as storyteller, quiet confirmer, stoic observer, emotional expressor, detail-oriented inquisitor, dominant participator or critical self-observer (Kettunen et al., 2000). Patients' participation during communication and their choice of communicative content or communication style were often affected by how the RNs communicated with them (Eide, Sibbern, Egeland, et al., 2011; Kettunen et al., 2000; Kim et al., 2001); for example, patient participation was affected by how RNs responded (Eide, Sibbern, Egeland, et al., 2011; Kettunen et al., 2000) or if they used professional terminology (Kettunen et al., 2000). Patients became more active when RNs expressed positive emotions, understanding or agreement and used small talk (Kim et al., 2001).

Patients often took the initiative to talk about emotional concerns (Eide, Sibbern, Egeland, et al., 2011; Heyn et al., 2013; Linn et al., 2020), and they sometimes used non-verbal cues (Heyn et al., 2013; Lam et al., 2020) and strategies, such as humour, when expressing difficulties or concerns (Mallett & A'Hern, 1996). However, some studies reported that patients avoided being explicit about their concerns with RNs (de Leeuw et al., 2014; Eide, Sibbern, Egeland, et al., 2011; Kettunen et al., 2000), whereas one study revealed that patients uttered more explicit concerns when talking to RNs who provided empathic responses, compared to RNs who did not (Eide, Sibbern, Egeland, et al., 2011).

## 5 | DISCUSSION

This study provides a state-of-the-art review, focused on empirical observational studies describing RN-patient real-time communication. This is considered an important area of research since a current review revealed relatively few articles on real-time RN-patient communication. The ecological validity in observational studies is considered high. Studies on real-time communication can contribute to knowledge gained directly from observations of communication and interactions, instead of retellings of experiences, for example, through interviews. Asking patients and RNs how they evaluate communication may not always reflect what happens in real life.

Although most of the studies focused on RN communication, including content and style, fewer studies focused on patient communication. The results further point to RN communication as being significant for interaction and relationship-building with patients, but few studies have revealed the influence of RN-patient communication on patient outcomes or patient safety. However, there are important differences between immediate, intermediate and long-term outcomes. The RN-patient communication is significant for immediate outcomes, for example, what happens in the interaction, which can be achieved by communication, and so do intermediate outcomes, such as medication adherence.

No explicit challenges regarding RNs' communication skills were reported in the results, which was surprising because, as previously stated, RNs are frontline healthcare professionals (Kaminsky et al., 2017) who often work independently and care for patients with complex conditions. Hence, it was expected that RNs would face high demands on their communication skills. Communication processes are also described as being complex (Parker et al., 2020), which would also be expected to challenge RNs' communication skills. However, it was observed that RNs could have poor abilities in answering questions or further exploring patients' doubts. There were also examples of RNs using a mixture of task-oriented and socioemotional communication, as well as RNs using different communication strategies based on situation or context, which may hint at some challenges and complexity of RN-patient communication. Research could benefit by making communication challenges more explicit or emphasizing the knowledge or skills needed by RNs to improve RN-patient communication. This may be related



to the complex nature of nursing, where challenges and shortcomings in communication and interaction may be related to how these phenomena often occur naturally during interventions and tasks, in contrast to physician–patient communication in, for example, consultations allowing for information exchanges under different circumstances.

The communication practice of nurses is still developing, and the studies in this review had a descriptive or exploratory nature to explore RN–patient communication. However, the results revealed no clear picture of the theoretical underpinnings of RN communication, and the integration of theories in the empirical studies was weak. Similar results were found by Fleischer et al. (2009), concluding that nursing theories were rarely used in studies on RN–patient communication. We propose the need for future utilization of empirical RN–patient communication research that is integrated with theory development of RNs' communication, the centring of patients' needs and communication as a core competence for nurses.

It was also found that communication and interaction were used interchangeably similar to the review by Fleischer et al. (2009). This is further supported by the communication theory provided by Watzlawick et al. (1967/2014), which states that all communication includes interaction and is described as a reciprocal and dyadic process that goes beyond a mere sender–receiver relationship.

The agenda for communication appears to be primarily set by RNs. The patients' communication styles were affected by how the RNs communicated. For example, patients used a more active communication style if RNs were positive, empathetic or prosocial. Moreover, the patient became more implicit and avoided explicit utterances when nurses were perceived as being less empathic in their communication. It is critical to provide space for patients to address their concerns and ask questions (Högländer et al., 2017). Communication is fundamental in nursing care; specifically, it is a critical starting point for understanding patients' needs and expectations (Caris-Verhallen et al., 1997). Proper and effective communication could demonstrate symmetry and build trust, which may help to facilitate patient-centred care. When integrating nursing tasks with the patients' views, more patient-centred styles of communication could be beneficial. Effective communication is emphasized to ensure high-quality care that supports and meets the patients' needs (Kwame & Petrucka, 2022).

RNs' communication with patients is often embedded in everyday activities (Högländer et al., 2020; McCabe, 2004; Sundler et al., 2016). Communication was closely linked to relationship building and socializing, and it must focus on more than just instrumental nursing tasks. Routinely, nurses may use more task-oriented communication, which may result in RNs missing opportunities for active listening and patient-initiated topics. However, patients may be vague or unclear in expressions of their concerns. Thus, the communication skills of RNs, such as active listening, being attentive and responding to implicit and explicit expressions during conversations with patients, are important in nursing.

This review focused on empirical studies of real-time RN–patient communication. Studies using, for instance, interviews were

excluded. Some of the included studies used participatory observations, even if most of the studies used direct observations, such as audio or video recordings. We argue that more studies of real-time communication using audio and video recordings are needed, as there may be gaps between what people report and recall in interviews about nursing care and how this care was delivered. There is a need for studies about RNs' real-time communication and how communication may hinder or facilitate quality and patient-centred care.

## 5.1 | Strengths and limitations

A strength of this review is the clearly defined inclusion of studies on RNs. Thus, this review adds to what is currently known about RN–patient communication and the methods and approaches that have been used within this field. However, the low number of articles that matched our inclusion criteria led to the decision to analyse articles regardless of context or situation, which made the analysis complex and the results broad. The results give an overview of the width and depth of observational research in nursing care and finding such a miscellaneous set of studies was an outcome in itself, which might indicate a less well-grounded field of research. A narrower inclusion could instead have resulted in an even fewer number of articles and risked excluding important research within this relatively unexplored research area.

The search strategy may have led to a limitation in eligible articles. Even if databases are perceived as being effective and efficient sources for literature searches, Whitemore and Knafl (2005) point out that an inconsistent search terminology or indexing problem may yield only a 50% search result. This became evident through the addition of articles from other sources that were not found in the initial database searches. However, the addition of articles through additional sources may be considered a strength that allowed for a more comprehensive literature search.

## 6 | CONCLUSION

This review gives an overview of the width and depth of observational studies on RN–patient communication research. The various set of studies in this area might indicate a less well-grounded field of research, with a need for further research. The relationship between RNs and patients is intertwined with communication, and communication will influence how an interaction develops. Hence, communication is a critical starting point for interaction and its development. It is important that RNs become aware of their communication styles and how their behaviour can affect the communication, otherwise, insensible and unreflective communication can lead to misunderstandings. RNs should understand the significance and meaning of the communication skills that they use, as well as how to facilitate patient-centred communication. The content and styles of communication revealed the use of different communication styles, as well as the fact that communication was multifaceted. Future research is needed on what communication skills are required for RNs to adapt

to different situations and circumstances. Further empirical studies and literature on RN–patient communication are also needed concerning how communication influences quality care, as well as common themes and phenomena within this research field that can be useful for the development of theoretical underpinnings of RN communication. There was a shortage of theoretical underpinnings for nursing-based communication in the reviewed articles, and few studies about patients' communication with RNs were found when conducting this review, thus indicating that further research is needed within these areas.

## AUTHOR CONTRIBUTIONS

JH: Methodology, Investigation and Writing (preparation of the original draft, as well as reviewing and editing). IKH: Conceptualization, Methodology, Investigation and Writing (reviewing and editing). AL: Investigation and Writing (reviewing and editing). SVD: Writing (reviewing and editing). HE: Writing (reviewing and editing). AJ: Conceptualization, Methodology, Investigation and Writing (preparation of the original draft, as well as Reviewing and Editing).

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE [<http://www.icmje.org/recommendations/>]):

1. substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
2. drafting the article or revising it critically for important intellectual content.

## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

## PEER REVIEW

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## DATA AVAILABILITY STATEMENT

Research data are not shared.

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# Communication with mechanically ventilated patients in intensive care units: A concept analysis

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## Abstract

**Aims:** The aim of this study was to perform a concept analysis of communication with mechanically ventilated patients in intensive care units and present a preliminary model for communication practice with these patients.

**Design:** The Im & Meleis approach for concept analysis guided the study.

**Search Methods:** A literature search was performed in January 2022 in MEDLINE, Embase, CINAHL, psycINFO and Scopus, limited to 1998–2022. The main medical subject headings search terms used were artificial respiration, communication and critical care. The search resulted in 10,698 unique references.

**Review Methods:** After a blinded review by two authors, 108 references were included. Core concepts and terminology related to communication with mechanically ventilated patients were defined by content analytic methods. The concepts were then grouped into main categories after proposing relationships between them. As a final step, a preliminary model for communication with mechanically ventilated patients was developed.

**Results:** We identified 39 different phrases to describe the mechanically ventilated patient. A total of 60 relevant concepts describing the communication with mechanically ventilated patients in intensive care were identified. The concepts were categorized into five main categories in a conceptual map. The preliminary model encompasses the unique communication practice when interacting with mechanically ventilated patients in intensive care units.

**Conclusion:** Highlighting different perspectives of the communication between mechanically ventilated patients and providers through concept analysis has contributed to a deeper understanding of the phenomena and the complexity of communication when the patients have limited possibilities to express themselves.

**Impact:** A clear definition of concepts is needed in the further development of guidelines and recommendations for patient care in intensive care, as well as in future research. The preliminary model will be tested further.

**Patient or Public Contribution:** No patient or public contribution, as this is a concept analysis of previous research.

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## KEYWORDS

communication, concept analysis, critical care, literature review, non-verbal communication, nursing, patient comfort, quality of health care, social theory

## 1 | INTRODUCTION

Since intensive care units (ICUs) began to develop in the late 1950s, there has been an outstanding technological evolution in these specialized departments and an increase in acute and critically ill patients receiving mechanical ventilation (Vincent & Creteur, 2019). In the United States alone, prior to the SARS-CoV-2 pandemic, an estimated 5–6 million patients received ICU care annually (Society of Critical Care Medicine, 2022). When critically ill patients are intubated and receive mechanical ventilation, the patient becomes voiceless (i.e. loses the ability to vocalize), due to the inflated cuff blocking the air passing through the vocal cords. Although the voicelessness may be transient, this can be scary, frustrating and a barrier to patient involvement in care and treatment decisions (Danielis et al., 2020; Egerod et al., 2015; Holm & Dreyer, 2018a). Both providers and patients have reported challenges in communication that impact the quality of care (Happ, 2021; Holm et al., 2020; Karlsen et al., 2020). Recently, a paradigmatic shift in treatment has resulted in the use of less sedative medication as this practice has proven beneficial for survival, length of ICU admission and days on mechanical ventilation (Devlin et al., 2018; Vincent & Creteur, 2015). A communicative, conscious mechanically ventilated patient is now more common in the ICU (Vincent, 2017; Vincent et al., 2016). This has gradually changed the focus towards a more comprehensive understanding of the long-term intensive care treatments' effects on the patient and relatives, and the need for a humanizing and caring environment (Kvande et al., 2021; Velasco Bueno & La Calle, 2020). During the covid pandemic, there have unfortunately been limited possibilities for inclusion of patients and surrogates in decision-making due to both hospital policies restricting visitation and lack of resources, as well as fear of spreading the disease while using communication aids that require cuff-deflation (Digby et al., 2022; Freeman Sanderson et al., 2021). It is uncertain if the pandemic might have contributed to a more paternalistic organization of ICUs.

## 2 | BACKGROUND

Although a variety of communication aids exist, such as communication boards with an alphabet or pictograms (electronic and manual), tracheostomy speech valves, above-cuff vocalization, or pen and paper, there is no consensus on the most efficient or effective communication aid for patients who are on mechanical ventilation (Carruthers et al., 2017; Kuyler & Johnson, 2021; Ten Hoorn et al., 2016). Additionally, patients who require mechanical ventilation vary and fluctuate in their level of communication skills,

both physically and cognitively, as well as their abilities to utilize aids. Previous research reveals gaps in the research on this topic, but also a need for a more holistic and humanistic approach in patient encounters in the ICU (Olding et al., 2016; Velasco Bueno & La Calle, 2020). It is also argued that most of the literature on treatment decision-making communication focused on the family who acts as surrogates in decision-making while the patient is admitted to the ICU. However, this picture may be inaccurate as the degree to which patients are able to participate is diverse and ranges from no participation (e.g. due to sedation) to a high level of participation (Lindberg et al., 2015; Olding et al., 2016).

Concepts and theories can guide practice, ensure a unified standard and create measurable variables for testing interventions. Concepts are 'formed by the identification of characteristics common to a class of objects and the phenomena and the clustering of these characteristics' (Im & Meleis, 2021, p. 11). Searching the literature about communication with mechanically ventilated patients quickly reveals that it is not very well-defined area. Despite the fact that communication strategies to ensure patients' informational needs are ranked as the fourth most important research topic by top ICU researchers (Blackwood et al., 2011), a concept analysis to describe the interpersonal communication between nurses and mechanically ventilated patients has to our knowledge still not been published. The research literature mostly focuses on the patient, nurse or family member's experience of communicating and how to 'solve' the communication challenges by introducing augmentative and alternative communication (AAC). Although strategies and tools can be used to optimize communication with voiceless patients (Beukelman et al., 2020; Garrett et al., 2007), there is a need for a new and more nuanced understanding of concepts to shed light on the existing communication practice (Im & Meleis, 2021). A deeper understanding of underlying concepts may also influence clinical practice and the development of robust, well-designed research.

## 3 | THE REVIEW

### 3.1 | Aims

The aim of this study was to perform a concept analysis on communication with mechanically ventilated patients in intensive care units and present a preliminary model for communication practice with these patients. The following research questions guided the process:

- How is the communication and interaction with mechanically ventilated patients described?

- Which phrases are used to describe the patient population?
- Which concepts are defined which relate to communication and interaction?
- Based on the knowledge of the communication, concepts and phrases used, what would a model to guide clinical practice look like?

### 3.2 | Design

Im & Meleis's approach for concept analysis (Im & Meleis, 2021) was chosen where we explored the phenomenon of communication with mechanically ventilated patients in ICUs through multiple perspectives to achieve a broad description (Elo & Kyngäs, 2008). An international expert panel was created of six nurses experienced in the ICU field and one nurse with expertise in communication research was constituted from three countries (Denmark, Norway and the United States of America), ensuring broad experience in research, education and practice.

We followed Im and Meleis's (2021) suggested steps for a concept analysis that involved (1) systematically gathering information about the most common concepts used in the field, (2) analysing the concepts, redeveloping and suggesting definitions and then (3) ultimately creating and encompassing the core concepts in a conceptual map. Concept analysis can also function as a vital part of the process of theory development (Im & Meleis, 2021; Rodgers et al., 2018).

### 3.3 | Search methods

A review of relevant published literature was performed. First, we synthesized several search strategies from literature reviews that the team members performed. In January 2022, the first author collaborated with two librarians to perform a search in MEDLINE ALL (Ovid), Embase (Ovid), CINAHL Complete (EBSCO), APA psychINFO (Ovid) and Scopus (Elsevier), limited to 1998–2022. The reason for this limitation is that 1998 was a turning point in the understanding of benefits of lighter sedation, due to new research which was published. This has led to the implementation of practice guidelines promoting analgesia before sedation (Devlin et al., 2018; Vincent et al., 2016; Vincent & Creteur, 2015). The main medical subject headings (MeSH) search terms used were artificial respiration, communication and critical care, but they were adjusted to each database. The search was also complemented with subheadings in the MeSH tree structure that were not included under the main headings relevant to the topic such as communication aids for disabled/intensive care units, augmentative communication or other frequently used free text words. Full search strategy can be found in Supplemental Material S1: Search strategy. The literature review and selection of literature were inspired by the systematic literature review approach (Rethlefsen et al., 2021), at the same time we wanted a search that captured a multitude of methods and concepts.

### 3.4 | Search outcome

A total of 17,603 references were identified. The librarian's removal of duplicates using Bramer et al.'s duplicate identification strategy (Bramer et al., 2016) resulted in 10,689 references. Two of the authors independently reviewed all of the retrieved literature ( $n = 10,689$ ) using a blinded approach in Rayyan (*Rayyan-intelligent systematic review* 2022) and then compared the results manually. Initially, 90 conflicts were identified but resolved based on the criteria. The included literature was then imported into an Endnote library for further investigation. A more thorough description of the literature search and a PRISMA scheme with additional information about the inclusion and exclusion criteria can be found in Figure 1.

The selected literature was also presented to the expert panel. The data collection phase resulted in 108 relevant sources for use in conceptual analysis, which can be found in Supplemental Material S2: Articles included in the concept analysis.

### 3.5 | Qualitative appraisal

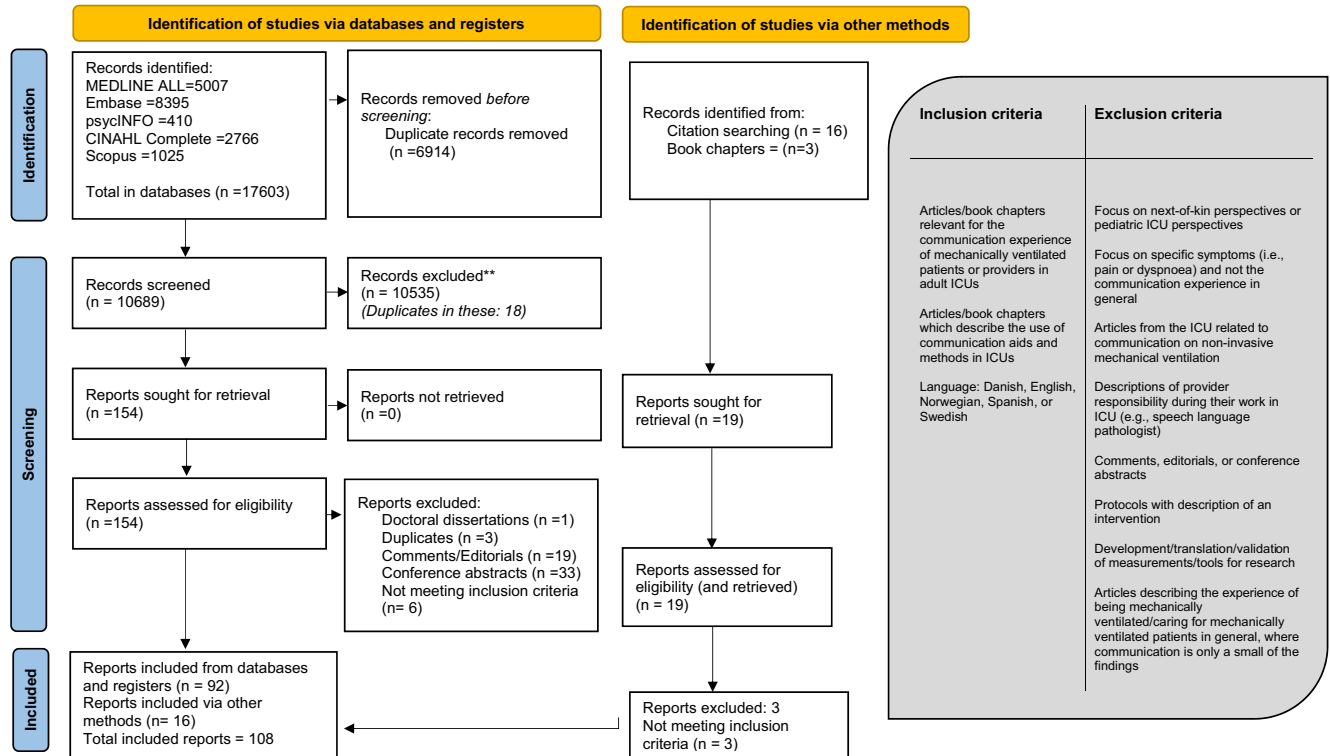
Quality assessment of the sources was not relevant for the concept analysis, as the sources were used to inform the expert panel about how, where and in what way communication with mechanically ventilated patients was described.

### 3.6 | Data abstraction

Central concepts used were identified and augmented by the expert panel's knowledge of the literature and content expertise, extensive research on the topic and experience in clinical practice about communication with patients on mechanical ventilation. We identified and extracted both concepts relevant to the communication and interaction, as well as phrases used to define the patient population in a deductive manner (Elo & Kyngäs, 2008). The first and second authors thoroughly reviewed this process to ensure rigour, transparency and not overlook central concepts.

### 3.7 | Synthesis

New definitions of the concepts were proposed condensing the existing definitions identified and will be presented in the results. The core concepts were then grouped into categories to obtain an overview of their connection and were illustrated in a conceptual map (Elo & Kyngäs, 2008). The final concepts were presented to the expert panel, which agreed on the central meaning of the concepts. The expert panel also held several meetings where the model was discussed and defined and multiple understandings of the phenomena were explored. Lastly, we created a preliminary model to describe communication practice in intensive care, based on the understanding of the identified concepts.



\*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

\*\*If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

FIGURE 1 PRISMA 2020 flow diagram

## 4 | RESULTS

The results are divided into three main topics: Definitions of core concepts of communication practice in ICUs, identified differences from normal communication practice, and model for communication practice with mechanically ventilated patients.

### 4.1 | Definitions of core concepts of communication practice in ICUs

In the literature, we found 39 words to describe the patient population. These are listed in.

#### Table 1.

As Table 1 shows, mechanically ventilated patients and their loss of voice due to the intubation are described in many ways. This highlights how different practice and research traditions define the patient population and their communication challenges in a variety of ways.

### 4.2 | Identified differences from normal communication practice

As in all human encounters, provider-patient communication is an interpersonal interaction with an exchange of thoughts, beliefs, opinions, concerns and needs. The main difference in the communication

practice with a patient on mechanical ventilation in ICUs compared to normal communication is that they lack the ability to deliver vocal messages and respond to the providers' communication. The messages and interaction can only be delivered if both communicators are aware that there is a need to express something of meaning. Normally, this occurs when a communicator uses his/her voice to say something. Therefore, the dialogic aspect is lacking to a large extent. This impedes communication if it is initiated by the patient since they need to achieve attention from the provider and then try to express themselves without vocal statements. Hence, patients must use other methods, either non-vocal (e.g. gestures, facial expressions) or communication aids (e.g. writing, communication boards, etc.). Another significant difference identified in the literature is the patient's absolute dependence on the providers' correct interpretation of their intended message. It is difficult for the patient to correct the provider if the interpretation is incorrect, and this may lead to confusion regarding the content of the communication and the patient's message. As the patient cannot use a natural communication style, it creates an unequal communication process. This may also lead to a communication breakdown if understanding is not achieved. These main challenges and characteristics of provider-patient communication in the ICU are illustrated in Figure 2.

Figure 2 illustrates that the patients on a mechanical ventilator have non-vocal opportunities to communicate, whereas the providers have both vocal and non-vocal opportunities. Additionally, the intensive care environment affects the communication setting; both as a place for acute-critical treatment, but also by the noise level, the number of providers and patients and the use of complex

TABLE 1 Phrases used to describe the patient population in intensive care units

<b>Phrases used to describe patient population by their abilities to vocalize</b>
Awake but unable to speak (Leung et al., 2017)
Inability to speak/communicate (Albayram & Yava, 2020; Choi & Tate, 2021; Foa et al., 2016; Hosseini et al., 2018; Ijssennagger et al., 2018; Sutt et al., 2015)
Intubated (intensive care unit) patients (being unable to speak; El-Soussi et al., 2015; Happ et al., 2014; Otuzoğlu & Karahan, 2013)
Lack of phonation (Freeman-Sanderson et al., 2016a)
Loss of voice (Freeman-Sanderson et al., 2016b)
Patients with transient speech loss (Mobasheri et al., 2016)
Temporary loss of speech function or permanent speech impairments (Holm et al., 2020)
Temporarily non-speaking patients (Happ, Roesch, et al., 2004; Happ, Tuite, et al., 2004)
Suddenly speechless critical care patients (Rodriguez et al., 2016)
Unable to speak (out loud) (Ariffin et al., 2020; Carroll, 2004, 2007; Yavuz & Gursoy, 2022)
Voiceless patients (in intensive care units; Ariffin et al., 2020; Carruthers et al., 2017; Ju et al., 2021; Koszalinski et al., 2015; Radtke et al., 2011)
<b>Phrases used to describe patient population by the level of consciousness or cognitive abilities</b>
Cognitively intact ventilator-dependent patient (Leder et al., 2013)
Conscious while receiving/during mechanical ventilator treatment/respirator treatment (Karlsen et al., 2022; Karlsson et al., 2012)
Conscious and mechanically ventilated critically ill patients (Ten Hoorn et al., 2016)
Critically ill patients (in the ICU, in a dependent and vulnerable position; Kuyler & Johnson, 2021; Lindberg et al., 2015; Miglietta et al., 2004; Ull et al., 2021; Zaga et al., 2019)
Fully conscious patients (Maringelli et al., 2013)
Communication vulnerable patients in intensive care (Johnson et al., 2021; Koszalinski et al., 2019)
Dysarthric ICU-patients (Maringelli et al., 2013)
Lightly sedated mechanically ventilated patients (Karlsen et al., 2022; Noguchi et al., 2019)
Patients with complex communication needs (Finke et al., 2008)
Patients' that are conscious over a longer period during their ICU stay (Holm, Karlsson, et al., 2021)
<b>Phrases used to describe patient population by being dependent on mechanical ventilation</b>
Clients on mechanical ventilator (Rathi & Baskaran, 2014)
Invasive (mechanically) ventilated patients (Salem & Ahmad, 2018; Ull et al., 2021)
Patients being (connected to/undergoing) mechanically ventilated (during critical illness) in intensive care units (Bayog et al., 2020; Danielis et al., 2020; Happ et al., 2014; Happ, Seaman, et al., 2015; Holm et al., 2020; Patak et al., 2004)
Patients requiring artificial ventilation (Wojnicki-Johansson, 2001)
Patients treated with mechanical ventilation (Khalaila et al., 2011)

(Continues)

TABLE 1 (Continued)

Tracheostomized patients in intensive care/Patients on tracheostomy receiving mechanical ventilation (Flinterud & Andershed, 2015; Mills et al., 2022; Panadian et al., 2019)
Ventilator dependent patients with tracheostomies (McGrath et al., 2016, 2019)
Ventilator supported individuals (Casbolt, 2002)
<b>Phrases used to describe patient population both by their communication abilities and being dependent on mechanical ventilation</b>
(Adult) Non-sedated (and more awake/mechanically ventilated) ICU patients (Albayram & Yava, 2020; Danielis et al., 2020; Holm & Dreyer, 2018b; Karlsen et al., 2020)
Conscious and alert (voiceless/oriented) patients under mechanical ventilation in intensive care units (Duffy et al., 2018; Holm & Dreyer, 2018b; Holm, Nikolajsen, et al., 2021; Karlsen et al., 2019)
Intubated patients' ability to communicate (Ijssennagger et al., 2018)
Mechanically ventilated patients who are awake and able to communicate (Danielis et al., 2020)
Mechanically ventilated patients who cannot communicate verbally due to endotracheal intubation/tracheostomy (Holm et al., 2020)
Nonspeaking (critically ill/hospitalized) patients treated with mechanical ventilation (in the intensive care unit; Foa et al., 2016; Happ et al., 2011; Happ, Roesch, et al., 2004; Yavuz & Gursoy, 2022)
Nonvocal (ventilated/critical care) patients (Carroll, 2004, 2007; Trotta et al., 2020)
Patient who are voiceless due to mechanical ventilation (Koszalinski et al., 2015)
Unable/able to speak/talk/communicate/verbally express themselves (as result of ventilation, because of their need for mechanical ventilation and respiratory tract intubation) (Carroll, 2004; Fitch et al., 1998; Foa et al., 2016; Guttormson et al., 2015; Hosseini et al., 2018; Koszalinski et al., 2015; Magnus & Turkington, 2005; Menzel, 1998; Panadian et al., 2019; Yavuz & Gursoy, 2022)
Ventilated patients (unable to converse in a normal manner) (Casbolt, 2002; van den Boogaard & van Grunsven, 2004)

technology. All these factors cause significant distractions, noise and interruptions, which may impede providers' abilities to see and understand the patients' attempts to communicate.

The review of existing knowledge also showed that intensive care patients vary greatly in their abilities to communicate, their needs to communicate and the length of stay. Hence, it is a heterogeneous patient population with the commonality that they are admitted to the ICU, mechanically ventilated and critically ill. Factors like fatigue, delirium, cognitive impairments, poor coordination and muscle weakness are concomitant with being a mechanically ventilated ICU patient. Hence, these factors also affect the communication process in clinical ICU practice. We found a total of 60 relevant concepts used, thematically organized under five overarching categories, which can be seen in Table 2.

The categorization of the core concepts was further illustrated in a conceptual map, as shown in Figure 3. This figure highlights

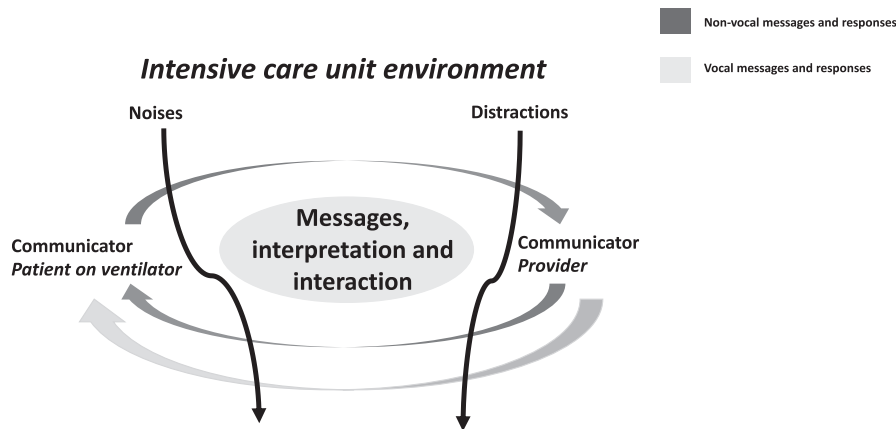


FIGURE 2 Characteristics of provider-patient communication in ICUs.

especially the core components of the identified concepts, 'communication assessment', 'communication styles', 'communication partners', and 'communication methods/strategies'. The core concepts are also linked to each other, as assessment will affect the styles and methods used, and vice versa.

### 4.3 | Model for communication practice with mechanically ventilated patients

Based on the analysis of core concepts and consensus in the expert group, we were able to develop a model for guiding the communication practice with mechanically ventilated patients, as illustrated in Figure 4.

The outer grey line in the model symbolizes the intensive care unit context, with communication barriers such as noise, technical equipment and the constant, demanding monitoring and assessment of the patients' status. The inner grey line symbolizes overarching theories of patient-centred care, patient involvement and standards for quality in the communication, guiding the providers in their practice. Overarching areas of communication and interaction are illustrated in the inner part of the figure and consist of (1) systematic assessment of communication abilities, (2) communication and interaction in the practice, as well as (3) documentation and evaluation of the communication. These three areas are interconnected to each other as illustrated by the arrows.

## 5 | DISCUSSION

The aim of this study was to perform a concept analysis and present a model for communication with mechanically ventilated patients in intensive care units. We found a great variety in the concepts used, both to describe the patient population and the communication and interaction between patient and provider. The results also show that communication with mechanically ventilated patients is distinguishable from communication with a vocally communicative person. The question is whether previous theories have guided providers sufficiently in their

communication, and if we have developed/achieved an evidence-based practice (Happ, 2021).

Research within healthcare communication generally tends to 'approach it from a pragmatic viewpoint, focusing more on ways to improve communication than on explaining how it works' (Berger et al., 2010). This means that essential components of communication, that is, the process of mutual influence and cognitive-affective factors are neglected (Berger et al., 2010). This is also the case in the ICU setting where the findings of this concept analysis, as well as other previous literature reviews, illustrate how AAC has been presented as a solution to the communication challenges, but also requires both careful consideration and competence (Holm et al., 2020; Rose et al., 2021; Ten Hoorn et al., 2016). However, it has also been thoroughly documented that AAC is not widely used in current practice in ICUs, and the studies applying AAC in intensive care are still limited, with small samples and few randomized, controlled trials (Carruthers et al., 2017; Happ, 2021; Karlsen et al., 2019). The AAC that have been used for other patients with communication barriers may not be as efficient in an ICU context, where it is necessary to continuously assess patients' fluctuating communication skills and cognitive capacity. Several of the reviews performed also highlighted the difficulty of comparing intervention studies, both due to lack of definitions, variety in the interventions and a lack of thorough descriptions of the patient population (Carruthers et al., 2017; Holm et al., 2020; Karlsen et al., 2019; Ten Hoorn et al., 2016).

Moreover, the lack of adequate definitions and vague conceptualizations, may lead to inadequate outcome measures, as represented in the literature (Carruthers et al., 2017). Overall, the inconsistency in definitions and lack of theoretical foundation makes it difficult to understand the actual practice. The use of various concepts may also be due to national and local differences in care and treatment procedures and patient characteristics, as well as a difficulty explaining the phenomena. An important impact of the results from this study can be a common ground to discuss concepts. An example of a rather ambiguous concept is 'effective/ineffective communication'. Is efficiency the same as good or humanizing communication providers strive to achieve, and how can a provider separate effective and ineffective measures in the communication when including a variety of unaided and aided communication methods? Identifying

TABLE 2 Concepts and condensation of core

<b>Communication and interaction with mechanically ventilated patients</b>	
Concepts related to communication and interaction.	
<b>Concepts</b>	<b>Condensation of core</b>
Communication (Albayram & Yava, 2020; Ariffin et al., 2020; Bayog et al., 2020; Carroll, 2004, 2007; Casbolt, 2002; Dithole et al., 2016a, 2016b; Flinterud & Andershed, 2015; Freeman-Sanderson et al., 2016b; Foa et al., 2016; Handberg & Voss, 2018; Holm & Dreyer, 2018a; Holm et al., 2020; Karlsten et al., 2019; Kuyler & Johnson, 2021; Momennasab et al., 2019; Panadian et al., 2019; Pina et al., 2020; Slatore et al., 2012; Ten Hoorn et al., 2016; Wojnicki-Johansson, 2001)	Communication is used to interact and form relationships, in a dyadic process. It is an essential part of living and our social life. The primary channel of conveying information and messages is communication. It involves several types of techniques, such as motoric and cognitive abilities (written, verbal or non-vocal). The patient can express needs, thoughts, preferences, wishes and concerns; the provider can inform, comfort and support the patient as well as assess the patient's status and emotions. Communication is also a central part of person-centred healthcare (to create alliances), a prerequisite for patient involvement, and may also be experienced therapeutic.
Interaction (Bayog et al., 2020; Finke et al., 2008; Happ, 2021; Karlsten et al., 2022; Kuyler & Johnson, 2021; Llenore & Ogle, 1999)	Dialogue and meaning are created through interaction between patients and providers. A relational phenomenon where joint meaning is created. Tend to be task-focused, provider-controlled and mainly associated with physical needs and/or procedures when the patients are critically ill such as in the ICU. Interaction is also affected by patient and provider characteristics.
Communication act or event (Happ et al., 2011, 2014)	A communication act or event is a unit of communication behaviour used for attempts to convey a message.
Communication barrier (Finke et al., 2008; Karlsten et al., 2019; Khalaila et al., 2011; Salem & Ahmad, 2018)	Communication barriers can be caused by both physical and mental abilities of the patients (as well the endotracheal tube), but also healthcare providers abilities to understand and the ICU environment in general. May impact the patients and lead to negative emotions.
Communication breakdown (Magnus & Turkington, 2005; Rathi & Baskaran, 2014; Santiago et al., 2019)	Communication breakdown occurs then either or both partners in a dialogue perceive they have not been able to adequately communicate their needs, wants, intentions or understood their communication partner. Communication breakdown leads to reduced quality in patient care, and access to functional communication. This can impact the patient's treatment and outcome.
Communication exchange (Happ et al., 2011, 2014)	A communication exchange is a cluster of communication acts
Communication quality (Happ, 2021; Happ et al., 2011, 2014)	Communication quality can be defined by positive or negative behaviour between providers and patients.
Dialogic interaction (Kuyler & Johnson, 2021)	Dialogic interaction is mutual engagement, between communication partners and creation of joint meaning during communication. To be efficient there must be established trust, and the communication partners need to be on an equal footing.
Language (Carroll, 2007; Karlsson et al., 2012)	Language is a part of human behaviour. Language is both verbal, non-vocal and written. The essence is the message that is expressed through language.
Non-verbal communication (Dithole et al., 2016a; Yavuz & Gursoy, 2022)	Non-verbal communication is gestural and physical communication. Includes facial expression or other muscle movement intended to communicate message.
Patient-centered care (Choi & Tate, 2021; Slatore et al., 2012)	Patient centred care is essential in ICUs both as a philosophy and to preserve patient's personhood.
Shared decision-making (Karlsten et al., 2020)	Shared decision making is a collaborative process between patients, providers and surrogate decision-makers when making healthcare decisions.
Voicelessness (Ariffin et al., 2020; Carroll, 2007; Happ, 2000, 2021; Holm & Dreyer, 2018a; Koszaliniski et al., 2015; Tembo et al., 2015)	Voicelessness is the loss of voice and thus the ability to communicate vocally. It impacts personhood and interaction with others. It may create negative emotions such as powerlessness or lack of control and contribute to dehumanization.
<b>Communication assessment</b> (Bayog et al., 2020; Happ, 2021; Holm & Dreyer, 2018a)	
Assessment of communication skills is a prerequisite for efficient use of communication tools and strategies. It Includes cognitive, mental and physical abilities, as well as level of consciousness, language, mode of intubation and hearing/vision.	

(Continues)



TABLE 2 (Continued)

Concepts	Condensation of core
Attention-seeking actions (Karlsen et al., 2019)	Attention-seeking attentions are efforts made to achieve joint attention and understanding from patients
Basic communication criteria (Happ, 2021; Holm & Dreyer, 2018b)	Basic communication criteria are linked to both physical, sensory and cognitive abilities of the person to communicate coherently.
Communication ability/inability (Ijssennagger et al., 2018; Foa et al., 2016; Freeman-Sanderson et al., 2019; Happ, 2021; Ju et al., 2021; Karlsen et al., 2019; Pina et al., 2020; Sutt et al., 2015)	The ability to communicate is defined by a successful message transmission and interpretation. The inability to communicate may lead to failed communication and negative outcomes. It is affected by physical, sensory, cognitive and environmental factors.
Communication difficulties/challenges/problems (Bayog et al., 2020; Carroll, 2004, 2007; Choi & Tate, 2021; El-Soussi et al., 2015; Happ, 2021; Happ, Tuite, et al., 2004; Holm & Dreyer, 2018a; Jansson et al., 2019; Khalaila et al., 2011; Llenore & Ogle, 1999; Menzel, 1998; Patak et al., 2004; Tembo et al., 2015; Tolotti et al., 2018)	Communication difficulties is a common phenomenon among mechanically ventilated patients. It is mainly caused by the intubation, and the patient characteristics (cognitive, sensory or language deficits, fatigue and/or reduced consciousness and muscle strength). Can result in poor establishment of meaningful relationships with providers and family, affect treatment and create negative emotions and psychological distress for the patient.
Communication disability (Happ, Sereika, et al., 2015)	Communication disability includes existing and acquired communication impairments while being ventilated. Is mostly caused by the tube when the patients is intubated, requires assessment and accommodation from providers.
Communication needs (Fitch et al., 1998; Jansson et al., 2019; Holm & Dreyer, 2018b; Mobasheri et al., 2016)	Communication needs are multi-dimensional and include physical, social, emotional and psychological aspects. Can alter depending on the patient's illness trajectory
Communication skills (Finke et al., 2008; Holm et al., 2020)	Adequate skills in communication are important in the interaction between patients and providers, to be able to understand each other efficiently.
Duration of talk (Nilsen et al., 2014)	Duration of talk is time spent communicating (verbally).
Failed communication (Guttormson et al., 2015; Holm et al., 2020)	The inability to successfully communicate and deliver messages between communication partners may lead to failed communication. This can impact patients' well-being, safety and comfort
Frequency (Happ et al., 2011)	Frequency is the number of exchanges per session of communication.
Giving up attempts to communicate (Karlsen et al., 2020)	Patients and providers may give up on their attempts to communicate. Can be caused by multiple experiences of failed communication.
Severe communication impairment (Finke et al., 2008)	Severe communication impairment is a temporary or permanently reduced ability to communicate.
Quality of phonation (McGrath et al., 2016, 2019)	Quality of phonation is the measurement of quality of the patient's voice sound.
<b>Communication methods/strategies</b> (Bayog et al., 2020; Finke et al., 2008; Happ, 2021; Khalaila et al., 2011; Kuyler & Johnson, 2021; Patak et al., 2004)	
Communication methods or strategies (or techniques) can be unaided (use of the body for communication) or aided (use of writing or tools). It can also be attention enhancing from the providers perspective by the use of eye contact, establishment of a communication friendly environment, waiting/pausing to give the patient time to express themselves, establishment of the patient's yes/no signalling, assessment of the patient's mode of communication etc.	
Concepts	Condensation of core
Above cuff vocalization (McGrath et al., 2016, 2019; Mills et al., 2022; Petosic et al., 2021)	Above cuff vocalization is a method to facilitate vocal speech, applying a flow of air via the subglottic port of a tracheostomy tube. The quality of the voice sound varies depending on each patients' abilities.
Aided communication (Rose et al. 2021)	Options for aided communication include non-vocal aids, that is visual-based augmentative and alternative communication aids including writing equipment, communication boards or digital apps that convey symptoms and basic needs without generating speech. Other non-vocal sound-based augmentative and alternative communication aids include speech-generating aids that generate static and dynamic digitized sound such as voice output communication aids (VOCA), speech-generating software and eye gaze technology. Another speech-generating option is the electrolarynx, a device that generates sound (not voice) via transmission of vibration through soft tissue, which is recognizable as speech with movement of the lips, tongue and jaw (articulators).

TABLE 2 (Continued)

Alternative strategies (Johnson et al., 2021)	Alternative strategies for communication can include interpretation of non-vocal signals or using communication aids of different types.
Augmentative and alternative communication (Bayog et al., 2020; Carruthers et al., 2017; Choi & Tate, 2021; El-Soussi et al., 2015; Finke et al., 2008; Foa et al., 2016; Freeman-Sanderson et al., 2019; Garry et al., 2016; Handberg & Voss, 2018; Happ, Roesch, et al., 2004; Happ, Seaman, et al., 2015; Happ, 2021; Holm & Dreyer, 2018b; Holm et al., 2020; Holm, Karlsson, et al., 2021; Hurtig & Downey, 2008; Istanbulian et al., 2020; Jansson et al., 2019; Kuyler & Johnson, 2021; Maringelli et al., 2013; Mobasheri et al., 2016; Modrykamien, 2019; Pina et al., 2020; Rose et al., 2021; Salem & Ahmad, 2018; Ten Hoorn et al., 2016; Ull et al., 2021)	AAC is all types of aided or unaided methods or strategies used to supplement vocal, non-vocal and verbal skills with the aim to aid comprehension. AAC can take the form of various forms of communication, such as: speech, text, gestures, sign language, symbols, images, electronic speech-generating devices, among others. There is a great diversity of AAC methods and tools, which must be adapted to the needs and characteristics of the people to whom they are applied.
Communication aid (Karlson et al., 2019; Rathi & Baskaran, 2014)	Communication aids are tools that may enable communication for some patients.
Communication board (Grossbach et al., 2011; Otuzoğlu & Karahan, 2013; Patak et al., 2006; Rathi & Baskaran, 2014; Rose et al., 2021)	A basic, non-vocal visual augmentative and alternative communication aid. Can exist in different types, such a magic slate board, magnetic plastic boards, or a simple writing board and include letters, words, or pictures describing basic needs, bodily functions or names of people. Can enhance the patient's possibility to express themselves and thereby improve the quality of care.
Communication cards (Albayram & Yava, 2020; Rose et al., 2021)	Basic, non-vocal, visual augmentative and alternative communication aid comprised by either letters, words, or pictures. Used to facilitate patients' communication of needs and emotions.
Electronic voice output communication aids (Happ, Roesch, et al., 2004; Koszaliniski et al., 2015; Maringelli et al., 2013; Modrykamien, 2019)	Electronic voice output communication aids are devices that produce either prerecorded, digitalized voice messages or synthesized speech with the aim to deliver a message to a communication partner.
Eye-tracking devices (Duffy et al., 2018; Garry et al., 2016; Maringelli et al., 2013)	Eye-tracking devices detect eye movements to enable communication through the patients' eyes.
Eye-gaze technology (Rose et al., 2021)	Eye-gaze technology uses technical solutions to determine eye position and gaze point, by gaze dwelling on text or symbols people can then generate speech.
Fenestrated tracheostomy tube (Panadian et al., 2019)	Fenestrated tracheostomy tubes restore and permit phonation allowing the air to enter from the tracheostomy tube into the subglottic area, towards the larynx.
In-line speaking valve (Sutt et al., 2015)	In line speaking valve blocks airflow redirecting it through the upper airways enabling functional use of the glottis to produce verbal communication in a tracheostomized patient.
One-way speaking valve (O'Connor et al., 2018; Panadian et al., 2019)	One-way speaking valve produces speech by airflow through the vocal cords allowing phonation.
Speaking tracheostomy tube (Leder et al., 2013)	Speaking tracheostomy tube permits the tracheostomy tube cuff to remain inflated. Air flows from an external source, into an airline on the outer cannula and exists through an opening superior to the cuff.
Voice restorative strategies (Istanbulian et al., 2020)	Voice restorative strategies can include use of various devices, some requiring cuff deflation and others not.
<b>Communication partners</b> To create joint, meaningful communication and interaction, the relationship with the patient is essential and providers function as communication partners that can facilitate these processes through their dialogue.	
<b>Concepts</b>	<b>Condensation of core</b>
Communication gatekeepers (Holm & Dreyer, 2018a, Holm et al., 2020; Patak et al., 2004)	The communication gatekeepers (providers) often hold the power of communication (regarding the content, duration and methods of communication) because of the patients reduced communication abilities.
Establishment of relationship (Wojnicki-Johanson, 2001)	Establishment of a relationship and collaboration with the patient, including functional communication, is a prerequisite for effective nursing.

(Continues)

TABLE 2 (Continued)

Communicative participation (Laakso et al., 2009)	Communicative participation is involvement in interaction/situations by the means of communication methods in various ways.
Interpersonal communication (Handberg & Voss, 2018; Karlsson et al., 2012; Modrykamien, 2019)	Interpersonal communication is communication between humans either by non-vocal or verbal communication, embedded in everyday interaction. It can be both positive or negative, building bonds or destroying relationships.
Joint attention (Karlsen et al., 2019)	Joint attention essential in interaction between two communication partners and exist when both communication partners acknowledge that there is a mutual attention.
Nurse-patient communication (Ariffin et al., 2020; Bayog et al., 2020; Dithole et al., 2016a; Happ, 2021; Holm & Dreyer, 2018a; Holm et al., 2020; Jansson et al., 2019)	Nurse-patient communication is a relationship build to form meaning making interaction, with a personal touch, as well as ensuring continuity of care and social encounters. It can be either by verbal or non-vocal methods, and includes a personal approach, engagement and meaning making. Communication is the essence of the relationship between the nurse and the patient.
Patient directives (Finke et al., 2008; Happ, 2000; Holm & Dreyer, 2018a)	Patient directives are attempts to communicate which can reveal patient preferences. It can be both non-verbal and written and involves interpretation from the providers or families.
Patient initiation (Happ et al., 2011)	Initiation /opening /induction of communication by patients by any form of communicative signals.
<b>Communication styles</b>	
Communication styles are different approaches to express thoughts, feelings and opinions in interaction with other people. In professional settings, such as healthcare, a communication style can also have a specific purpose, especially related to increase well-being and health.	
<b>Concepts</b>	<b>Condensation of core</b>
Caring/non-caring communication (Karlsson et al., 2012)	Caring communication is when the patient experiences being understood, can express emotions and feels connected, involved and secure. Non-caring communication occurs when providers are neglectful and/or absent.
Effective/ineffective communication (Ariffin et al., 2020; Bayog et al., 2020; Carroll, 2004, 2007; Carruthers et al., 2017; Choi & Tate, 2021; Dithole et al., 2016a; El-Soussi et al., 2015; Finke et al., 2008; Fitch et al., 1998; Freeman-Sanderson et al., 2019; Garry et al., 2016; Guttormson et al., 2015; Ju et al., 2021; Khalalia et al., 2011; Leung et al., 2017; Modrykamien, 2019; Momennasab et al., 2019; Otuzoğlu & Karahan, 2013; Rathi & Baskaran, 2014; Salem & Ahmad, 2018; Wojincki-Johansen, 2001; Yavuz & Gursosy, 2022)	Effective communication is dependent on two individual and environmental factors and occurs when both the sender and receiver of messages achieve shared meaning and understanding. Effective communication can help patients cope with their situation and improve patient outcomes and wellbeing. It is also a quality indicator in healthcare and the foundation of patient-centred care. Ineffective communication is when the communication is not fully understood by either or one of the communication partners, or communications attempts are not acknowledged. It can also occur when one of the communication partners use inadequate communication methods. Ineffective communication can lead to negative emotions/ psychological outcomes for the patient, decreased patient satisfaction and reduced quality of care.
Good/poor communication (Casbolt, 2002; Karlsen et al., 2022; Laakso et al., 2009)	Good and positive communication involves behaviours that facilitate understanding and meaningful interaction between the partners. It is involving and may be therapeutic. Poor communication involves behaviours that do not facilitate understanding and response by the partner. It has proven to be one of the main causes of psychological problems faced by patients after an ICU stay, an upsetting experience that can hinder recovery.
Health-related decision making (Happ et al., 2007)	Health related decision making is related to choices in treatment.
Humanizing/dehumanizing communication (Bayog et al., 2020; Carrol, 2007; Kvande et al., 2021)	Humanization is created through interaction and communication among fellow human beings. To achieve humanizing communication providers must have appropriate training, since focus on machines and procedures in the interaction in the ICU rather than the human being can be experienced as dehumanization.
Micro-decisions (Karlsen et al., 2020)	Micro decisions are small scale decisions "every day" made at the patient's bedside.

TABLE 2 (Continued)

<p>Patient involvement (Happ et al., 2007; Olding et al., 2016)</p>	<p>Patient involvement is inclusion by providers but also recognition of patient's expressions and desire for involvement or prior statements of preference. May enhance the patient's feeling of being in control of the situation.</p>
<p>Successful/unsuccessful communication (Carroll, 2004; Flinterud &amp; Andershed, 2015; Jansson et al., 2019)</p>	<p>Successful communication is when the communication partners understand each other's communication methods and needs. Successful communication plays a key role in the well-being of critically ill patients, using aids, caring environment and understanding contributing to recovery. Unsuccessful communication is the opposite of successful communication where there is a lack of understanding appropriate methods of communication or needs. This may lead to misunderstandings, or feelings of not being understood.</p>

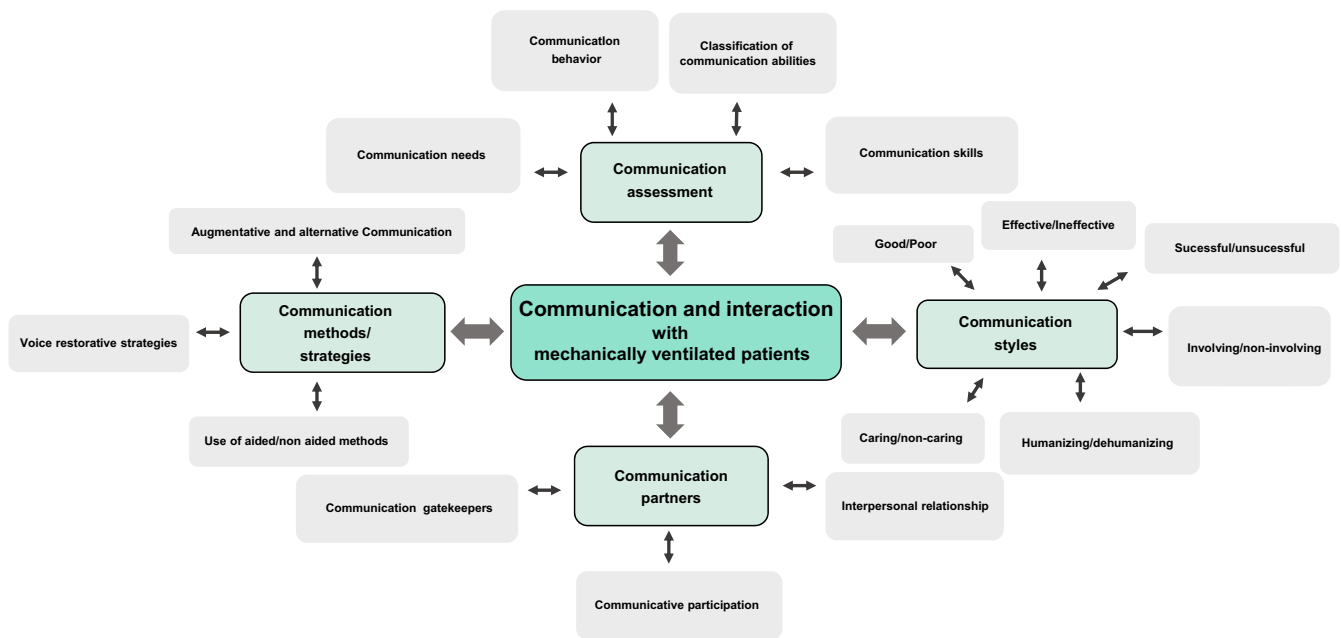


FIGURE 3 Conceptual map

indicators that distinguish between good and poor communication can therefore be a challenge for providers in patient care, although this is an important part of their practice. Laakso et al. (2009, p. 154) identified poor communication as 'one of the main causes for psychological problems faced by patients after an ICU stay, an upsetting experience that can hinder recovery'. In a communication intervention study, Happ et al. (2014) used pre-established for distinguishing between positive and negative nurse communication behaviour, such as acknowledging and augmenting communication using appropriate techniques, ignoring patients' attempts to communicate and not establishing contact with the patient through either verbal means or eye contact. Communication acts from providers can reduce or enhance the quality of communication; however, the communication between patients and providers in ICUs has been previously described as a movement between frustration and comprehension, and is a challenge not only for the patients but also the providers (Holm & Dreyer, 2018a). Communication is complex, and good/poor communication practices can also be linked to processes over time, lack of competency, organizational factors such as lack of

appropriate resources (both physical presence of AAC or staff), or even miscommunication between providers.

To increase the clinical relevance of the model and the concept analysis results, exemplification of communication styles might be useful in a more narrative style in future theoretical development but might require more observational research. The concept analysis may also provide valuable insight into the complexity of communication in healthcare. Theories on communication in healthcare often tend to focus on the interaction between patient and provider using verbal language (since most patients do have the ability to speak), and how patients can receive adequate healthcare, improve their health and cope with illness by verbalizing their needs, preferences and thoughts (The routledge handbook of health communication, 2021).

Im and Meleis (2021) argue that concepts which have not previously been considered relevant can evolve into important concepts in future nursing. The different treatment approaches in ICUs (ABCD[E]; eCASH, analgosedation, humanizing ICUs) have many of the same core values and have interestingly appeared without (yet) any attempt of linkage between them (Balas et al., 2012; Devlin

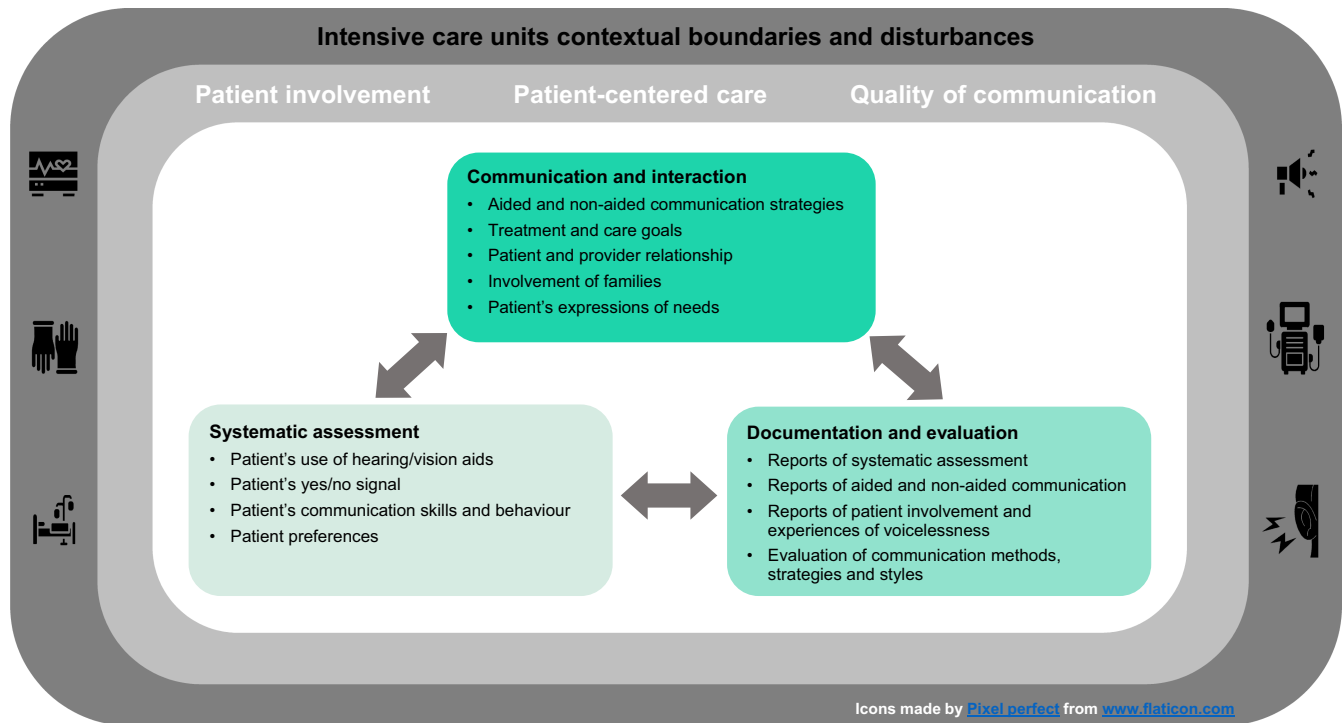


FIGURE 4 Communication between providers and mechanically ventilated patients

et al., 2018; Velasco Bueno & La Calle, 2020; Vincent et al., 2016). These approaches almost ignore, or at least gloss over, the communication challenges that arise but are clearly inspired by person-centred care emphasizing communication as an important task for providers. The communication challenges will also affect all providers working in ICUs but are especially relevant to nurses who are always bedside. Cheraghi et al. (2017) present in their figure of patient-centred care, processes of four steps that are necessary to quality improvement; patient acceptance, assessment, identification and understanding of patient empowerment. Our model (Figure 4) is process-related but also addresses the necessity to document and evaluate the communication approaches. Providers have a unique responsibility to facilitate the processes of communication and interaction to empower the patients, as these patients are both critically ill and voiceless. The model also points to core areas in which quality can be assessed as part of quality improvement projects or research in the future.

## 5.1 | Strengths and limitations

Concepts are building blocks of a theory, but lack of clearly defined or presence of competing concepts can limit our understanding and ability to grasp the phenomena. The concepts and terms found may only be a partial description and changeable with time (Bergdahl & Berterö, 2016; Im & Meleis, 2021). Incorporating descriptions of concepts from both quantitative and qualitative research aimed to ensure a comprehensive view of the phenomena; however, most of the literature identified used qualitative measures which might limit our

understanding (Im & Meleis, 2021). The expert panel had extensive experience but consisted solely of nurses. This might have biased our perspectives on the findings. The methodological approach included literature from other healthcare providers in the analysis, specifically speech-language pathology and communication disorders science. We are planning to test and refine the model with other healthcare professionals in the future.

Frequent dialogue occurred among the international expert panel, which had extensive knowledge about the topic and familiarity with the scientific literature in the field but also in clinical practice, research and education (Elo & Kyngäs, 2008), was a strength. Two authors separately reviewed the literature, the terminology and the concept analysis to ensure trustworthiness and credibility.

The core concepts are synthesized from a broad range of international literature which also strengthens the findings generalizability and transferability to various ICU contexts. In the process of selecting literature to comprise the concept analysis, focusing on literature from the last two decades may have left out a substantial work of pioneers from this area. However, it was important to relate the concepts to today's ICU context, and therefore necessary to use updated literature (Devlin et al., 2018; Im & Meleis, 2021).

## 6 | CONCLUSION

The concept analysis has outlined the most common core concepts of communication with mechanically ventilated patients in intensive care units, which is illustrated in the conceptual map as

communication and interaction with mechanically ventilated patients, communication assessment, communication styles, communication partners and communication methods/strategies. By highlighting different perspectives of the communication and interaction between conscious, mechanically ventilated patients and care providers, we have developed a model to guide a deeper understanding of the phenomena. The findings of the concept analysis can be used in direct clinical practice and for research and quality improvement purposes but can also require further testing. The model is still evolving and will be tested and refined in the future, and may also be a basis for quality improvement projects and further development within research. The goal is to create a theory of communication with mechanically ventilated patients in intensive care which includes a practical model to guide providers in their clinical practice and incorporate examples of best practices. This could also include the facilitation of interventions directed to improve communication from speech language pathologists, occupational therapists, physicians or other providers with treatment responsibility in the ICU-setting.

## AUTHORS' CONTRIBUTIONS

MMWK, AH, MEK, LGH, JAT, PD, MBH: made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; MMWK, AH, MEK, LGH, JAT, PD, MBH: involved in drafting the manuscript or revising it critically for important intellectual content; MMWK, AH, MEK, LGH, JAT, PD, MBH: given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; MMWK, AH, MEK, LGH, JAT, PD, MBH: agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE\*):

1. substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
2. drafting the article or revising it critically for important intellectual content.

\*<http://www.icmje.org/recommendations/>

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No conflict of interest has been declared by the authors.

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Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# The mental health impact of COVID-19 on pre-registration nursing students in Australia: Findings from a national cross-sectional study

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## Abstract

**Aim:** The study aimed to measure and describe the mental health impact of COVID-19 on Australian pre-registration nursing students.

**Background:** The COVID -19 pandemic has had a swift and significant impact on nursing students across the globe. The pandemic was the catalyst for the closure of schools and universities across many countries. This necessary measure caused additional stressors for many students, including nursing students, leading to uncertainty and anxiety. There is limited evidence available to identify the mental health impact of COVID-19 on Australian pre-registration nursing students currently.

**Design:** A cross-sectional study was conducted across 12 Australian universities.

**Methods:** Using an anonymous, online survey students provided demographic data and self-reported their stress, anxiety, resilience, coping strategies, mental health and exposure to COVID-19. Students' stress, anxiety, resilience, coping strategies and mental health were assessed using the Impact of Event Scale-Revised, the Coronavirus Anxiety Scale, the Brief Resilience Scale, the Brief Coping and the DASS-21. Descriptive and regression analyses were conducted to investigate whether stress, anxiety, resilience and coping strategies explained variance in mental health impact. Ethical Approval was obtained from the University of New England Human Research Ethics Committee (No: HE20-188). All participating universities obtained reciprocal approval.

**Results:** Of the 516 students who completed the survey over half ( $n = 300$ , 58.1%) reported mental health concerns and most students ( $n = 469$ , 90.9%) reported being impacted by COVID-19. Close to half of students ( $n = 255$ , 49.4%) reported signs of post-traumatic stress disorder. Mental health impact was influenced by students' year level and history of mental health issues, where a history of mental health and a higher year level were both associated with greater mental health impacts. Students experienced considerable disruption to their learning due to COVID-19 restrictions which exacerbated students' distress and anxiety. Students coped with COVID-19 through



focusing on their problems and using strategies to regulate their emotions and adapt to stressors.

**Conclusion:** The COVID-19 pandemic has considerably impacted pre-registration nursing students' mental health. Strategies to support nursing students manage their mental health are vital to assist them through the ongoing pandemic and safeguard the recruitment and retention of the future nursing workforce.

**Impact statement:** This study adds an Australian understanding to the international evidence that indicates student nurses experienced a range of negative psychosocial outcomes during COVID-19. In this study, we found that students with a pre-existing mental health issue and final-year students were most affected. The changes to education in Australian universities related to COVID-19 has caused distress for many nursing students. Australian nursing academics/educators and health service staff need to take heed of these results as these students prepare for entry into the nursing workforce.

**Patient or public involvement:** The study was designed to explore the impact of COVID-19 on the mental health of undergraduate nursing students in Australia. Educators from several universities were involved in the design and conduct of the study. However, the study did not include input from the public or the intended participants.

#### KEYWORDS

clinical placement, COVID-19, mental health, nurse education, nursing, students

## 1 | INTRODUCTION

In March 2020, the World Health Organization formally labelled the global spread of the SARS-CoV-2 strain of coronavirus as a pandemic (hereafter known as COVID-19) (WHO, 2020). Since this time, the COVID-19 pandemic has gone on to have impact on almost every aspect of modern living. The healthcare sector has seen significant upheaval during this time, with impact on all areas of health delivery, from policy development, research, clinical practice and education. As the largest professional group in the global healthcare workforce, nurses have been at the forefront of the healthcare response and consequently, the COVID-19 pandemic has had a major influence on nursing education, with the actions taken to 'flatten the curve' of transmission having impact on nursing students across the globe (Fowler & Wholeben, 2020).

In response to the first case of COVID-19 in Australia in January 2020, the government introduced the Australian Health Management Plan for Pandemic Influenza (Australian Government, 2020) to limit the spread of the virus resulting in the implementation of social distancing policies and imposed limitations on social gatherings. At certain time of the pandemic, lockdown on movements of people within and between States and territories were enforced (Australian Government Department of Health, 2020) and the national borders were closed from March 2020. The effect of the pandemic varied across Australia with the most severe lockdowns occurring in Victoria. The prevention strategies led to closure of schools and

### What is already known about the topic?

- The COVID-19 pandemic has impacted the healthcare sector on a global scale
- Healthcare professionals, in particular nurses, have been at the forefront of the healthcare response to the pandemic
- Nursing students have been impacted two-fold: as members of society where imposed quarantine has resulted in isolation and as students learning in educational and clinical settings affected by the pandemic

### What this paper adds

- Most students reported being impacted by the COVID-19 pandemic, and more than half of students reported mental health concerns.
- Despite students reporting these mental health concerns, students displayed levels of resilience and utilized coping strategies to adapt to their situation.

universities, and cancellation of non-urgent surgeries and health services (Wahlquist, 2020). The closure of universities led to the rapid transformation of nursing education into online delivery modes (Cao et al., 2020), and clinical placements were cancelled or offered as

online simulations (Carolan et al., 2020). Given previous research indicates that nursing students experience high levels of distress related to clinical placements during pandemics (Dewart et al., 2020), the cancellation of placements or transfer to simulated learning may have also caused distress to nursing students in Australia.

In this study, we sought to examine the background variables (e.g. year of study, previous mental health issues) in relation to the impact of COVID-19 and related educational changes on undergraduate nursing students in Australia. A deeper understanding of these impacts may help identify the need for system level changes to improve nurse education delivery and foster a smoother transition to the nursing workforce.

## 2 | BACKGROUND

The pandemic has resulted in many changes to nursing education programs across the globe (Carolan et al., 2020). The states and territories of Australia adopted a containment strategy attained through various systems of tracing, social restrictions, lockdowns and other measures from March 2020 and only relaxing these measures from late 2021 once sufficient vaccination was attained and appropriate treatments were established. These measures included the closure of schools and universities across Australia and globally (Viner et al., 2020). For many nursing students, the isolation resulted in the cancellation of classes and clinical placement activities, the introduction of virtual or hybrid learning approaches (Haslam, 2021; Suliman et al., 2010), replacement of clinical placements with other models of clinical learning (Canet-Vélez et al., 2021; Casafont et al., 2021; de Almeida Peres et al., 2020), or working or attending clinical placements in hospitals where they may be required to care for infectious people, and/or risk exposure to infected patients and staff (Cao et al., 2020; Usher, Wynaden, Bhullar, et al., 2020).

As a result of the quarantine strategies, nurse educators altered modes of delivery of education and clinical practice activities; many of which were continued for some time (Ion et al., 2021) and in some instances continue today (Ramos-Morcillo et al., 2020). The need to rapidly alter the way in which curricula and courses were delivered has caused disruption to the education of thousands of nursing students, with evidence suggesting that many students will be delayed in their progression and graduation (Jackson & Usher, 2022). Delays in progression for nursing students have been linked to negative mental health outcomes (Palese et al., 2020) with potential to impact the student as an individual, nursing as a profession, as well as the healthcare system. Indeed, uncertainty over the pandemic, and the ongoing interruptions to study and clinical placement have resulted in some nursing students deciding to leave the profession (Eweida et al., 2020; González et al., 2021), though conversely some students have reported that participating in pandemic-related duties reinforced a desire to enter the nursing profession (Michel et al., 2021).

Little is known about the potential short- and longer-term impacts of the COVID-19 pandemic on nursing students (Jackson & Usher, 2022). Previous studies have identified an impact of the

COVID-19-related changes to nursing education on student mental well-being (Aslan & Pekince, 2021; Patelarou et al., 2021; Reverté-Villarroya et al., 2021; Savitsky et al., 2020). International students have been identified as a particularly vulnerable group of nursing students who may be more isolated and hence more at risk to the negative effects of imposed quarantine strategies (Andrew, 2020). In the Australian state of Victoria, which unquestionably experienced the most stringent and most prolonged restrictions, it is known that nursing students experienced significant stress, anxiety, isolation and loss of motivation as a result of the pandemic (Rasmussen et al., 2022). However, moving beyond the state of Victoria, looking nationally to the whole of Australia, the picture of psycho-social and mental health impacts on nursing students is less clear.

Similar to other countries, Australia is facing a significant shortage of skilled graduate nurses and this shortage is predicted to become more acute as COVID-19 places increasing burden on nurses and midwives and the healthcare system (Adelson et al., 2021). Thus, a national understanding of the mental health impacts of COVID-19 on Australian pre-registration nursing students will provide important information that can inform health and education providers to better support students in the future. The objectives of the study were to measure the mental health impact of COVID-19 on Australian pre-registration nursing students, and to determine if effects are linked to factors such as location/university, experience, degree or years completed.

## 3 | THE STUDY

### 3.1 | Aim

The study aimed to measure and describe the mental health impact of COVID-19 on Australian pre-registration nursing students. In addition, we explore related variables (for example year of study and previous history of mental health issues) and level of distress. The objectives of the study were to:

- Measure the mental health impact of COVID-19 on Australian pre-registration nursing students.
- Determine if the mental health impact of COVID-19 on Australian pre-registration nursing students is linked to location or university, experience, degree, years completed or level of resilience.

### 3.2 | Design

A national multi-centre, cross-sectional survey was administered via Qualtrics® between the 27 February and 3 November 2021. The G\*Power 3.1 program was used to calculate sample size requirements to determine whether PTSD (IES-R), COVID-19 anxiety (CAS), resilience (BRS) and coping strategies (Brief COPE Inventory) predict mental health impact (DASS-21), and which predictors explain variance in this outcome. A total of 261 participants were required to

detect a small effect size of 0.10, with a power ( $1-\beta$ ) of .90 for 17 predictors (IES-R x 3 sub-scales, CAS x 5 items, BRS x 6 items, 3 COPE sub-scales) in a linear multiple regression model.

Several valid and reliable instruments were used to measure the effect of independent (location or university, experience, degree, years completed and level of resilience) on the dependent variable (mental health impact of COVID-19). Demographic variables included age, sex, postcode, indigenous status, relationship status, local or international student status, year of enrolment in the degree, living arrangements and employment status, in addition to whether students had a history of mental health problems or COVID-19 exposure. There were three open-ended questions to ascertain students' perceptions of challenges linked to COVID-19-related clinical placement delays, attendance at clinical placement during COVID-19, issues related to isolation and the inability to attend face-to-face classes, and laboratory learning sessions during periods of COVID-19 restrictions (this information will be presented in a later paper). This cross-sectional study has been reported using the STROBE guidelines (Vandenbroucke et al., 2007).

### 3.3 | Participants

A convenience sample of pre-registration nursing students from 12 Australian universities was invited to participate via email or their university-specific online learning platform. Several university schools of nursing were invited to participate in the study; those that responded were included. The final sample included representative universities from New South Wales, Tasmania, South Australia, Victoria, Western Australia and Queensland. The Australian Capital Territory and the Northern Territory were not included in the sample and not all universities in included States participated in the study. The total potential sample was approximately 11,500 students. We did not record numbers from individual universities as the ethics committee was not prepared to endorse that request.

### 3.4 | Data collection

Invitations were sent by student administration services with a reminder sent 2–4 weeks after the initial invitation. The online survey was comprised of three key sections to ascertain sample demographics (Section 1), independent variables (Section 2) to assess effect on mental health impact including post-traumatic stress, COVID-19 distress and anxiety, level of resilience and coping strategies and the dependent variable mental health impact (Section 3). Section 3 was comprised of three open-ended questions to ascertain students' perceptions of challenges linked to COVID-19-related clinical placement delays, attendance at clinical placement during COVID-19, issues related to isolation and the inability to attend face-to-face classes and laboratory learning sessions during periods of COVID-19 restrictions. The survey took an estimated 50 min to complete.

### 3.5 | Ethical considerations

Permission to conduct the study was initially received from the University of New England Human Research Ethics Committee (HREC) (#HE20-188). Other participating higher education schools of nursing submitted an ethics application at their relevant university after the initial ethical clearance was received from the lead university. The invitation was not linked to any course materials and academic teaching staff were not involved in recruitment to mitigate potential perceptions of coercion. The participant information sheet was embedded within the survey. Consent was implied by survey completion. As the survey had potential to cause emotional distress, participants were provided with numbers for mental health support services and were provided with the access details to a local support person should they become distressed. As surveys were anonymous, there was no way to follow-up students who did indicate distress directly. However, the Participant Information sheet did provide the details for the lead researcher. As the outcomes of this survey have important results for the participants, dissemination of results will include the development of a one-page handout of the results will be developed and shared with universities schools of nursing and health service providers.

### 3.6 | Data analysis

Survey data were extracted from Qualtrics® into an IBM SPSS® (Statistical Package for the Social Sciences Version 27.0: IBM Corp.) file for analysis. Data were screened and cleaned. Continuous data were analysed using descriptive statistics presented as mean (M) with standard deviation (SD), or median (Med) and inter-quartile range when abnormally distributed (IQR). Frequency ( $n$ ) and proportion (%) were calculated for categorical variables. Likert scale item responses that did not meet assumptions of normality were treated as ordinal categorical data and described using frequency and proportion for each response. DASS-21 scores are reported as mean (M) with standard deviation (SD) and proportion of responses in each category. To enable categorization according to developers' recommendations and comparisons with population norms, scores were doubled. Mental health impact is reported as extremely severe ( $\geq 82$ ), severe (62–79), moderate (43–59), mild (33–40) or normal (0–30).

The characteristics of participants who did and did not complete Section 3 of the survey were compared to determine whether there were factors that might have influenced the decision to complete survey items. Apart from two factors, demographics did not differ. Those who did not complete were younger ( $M$  24.1,  $SD$  7.8 vs.  $M$  26.7,  $SD$  8.6 years;  $t$  [735] =  $-3.9$ ,  $p < .001$ ) and more likely to have had professional treatment for mental health problems ( $n = 204$ , 70.1% vs.  $n = 87$ , 29.9%;  $\chi^2$  [1, 291] 4.08,  $p = .04$ ). Incomplete responses for independent and dependent variables were subsequently excluded from further analyses. Univariate comparisons were completed to determine whether there were any differences in the demographic characteristics of responders according to the primary endpoint of mental health impact as indicated by total

DASS-21 score. Independent samples *t*-tests or one-way analysis of variance (ANOVA) for more than two group comparisons, were used to explore group differences in mental health impact (DASS-21). Hierarchical multiple regression analyses were completed to examine whether PTSD (IES-R), COVID-19 anxiety (CAS), resilience (BRS) and coping strategies (Brief COPE Inventory) as a set of predictors explained variance in mental health impact (DASS-21) in a model adjusted for univariate group differences. The study has been reported according to the STROBE guidelines.

### 3.7 | Validity and reliability

Quantitative assessment of mental health involved the use of validated reliable instruments that captured responses on a 4- or 5-point Likert scale.

#### 3.7.1 | Impact of Event Scale-Revised

This 22-item scale (Weiss & Marmar, 1997) assesses general negative affectivity related to a traumatic experience. The tool is not intended as a diagnostic tool but rather offers a way to measure the subjective response to a specific traumatic event. There is no true cut-off score but scores higher than 24 are considered worrisome with scores higher than 33 indicate the presence of post-traumatic stress disorder (PTSD) and associated mental health consequences (McCabe, 2019; Weiss, 2007). The scale has good psychometric scores; the three subscales were found to be very high, with intrusion alphas ranging from .87 to .92, avoidance alphas ranging from .84 to .86 and hyperarousal alphas ranging from .79 to .90 (Briere & Elliott, 1998). The IES-R has been used to evaluate the impact of COVID-19 with good fit, reliability and convergent validity (Nia et al., 2021; Vanaken et al., 2020).

#### 3.7.2 | Coronavirus Anxiety Scale

This 5-item scale (Lee, 2020a, 2020b) is brief mental health screener for the COVID-19 pandemic-related anxiety. Principal component and factor analyses for the CAS were shown to be highly reliable ( $\alpha = .93$ ), thematically consistent (i.e. distressing physical symptoms associated with coronavirus fear and anxiety) and stable (i.e. CFA confirmed PCA results). In addition, the CAS was shown to measure anxiety symptoms in similar ways across demographic groups and was recommended as a useful screening tool (Lee, 2020a, 2020b).

#### 3.7.3 | Brief Resilience Scale

This 6-item scale (Smith et al., 2008) measures resilience or how well one is equipped to bounce back after hard times or stressful life

events and an ability to recover from stress. The BRS reliability was tested across four samples with a Cronbach's alpha ranging from .80 to .91 (Smith et al., 2008). The BRS has further been validated and recommended as a reliable tool (coefficient alpha of .71) to examine resilience among undergraduate students (Fung, 2020).

#### 3.7.4 | Brief COPE Inventory

This 28-item scale assesses problem-focused, emotion-focused coping and avoidant coping styles using responses (Carver et al., 1989). Response categories for Likert scale items were assigned the lowest value at the negative end of the scale (e.g. Strongly Disagree), the highest value at the positive end (e.g. Strongly Agree) and a zero for 'no' or 'not at all', with the exception of three items in the BRS that had reverse scoring.

#### 3.7.5 | Depression Anxiety Stress Scale

This 21-item scale (Lovibond & Lovibond, 1995) measures symptoms of depression, anxiety and stress. The severity of mental health impact as the primary endpoint measure was assessed using the Depression Anxiety Stress Scale (DASS-21). This 21-item survey (Lovibond & Lovibond, 1995) provides a continuous estimate of level of distress that can be further scrutinized according to the separate sub-scales of depression, anxiety and stress. The depression sub-scale was categorized as extremely severe ( $\geq 28$ ), severe (21–27), moderate (14–20), mild (10–13) or normal (0–9); Anxiety as extremely severe ( $\geq 20$ ), severe (15–19), moderate (10–14), mild (8–9) or normal (0–7) and Stress as extremely severe ( $\geq 34$ ), severe (26–30), moderate (19–25), mild (15–18) or normal (0–14). Internal consistency (Cronbach's alpha coefficient) of the sub-scales in this sample was assessed and a value of 0.75 or higher indicative of good reliability.

#### 3.7.6 | The Brief COPE Inventory

(Carver, 1997) has recently been validated among nurses with a reliable second-order exploratory factor analysis of 0.81 and 0.86 (Abdul Rahman et al., 2021).

## 4 | RESULTS

Of the 858 students that accessed the survey 516 (60.1%) completed all survey items. Sample characteristics are listed in Table 1. There were similar proportions of students in years one, two or three of their degree with 35 (6.8%) enrolled beyond 3 years because they had progress issues secondary to COVID-19 ( $n = 7$ , 1.4%), changed degrees ( $n = 8$ , 1.6%), were enrolled part time ( $n = 10$ , 1.9%) or were in enrolled a double degree ( $n = 10$ , 1.9%). Most students lived in metropolitan

TABLE 1 Participant characteristics

Characteristic	n, M	%, SD
Age	26.7	8.5
Female	453	87.8
Aboriginal or Torres Strait Islander	10	2.0
Geographical location		
Metropolitan	326	63.2
Regional	126	24.4
Rural	47	9.1
Remote	4	0.8
Lockdown Affected (NSW, VIC)	198	38.3
Year of enrolment		
First year	144	27.9
Second year	166	32.2
Third year	171	33.1
International student	105	20.3
Not in a relationship	247	47.9
Partnered	252	48.8
Lives with others	474	91.9
Lives alone	42	8.1
Full-time employment	27	5.2
Part-time/casual employment	290	56.2
Unemployed looking for work	77	14.9
Unemployed not looking	46	8.9
Mental health history	300	58.1
Professional mental health treatment	205	39.7
Impacted by COVID-19	469	90.9
COVID-19 Positive	20	3.9

Note: Figures may not equal 100% due to missing data.

locations ( $n = 326$ , 63.2%). Students ( $n = 293$ , 56.8%) in Australian States largely unaffected by ongoing lockdowns (WA  $n = 127$ , 24.6%; QLD  $n = 42$ , 8.1%; NT  $n = 1$ , 0.2%; Tasmania  $n = 38$ , 7.4%; SA  $n = 85$ , 16.5%) were surveyed in March or April. The remaining students from Victoria ( $n = 74$ , 14.3%) and NSW ( $n = 124$ , 24.0%) completed the survey in July or August when Victoria was in lockdown for the sixth time and Sydney had a 5 km travel restriction in place.

Mental health problems had been experienced by just over half ( $n = 300$ , 58.1%) of the participants and most ( $n = 469$ , 90.9%) claimed they had been impacted by COVID-19. Students' experience of COVID-19 at the time of the survey influenced their responses a lot or a great deal ( $n = 228$ , 44.2%), moderately ( $n = 159$ , 30.8%) or had little to no influence ( $n = 122$ , 23.6%). CAS scores indicative of dysfunctional anxiety ( $\geq 9$ ) secondary to COVID-19 were evident in only a small proportion of respondents ( $n = 41$ , 7.9%) but most participants agreed COVID-19 was distressing (Table 2).

According to IES-R scores, 49.4% of students ( $n = 255$ ) had at a minimum, signs of clinically concerning PTSD. Of these students, 10.9% ( $n = 28$ ) had probable PTSD and 56.4% ( $n = 144$ ) had levels

of stress consistent with immune system suppression and severe PTSD. Notably, level of resilience was within normal limits (BRS  $M = 3.1$ ,  $SD = 0.5$ ,  $IQR = 4.0$ ) at the time of the survey. Coping strategies to deal with stressors were explored using the Brief COPE inventory that revealed students' approach to coping was generally underpinned by being problem focused ( $M = 18.8$ ,  $SD = 5.5$ ,  $IQR = 24.0$ ) using strategies to regulate their emotions ( $M = 26.5$ ,  $SD = 6.6$ ,  $IQR = 34$ ) and to adapt to stressors ( $M = 14.8$ ,  $SD = 4.4$ ,  $IQR = 23.0$ ).

In this cohort, the DASS-21 had excellent internal consistency with a Cronbach alpha coefficient of .91. Cronbach alpha coefficients for the stress (.86), anxiety (.79) and depression (.82) sub-scales were also indicative of good reliability. Mean scores for the DASS-21 sub-scales for students for stress ( $M = 8.4$ ,  $SD = 5.3$ ), anxiety ( $M = 5.7$ ,  $SD = 4.9$ ) and depression ( $M = 7.6$ ,  $SD = 5.8$ ) were much higher than pre-pandemic Australian population means of 3.99, 1.74 and 2.57 respectively. In this sample, the impact of COVID-19 on mental health was not problematic ( $n = 202$ , 39.1%), mild ( $n = 65$ , 12.6%), moderate ( $n = 110$ , 21.3%), severe ( $n = 75$ , 14.5%) or extremely severe ( $n = 64$ , 12.4%). The proportion of students for each category of the stress, anxiety and depression sub-scales is shown in Table 3.

Mental health impact differed according to two demographic characteristics. The higher the year of study the greater the DASS-21 score for students;  $F(3, 512) = 3.0$ ,  $p = 0.03$ . Post hoc comparisons using the Tukey test indicated the mean score for first-year students ( $M = 18.6$ ,  $SD = 13.8$ ) was significantly different from that of third-year students ( $M = 23.2$ ,  $SD = 14.7$ ) whose scores were not unlike those in second ( $M = 22.1$ ,  $SD = 15.0$ ) and fourth year ( $M = 24.1$ ,  $SD = 16.9$ ). Those students who had a previous history of mental health issues ( $n = 300$ , 58.1%) were also more likely to have higher DASS-21 scores ( $M = 26.4$ ,  $SD = 14.2$  versus  $M = 15.1$ ,  $SD = 13.0$  years;  $t[514] = -9.4$ ,  $p < 0.001$ ). Hierarchical multiple regression was used to identify predictors of mental health impact, after controlling for the influence of year of study and previous mental health issues. Preliminary analyses confirmed no violation of required assumptions. Year of study and previous mental health issues were entered at Step 1 explaining 15.9% of the variance in mental health impact. After entry of variables used to assess PTSD (IES-R), COVID-19 anxiety (CAS), resilience (BRS) and coping strategies (Brief COPE Inventory) in Step 2 the total variance explained by the model was 64.1%,  $F(19, 496) = 46.6$ ,  $p < .001$ . In the final model factors associated with increased mental health impact were previous mental health issues ( $\beta = .14$ ,  $p < .001$ ), feeling nauseous as a symptom of anxiety when exposed to information about COVID-19 ( $\beta = .99$ ,  $p = .02$ ), hyperarousal as a symptom of PTSD ( $\beta = .36$ ,  $p < .001$ ), finding it hard to make it through stressful events ( $\beta = .08$ ,  $p = .03$ ), not being able to regulate emotions to cope ( $\beta = .18$ ,  $p < .001$ ), and having to use physical or cognitive efforts to disengage from stress to cope ( $\beta = .20$ ,  $p < .001$ ).

## 5 | DISCUSSION

This study aimed to explore whether the changes related to the COVID-19 pandemic affected the mental health of Australian



TABLE 2 Covid-19 distress

Item	Response						M	SD
	Disagree		Neutral		Agree			
	N	%	n	%	n	%		
Anxious about negative consequences of COVID-19	53	10.3	66	12.8	397	76.9	3.9	0.9
Distressed that COVID-19 might affect me, family or friends	53	10.3	57	11.0	406	78.7	3.9	0.9
Plan to carry out actions to protect myself or others from COVID-19 impacts	16	3.1	38	7.4	462	89.5	4.2	0.8
Find it hard to get on with things because am thinking about COVID-19	212	41.1	121	23.4	183	35.5	2.9	1.2
Watching news stories about the pandemic makes me nervous or anxious	114	22.1	107	20.7	295	57.2	3.5	1.1
Stressed around other people in case I catch COVID-19	219	42.4	123	23.8	174	33.7	2.9	1.2
Thinking about COVID-19 makes me feel threatened	199	38.6	130	25.2	187	36.2	2.9	1.2
COVID-19 has negatively impacted me financially	136	26.4	87	16.9	293	56.8	3.5	1.3
Has been difficult to get essential resources I need because of COVID-19	232	45.0	128	24.8	156	30.2	2.8	1.2
COVID-19 has impacted my psychological health negatively	97	18.8	93	18.0	326	63.2	3.6	1.1
I spend a lot of time trying to find updates about COVID-19	272	52.7	107	20.7	137	26.6	2.6	1.2

TABLE 3 Categories of stress, anxiety and depression as indicated by DASS-21 sub-scale scores

Dass-21 sub-scales	Normal		Mild		Mod		Severe		Extreme	
	n	%	n	%	n	%	n	%	n	%
Stress	244	47.3	71	13.8	84	16.3	56	10.9	61	11.8
Anxiety	199	38.6	52	10.1	111	21.5	43	8.3	111	21.5
Depression	186	36.0	60	11.6	121	23.4	63	12.2	86	16.7

pre-registration nursing students. The study found that mental health problems had been experienced by just over half ( $n = 446$ , 56.6%) of the participants, and 65% ( $n = 290$ ) had sought professional help or treatment for their mental health problem. Most participants ( $n = 717$ , 91%) claimed they had been impacted by COVID-19 and 33 (4.2%) had tested positive, 49.4% of students ( $n = 255$ ) had at a minimum, signs of clinically concerning post-traumatic stress disorder (PTSD). Issues ranged from disconnection or breakdown of social support of the family and friends; disconnection with industry professional networks; making poor decisions around their health and well-being; to the deeper psychological impacts of hyperarousal, physical symptoms of anxiety and being unable to regulate emotions to disengage from stress or cope. The deeper psychological impacts on the participants in this study were more pronounced among students in their final year of study and those with a pre-existing mental disorder. The combined impact of these two variables explained 15.9% of the variance, with the pre-existing mental health conditions showing statistically significant findings ( $\beta = .14$ ,  $p < .001$ ). These results echo similar studies undertaken with nursing students

during the COVID-19 pandemic (Aqeel et al., 2021, Cao et al., 2020, Reverté-Villarroya et al., 2021).

The fact that final-year students reported higher levels of distress in this study is worrying. These students are close to completion and will soon enter the workforce. Previous researchers have also reported similar findings (Aqeel et al., 2021, Cao et al., 2020, Reverté-Villarroya et al., 2021). Reverté-Villarroya et al. (2021) found that final-year nursing students who experienced COVID-19 experienced a two-times greater risk of experiencing mental health issues than previous final-year students who did not experience COVID-19. In addition, also found that final-year students reported more symptoms of mental health distress. These final-year students will soon transition to the workforce and will be charged with providing caring for unwell people. Given the current shortage of registered nurses in Australia and across the globe, it is paramount that educators recognize the risk of mental distress in nursing students and develop appropriate interventions to assist students to manage their symptoms (Li et al., 2021). Furthermore, as these students transition to the practice environment, they must be supported to



manage their distress and must be provided with adequate support and counselling as needed.

The finding that 49.4% of the participants in this study reported severe signs of PTSD are concerning. Previous studies have, however, presented similar results. For example, reported 44.5% of nursing students with signs of PTSD. The greater levels of psychosocial distress and PTSD reported by final-year students in this study is concerning as these students are close to entering the workforce as registered nurse professionals. It is important for the health services to recognize that many new registered nurses will still be experiencing symptoms of PTSD and may require professional support such as mentoring during the transition period.

The findings of this study revealed that students with a pre-existing mental health condition were more likely to experience greater levels of mental distress related to the pandemic and the changes to their course than other students. Pre-existing mental health conditions are becoming more evident in students enrolling in nursing courses (Ramluggun et al., 2018, Yang & Yoon, 2015). It is also known that students in nursing experience high levels of stress (Reeve et al., 2013) which makes them more vulnerable in times of great change and distress such as the recent pandemic. These students need greater levels of support from universities and educators must be careful that course demands are addressed to ensure they do not cause students' undue distress. It is also necessary for universities to include inclusive teaching and learning approaches to ensure the needs of all students are better accommodated (Ramluggun et al., 2021).

The introduction of virtual or hybrid learning approaches (Haslam, 2021; Suliman et al., 2010), introduced to ensure nurse education could continue during the pandemic. Poor psychosocial outcomes, as identified in this study, affect active learning (Rasmussen et al., 2022), reduce motivation to learn, decrease concentration and impact the learning process (Alici & Copur, 2021), which may be even worse when a totally new learning strategy is introduced. While only 105 international nursing students from across Australia participated in the study, we know that they are more likely to live in isolation from family and friends if they remained in Australia which left them with little active support; hence they may have been more at risk of developing distress. In addition, most international students were sent home during the pandemic but when they returned, the education experience they returned to had differed greatly. Outcomes of increased mental distress are likely to lead to poorer academic achievements, which may have impacted student completion and progression. To overcome this potential problem, students need to be offered mental health support and counselling during their education to avoid worsening mental health.

The prevalence of PTSD in a community has been linked to how well a particular community is managing COVID-19 and the impact it is having on community members. The unprecedented coverage of the pandemic on social and other media sources may also account for high levels of PTSD (Horesh & Brown, 2020). Researchers have reported that the prevalence of PTSD during COVID-19 in the community ranges from 8 to 50% (Cenat et al., 2021). For many nursing

students, the experience of living through COVID-19 while trying to complete their nursing program has been a significant traumatic event with almost half of the students surveyed in this study describing clinically concerning signs of PTSD.

Some research has identified that younger females experience higher levels of PTSD than other groups in the population (Rodriguez-Rey et al., 2020). As nursing is a predominantly female profession, this is an important factor to identify in managing support programs both in the university and health settings. In this study, younger students.

Additionally, there is a risk to participant confidence and negative mental health outcomes (Palese et al., 2020) including their registration status and future career if they unknowingly or through lack of experience do not have strong clinical decision-making skills and near-miss or clinical errors occur. Furthermore, due to other factors compounded by the pandemic including staff attrition, burn-out or increased acuity recipients of care, staffing skill mix may not be optimum (Galanis et al., 2021; Peters et al., 2021). Mandated numbers of staff may not reflect a deeper issue of lack of high-level knowledge, skills and capability of the complexity of nursing within healthcare environments that may further exacerbate feelings of under preparedness or inadequacy. These new graduates may lack mentoring or opportunities to access knowledge, skills and capability of advanced practitioners due to changes in workforce within healthcare environments created by the burden of the pandemic (Galanis et al., 2021).

Participants reported negative financial impacts of delayed preparation or inadequate preparation through a change in mode of delivery to be more heavily weighted to online learning and inability to practise nursing skills in a simulation environment (Ion et al., 2021).

The acute psychosocial distress and rates of post-traumatic stress disorder identified in this population will undoubtedly have lasting impact on this cohort and the emerging nursing workforce. While many may have been able to adapt to psychological distress in the early stages of the pandemic, additional and long-term stressors can potentially trigger mental health conditions (Sampaio et al., 2021). Changes to health and well-being can affect the entry and transition into the nursing workforce. The disruption to learning/education and the resulting elevated distress experienced by participants is yet to be actualized in the emerging new nurse workforce (Haslam, 2021). However, these factors in combination with emerging global workforce concerns, such as population health trends and an ageing workforce, are likely to impact sustainability, recruitment and retention of the global nursing workforce and undoubtedly exacerbate predicted future nursing shortages in Australia and across the globe. If unprecedented and unexpected challenges to the transition from nursing student to graduate nurse because of the pandemic continue, nurses may leave the profession, increasing the impact on future workforce numbers (Udod et al., 2021). Delays in graduation have been predicted to affect the support and development of the nursing workforce in the short term (Kennedy, 2021), with the disruption to the supply of newly

graduating nurses hindering efforts to re-establish nursing skill mix and ratios in the wake of the pandemic (Kennedy, 2021).

While there is much discussion on the negative impacts of the pandemic on nursing students, some suggest that the multiple challenges have equipped this group with enhanced information and technological skills (Wallace et al., 2021). In this study, the finding that students' coping scores were quite unaffected even though high levels of distress were reported, indicated that the participants were coping quite well despite the challenges faced because of the pandemic. Furthermore, these participants have adapted to unprecedented challenges potentially strengthening personal resilience and adapted coping styles as reported elsewhere (Drach-Zahavy et al., 2022). Regardless, the COVID-19 pandemic highlighted existing challenges within the existing nursing workforce, and although the effect will continue to be felt soon (Dow et al., 2020; Weston, 2022), the impact of the COVID pandemic on the emergent and future workforce is yet to be fully realized.

### 5.1 | Implications for education, practice and research

Nursing students have clearly been negatively impacted by COVID-19 and have experienced a range of mental health issues that may have long-reaching effects including causative triggers for PTSD as future registered nurses. It is recommended that in the aftermath of the COVID-19 pandemic, nursing students are supported by their university for the remainder of their educational preparation through the provision of counselling and mental health support services. Furthermore, nursing students need to be cognisant of the potential for post-pandemic PTSD both short term as a nursing student, but also in the coming years as a registered nurse, where other significant healthcare events and pressures may trigger negative feelings and emotions related to the impact of COVID-19. Further studies of the longer-term impact of the COVID-19 pandemic on nursing students should be undertaken. The research should focus on ongoing mental health problems, transition to practice by students affected by the pandemic and the competence and confidence of new graduates.

### 5.2 | Limitations

Inherent limitations of cross-sectional studies are that they capture one moment in time and are inherently prone to certain biases thus accurately interpreting the outcome and association must be undertaken with some caution. The COVID-19 outbreaks occurred at different times across the States and territories of Australia; hence timing of our data collection may have impacted the results. The 8-month data collection period potentially was a multiplying effect of COVID-19 that potentially had a greater impact for the student nurses who completed the survey later in the study administration period. The use of self-reported scales is also an issue as reporting may have been influenced by individual emotional state and/or

insight into the issue causing a biased sample. It also has an impact on whether participants decide to participate in the study or complete the survey in its entirety. As the survey used in this study was quite lengthy, the high number of students who did not complete the entire survey may be because of this fact. The recruitment of students from 12 universities in Australia and the sample size may modify the limitations to some degree.

## 6 | CONCLUSIONS

Today's nursing students are tomorrow's nursing workforce; society will depend on this labour force in the event of future public health crises such as a pandemic. The findings of this study provide crucial information about the effects of the COVID-19 pandemic on student nurse's mental health and exposes their vulnerability during the pandemic. As educators, understanding underlying mental health conditions that may impact students are fundamental to our duty of care. It is therefore vital that information about any negative sequelae associated with the pandemic is recognized and quantified, and that strategies are put into place to support nursing students and mitigate any residual distress in the future. As the COVID-19 epidemic continues information gained through this study provides evidence to inform the provision of health and educational services to support students in the event of further pandemic-associated restrictions to social participation and disruptions to education. Importantly, further research is needed to determine if these findings reveal longer-term impacts of this cohort.

### AUTHOR CONTRIBUTIONS

Kim Usher AM and Debra Jackson were involved in conceptualizing the study and designing the protocol. Kim Usher AM led the project. Rochelle Wynne conducted the statistical analysis. All authors contributed to the interpretation of results. All authors contributed to the writing of the manuscript, and all authors read and approved the final manuscript.

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### CONFLICT OF INTEREST

The authors declare no conflicts of interest.

### PEER REVIEW

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### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

### ETHICS STATEMENT

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# The identification of clusters of risk factors and their association with hospitalizations or emergency department visits in home health care

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## Abstract

**Aims:** To identify clusters of risk factors in home health care and determine if the clusters are associated with hospitalizations or emergency department visits.

**Design:** A retrospective cohort study.

**Methods:** This study included 61,454 patients pertaining to 79,079 episodes receiving home health care between 2015 and 2017 from one of the largest home health care organizations in the United States. Potential risk factors were extracted from structured data and unstructured clinical notes analysed by natural language processing. A K-means cluster analysis was conducted. Kaplan–Meier analysis was conducted to identify the association between clusters and hospitalizations or emergency department visits during home health care.

**Results:** A total of 11.6% of home health episodes resulted in hospitalizations or emergency department visits. Risk factors formed three clusters. *Cluster 1* is characterized by a combination of risk factors related to “impaired physical comfort with pain,” defined as situations where patients may experience increased pain. *Cluster 2* is characterized by “high comorbidity burden” defined as multiple comorbidities or other risks for hospitalization (e.g., prior falls). *Cluster 3* is characterized by “impaired cognitive/psychological and skin integrity” including dementia or skin ulcer. Compared to *Cluster 1*, the risk of hospitalizations or emergency department visits increased by 1.95 times for *Cluster 2* and by 2.12 times for *Cluster 3* (all  $p < .001$ ).

**Conclusion:** Risk factors were clustered into three types describing distinct characteristics for hospitalizations or emergency department visits. Different combinations of risk factors affected the likelihood of these negative outcomes.

**Impact:** Cluster-based risk prediction models could be integrated into early warning systems to identify patients at risk for hospitalizations or emergency department visits leading to more timely, patient-centred care, ultimately preventing these events.

**Patient or Public Contribution:** There was no involvement of patients in developing the research question, determining the outcome measures, or implementing the study.



## KEYWORDS

clinical deterioration, cluster analysis, home health care, natural language processing, nursing informatics, Omaha system, risk assessment

## 1 | INTRODUCTION/BACKGROUND

Home health care (HHC) includes skilled nursing care, occupational and physical therapy, social work service, and personal care assistance. A patient is eligible to receive care at home based on an assessment of the patient's condition by a healthcare provider (e.g., physicians). Intermittent services are typically provided in person to patients at home with the goal of promoting recovery from illness and the prevention of deterioration (The Medicare Payment Advisory Commission, 2019). Over the past decades, the need for HHC has grown substantially in the United States (U.S.) and internationally, and the demand will likely continue to grow with an ageing population and longer life expectancies (Landers et al., 2016). The current trends of shorter hospital stays have contributed to increased clinical complexity of patients admitted to HHC (Burke et al., 2015). In the U.S., HHC services are usually provided for an "episode" which is a period up to 60 days paid for by the Centers for Medicaid and Medicare Services (Centers for Medicare & Medicaid Services, 2017) (see Footnote<sup>1</sup>). The patient may recertify for the continuation of the HHC during the comprehensive reassessment, or the patient may be discharged from the HHC upon reaching the clinical goals of their plan of care (The Medicare Payment Advisory Commission, 2019).

Although continuous efforts are made to reduce negative outcomes in HHC, such as the utilization of acute care services (i.e., hospitalizations or emergency department (ED) visits), on average more than 20% of HHC patients are admitted to the hospital or visit an ED within the first 60 days after beginning HHC services (Centers for Medicare and Medicaid Services, 2019). Up to 40% of these events are preventable with timely care (National Center for Health Statistics, 2018; O'Connor et al., 2014; Solberg et al., 2018), so it is imperative to identify the patients at risk early so that healthcare providers are able to intervene (Zolnoori et al., 2021). Awareness of a patient's risk status allows healthcare providers to better monitor patients for worsening symptoms and provide early interventions when needed. These early interventions could include more frequent HHC visits, acute care interventions at home (e.g., intravenous therapies, medication adjustments), or telemonitoring.

In previous studies, risk factors associated with hospitalizations or ED visits in HHC were examined using standardized assessments, such as the Outcome and Assessment Information Set (OASIS) (Fortinsky et al., 2014; Lohman et al., 2018; Ma et al., 2017). Risk factors for hospitalization included being male, being Black, having a history of previous hospitalizations or polypharmacy, depressive symptoms, greater functional disability, dyspnea severity, and more. However, these risk factors commonly co-exist and are therefore likely to be frequently seen together in a patient's medical history (Shi & Stevens, 2005). Several studies conducted among patients

with heart failure, other cardiovascular diseases, and stroke have demonstrated higher risk of adverse clinical outcomes when two or more risk factors are present at the same time (Peters et al., 2018; Son & Won, 2018). To support early identification of patients at risk, determining the combination of risk factors can potentially be more effective than identifying risk factors in isolation.

Cluster analysis is a data mining technique that groups similar observations into a number of data groups (i.e., clusters) based on measured characteristics to identify representation in specific groups (Tan et al., 2013). In recent years, cluster analysis has been used to identify phenotypes that have similar combinations of clinical factors (Sharma, 2021). Various clustering algorithms such as connectivity-based clustering (e.g., hierarchical clustering analysis), centroid models (e.g., K-means), and distribution models (e.g., expectation-maximization algorithm) have been applied to group a variety of factors including similar symptoms, patients with similar experiences, or risk factors (Li et al., 2019; Streur et al., 2018). Clustering is a method for aggregating the data, making it clinically meaningful and useful for prediction purposes (Alonso-Betanzos & Bolón-Canedo, 2018). Such data aggregation methods can reveal hidden patterns in the data, thus improving risk prediction accuracy by revealing data structure and regularities (Dalmajier et al., 2022; Huang et al., 2019). In essence, clustering methods help to identify the complex interplay between different patient-level risk factors affecting a certain outcome rather than examining the impact of individual risk factors. Additionally, such an approach would be able to provide a more comprehensive picture of the patient's condition, along with identifying patient cohorts who need tailored treatment. As part of their efforts to develop personalized symptom management therapies, the National Institute of Nursing Research has identified the importance of managing co-occurring symptoms, which can be detected through grouping or clustering symptoms together (National Institute of Nursing Research, 2019). Despite clustering being a promising method for identifying hidden combinations of risk factors, no previous studies in HHC have examined clusters of risk factors and their association with hospitalization or ED visits over time.

## 2 | THE STUDY

### 2.1 | Aims

To address this knowledge gap, the aims of this study were to: (1) identify clusters of risk factors in HHC using unsupervised and data-driven analysis, (2) investigate the association between clusters of risk factors and hospitalizations or ED visits within 60 days considering time-to-event for each cluster, and (3) examine the associations

between clusters of risk factors and the timing of hospitalization or ED visits.

## 2.2 | Design

This retrospective observational cohort study used the data obtained from one of the largest non-profit HHC organizations in the Northeastern U.S.

## 2.3 | Sample/participants

This study sample included patients who received HHC services between 1 January 2015 and 31 December 2017. An HHC “episode” refers to all services provided between the patient's admission and discharge from the HHC or 60days, whichever occurs first. This study included 79,079 HHC episodes pertaining to 61,454 unique patients, since patients could have multiple episodes during the study period.

## 2.4 | Data collection

Two major data sources were retrieved: structured data (i.e., Outcome and Assessment Information Set (OASIS) and other assessment items from the electronic health record (EHR)) and unstructured data (i.e., clinical notes).

### 2.4.1 | Structured datasets: OASIS and EHR

The Center for Medicare and Medicaid Services mandates OASIS as a standardized outcome and assessment tool for HHC. At the time of admission and at the end of an episode of HHC, an OASIS assessment must be completed for each patient. The OASIS assessment captures over 100 patient characteristics including socio-demographics, physiologic conditions, comorbidities, medication and equipment management, cognitive and behavioural status (e.g., Activities of Daily Living (ADL)/Instrumental Activities of Daily Living (IADL)), and utilization of health care during the HHC episode (Tullai-McGuinness et al., 2009). We used both OASIS-C1 released in 2015 and OASIS-C2 released in 2017.

A dataset from the institution's EHR included features beyond OASIS, such as socioeconomic factors, insurance, county of residence, information on comorbidities, admission and discharge dates, and medications.

### 2.4.2 | Unstructured dataset: Clinical notes

The study cohort had about 2.3 million clinical notes generated during their episodes of care. Clinical notes were primarily written by

nurses, but physical and occupational therapists and social workers also contributed. Clinical notes included (1) visit notes detailing the patient's condition and treatment during the HHC visit (total  $n = 1,029,535$ ), and (2) care coordination notes describing the exchange of information between healthcare clinicians and other administrative duties (total  $n = 1,292,442$ ).

In a previous study, our team developed a natural language processing algorithm (NLP— an artificial intelligence field in which computers analyse, understand, and extract meaning from human language in a text form) to extract the risk factors for hospitalizations or ED visits from HHC clinical notes (Song, Ojo, et al., 2022). Details on our previous NLP development and validation are described elsewhere (Song, Ojo, et al., 2022). In essence, based on the Omaha System—a standardized nursing terminology commonly utilized in community health (Martin, 2005)—a subset of 31 Omaha System problems, including “Circulation,” “Respiration,” “Healthcare supervision,” etc., were identified as risk factors for hospitalizations or ED visits in HHC. Then, using the Omaha System as a tag of risk factors, the NLP algorithm was applied on all the clinical notes to identify risk factors for hospitalizations or ED visits. The NLP algorithm achieved high-risk factor identification accuracy with precision of 0.95, recall of 0.78 and an F-score of 0.84 (a harmonic means between precision and recall). A summary of the development of NLP is described in Appendix S1, and the risk factors identified for hospitalizations or ED visits are listed in Appendix S2.

### 2.4.3 | Outcome: Utilization of acute care services (i.e., hospitalizations or ED visits)

Hospitalizations or ED visits were identified from OASIS item M0100: “reason for completing assessment at present” (i.e., transfer to an inpatient facility including patient discharged or not discharged) and M2301 “emergent care” (i.e., utilization of the hospital ED, including hospital admission or non-admission). Time to hospitalizations or ED visits was calculated as the number of days between the date of HHC admission and the date of hospitalization or ED visit. For patients who did not have the outcome during the episode of care (censored), we defined follow-up time as the number of days between HHC admission and discharge or 60days, whichever occurred first. All analyses were conducted at the HHC episode level.

## 2.5 | Ethical considerations

The study was approved by the Institutional Review Board of the participating institution (IRB# I20-003). Since our study used retrospective anonymous data, a waiver of informed consent was obtained. De-identified data were analysed. The highest safety standards were been followed with protection of study subject confidentiality as per national and international regulations for studies on human subjects included in the Declaration of Helsinki on Biomedical Research.

## 2.6 | Data analysis

### 2.6.1 | Variable selection

A full dataset was created including all available structured data elements (e.g., sociodemographic characteristics, comorbidities, functional status) and all variables derived by applying the NLP algorithm to clinical notes. We then applied the criteria described below to guide our selection of variables for inclusion in the clustering analysis. As done in our previous work (Song, Hobensack, et al., 2022; Song, Woo, et al., 2021; Song, Zolnoori, et al., 2021), variables with missing data over 20% were excluded, and the remaining variables with missing data were replaced with the median for continuous variables and the mode for categorical variables. To avoid linear dependency issues, we excluded redundant variables with strong correlations (Pearson correlation coefficient above 0.5 or below -0.5) and retained only variables with a higher frequency. Afterwards, we conducted a bivariate analysis (Student's *t*-test or Fisher exact test) between patients with hospitalizations or ED visits and those without to identify the variables that were statistically significant ( $p < .05$ ). Lastly, to reduce the noise caused by small samples within each variable when conducting clustering tasks, those variables in which only less than 10% of the data indicate a presence of corresponding variables were excluded (Im et al., 2020). Our variable selection process resulted in 45 variables for use in the clustering analysis: 36 of these variables were derived from the OASIS assessment or the EHR data and 9 variables were derived from the application of NLP to the clinical notes.

### 2.6.2 | Cluster analysis

We sought to discover clusters of clinical characteristics using the K-means cluster analysis (Likas et al., 2003)—an unsupervised machine learning technique widely used in data mining, pattern recognition, and decision support. Clustering by K-means is the process of grouping *N* observations into groups of *K*. To classify observations into groups, the degree of similarity/dissimilarity or distance between observation pairs was calculated using the Euclidean distance (Singh et al., 2013). The centre of the cluster (i.e., centroid) represents the average of all observations assigned to the cluster. Then, each object is assigned to its closest centroid based on the distance between the observations and the centroid. Ultimately, each observation belongs to the group with the closest cluster mean or centroid (Likas et al., 2003). An elbow method was used to determine the optimal number of clusters, in which the sum of squares for each *K* within a cluster is plotted over a curve, and the point where the curve appears sharpest indicates the optimal number of clusters (Syakur et al., 2018).

### 2.6.3 | Statistical analysis

Following K-means cluster analysis, differences in clinical characteristics between patients with hospitalizations or ED visits versus

patients without those outcomes were compared using analysis of variance (ANOVA) test. Then, a Kaplan–Meier analysis was used to estimate the survival rate from hospitalizations or ED visits in HHC within 60 days between clusters (i.e., a combination of risk factors), and a log-rank test was used to compare differences between clusters. The hazard ratio (HR) and 95% confidence interval (CI) were presented to estimate the association of clusters on time-to-event outcomes (i.e., hospitalizations or ED visits). Lastly, we performed a post-hoc ANOVA on episodes that included hospitalizations or ED visits to examine the association between the timing of hospitalizations or ED visits and clusters. For all analyses, a *p*-value  $< .05$  (two-tailed) was considered statistically significant. All analyses were implemented using R software version 4.1.0 (Foundation of Statistical Computing, Vienna).

## 2.7 | Validity, reliability and rigour

Through K-means cluster analysis as an unsupervised machine learning technique, large numbers of observations can be categorized into groups with similar properties. The credibility of K-means cluster analysis has already been recognized and used (Likas et al., 2003). A discussion was held within the research group concerning the data analysis to guarantee methodological coherence, adequate sampling, and responsiveness. The lead author of this paper conducted the analyses independently, but the other authors critically reviewed the findings, which led to a consensus on the themes and labelling of clusters based on their characteristics.

## 3 | RESULTS

During the study period, 11.6% (9182/79,079) of HHC episodes resulted in utilization of acute care services (i.e., hospitalizations or ED visits).

### 3.1 | Cohort demographics and clinical characteristics

The average patient age was 78.8 years, and 64% of patients were female. Hypertension, diabetes, and arthritis were the most common diagnoses (65%, 30%, and 24%, respectively). Approximately 24% of patients experienced multiple hospitalizations within the 6 months before receiving HHC services; a history of prior hospitalization was more common in patients who experienced hospitalization or ED utilization during their HHC episode compared to those who did not experience these outcomes (40% vs. 22%, respectively). The most frequently documented risk factors in clinical notes were “Pain,” followed by “Neuromusculoskeletal function,” “Circulation,” and “Mental health” issues (48%, 46%, 35%, and 31%, respectively). The following problems were more frequently documented in the clinical notes of patients with hospitalizations or ED visits than those

without: "Circulation (42 vs. 33%)," "Cognition (20 vs. 15%)," "Mental health (39 vs 30%)," "Pain (50 vs. 46%)," and "Skin (28% vs. 18%)." Additional details are presented in [Table 1](#).

### 3.2 | Cluster analysis of risk factors

Using elbow methods, the optimal number of clusters was determined to be three.

[Table 2](#) presents the distinct clinical characteristics of clusters associated with each of the clusters. *Cluster 1* is characterized by a combination of risk factors for "impaired physical comfort with pain". For this cluster, there was predominant documentation of pain in clinical notes and in OASIS, as well as clinical situations that could potentially increase pain, such as the history of arthritis or surgical wounds. *Cluster 2* is labelled "high comorbidity burden" defined as multiple comorbidities (such as diabetes or cardiovascular disease) and multiple other risks for hospitalization (such as prior falls and multiple prior hospitalizations) compiled from OASIS, as well as circulatory or respiratory problems documented in clinical notes. *Cluster 3* is characterized by "impaired cognitive/psychological and skin integrity". Patients in this cluster had: (a) significant cognitive/psychological issues such as dementia, confusion, or anxiety noted in the OASIS, or mental health or cognition issues documented in clinical notes, and (b) significant skin issues, such as an open wound or skin ulcer, noted in the OASIS, or a skin condition documented in clinical notes.

### 3.3 | Association of the Clusters with risk for hospitalization or ED visit

Compared with the *Cluster 1* group of risk factors, those with *Cluster 2* and *Cluster 3* risk factors were at higher risk of being hospitalized or visiting the ED within 60 days of admission to HHC. The risk of hospitalizations or ED visits was 1.95 times higher for *Cluster 2* (hazard ratio (HR), 1.95 [95% CI, 1.86–2.04]) and 2.12 times higher for *Cluster 3* (HR, 2.12 [95% CI, 1.99–2.26]) compared with *Cluster 1* (all  $p < .001$ ).

In the post-hoc analysis that included only patients with hospitalizations or ED visits, the time to event was 38 days (standard deviation [SD] = 18.1) in *Cluster 1*, 41.7 days (SD = 17.5) in *Cluster 2*, and 38.7 days (SD = 18.2) in *Cluster 3*. Thus, among patients who were hospitalized or used the ED, those with *Cluster 1* symptoms (impaired physical comfort with pain) had the shortest time to event, which was slightly shorter than *Cluster 3*, and significantly shorter than *Cluster 2* ( $p < .001$ ).

## 4 | DISCUSSION

Our study is the first to our knowledge to evaluate the clusters of risk factors in HHC and their association with risk for hospitalizations

or ED visits. Using data mining-based unsupervised cluster analysis, hidden patterns and combinations of risk factors were identified in a large sample of patients receiving HHC service. A heterogeneity of the combination of risk factors was observed, with distinct characteristics in each cluster: *Cluster 1*—Impaired physical comfort with pain; *Cluster 2*—High comorbidity burden; *Cluster 3*—Impaired cognitive/psychological and skin integrity.

Although the themes of clusters (i.e., pain, comorbidities, cognitive impairment and poor integumentary status) can be mapped to established risk factors for hospitalization and ED visits (Fortinsky et al., 2014; Lohman et al., 2018; Ma et al., 2017; Shang et al., 2020; Song, Woo, et al., 2021), our attempt to identify combinations of risk factors in HHC patients is novel. Our results also support previous studies showing that clinical characteristics should not be considered as isolated factors, since they tend to cluster together (Murphy et al., 2019). Characterizing these groups with the different combinations of risk factors can provide a basis for tailoring treatment for patients with these risk factors. Based on the results of this study, HHC health care providers should identify patients at risk of pain, comorbidities, cognitive impairment, and poor integumentary status early across HHC treatments to plan the most effective interventions and follow-up during HHC trajectories. For example, an early pain management strategy including postoperative pain control, mobilization with therapy, early referral for interdisciplinary pain management may help patients with risk factors in *Cluster 1* avoid hospitalization or ED visits (Wells et al., 2008). Patients in the *Cluster 2* group may benefit from assistance with planning self-management strategies to deal with the burden of chronic disease or from more frequent monitoring for medication adjustments and/or to ensure adherence to medication for chronic disease (Grady & Gough, 2014). Lastly, patients in the *Cluster 3* group might benefit from cognitive function stimulation or counselling strategies (Silva et al., 2021), or wound management (Karadağ & Çakar, 2022).

Notably, associations between clinical characteristics were identified within each cluster. For example, in *Cluster 3*, older age was clustered together with the risk of cognitive impairments (e.g., dementia) and the risk of having sensory impairments (e.g., difficulty seeing, hearing, and speaking) (Loughrey et al., 2018). In addition, elderly patients with cognitive decline are more prone to having pressure ulcers and requiring greater assistance with ADLs/IADLs due to their vulnerability to poor self-care and decreased mobility (Edwards et al., 2020; Jaul et al., 2018). This cluster also included a higher proportion of Hispanic patients; these patients are indeed more likely to be diagnosed with dementia compared to White patients (Chen & Zissimopoulos, 2018). Thus, cluster analysis could reveal hidden patterns by incorporating the clinical characteristics that are potentially associated with a cluster.

Our findings also showed that a certain combination of risk factors (i.e., clusters) was associated with the time to or incidence of hospitalization or ED visits. In a previous study in which individual risk factors for hospitalizations or ED visits in HHC were examined, chronic comorbidities (e.g., diabetes), mental illness, or psychological issues were not identified as statistically significant in a multivariate

**TABLE 1** Patient characteristics and information extracted from clinical notes between patients with hospitalization/ED visit and those without. For bivariate analysis, student t-tests or fisher exact tests were used, as appropriate (all  $p$ -value  $<.05$ )

	Patients without hospitalizations/ED visits (N = 69,897)	Patients with hospitalizations/ED visits (N = 9182)
Length of episode (mean: days, SD)	30.6 (14.1)	39.9 (17.9)
Structured data (OASIS Item): Socio-demographic factor		
Age (mean: years, SD)	77.9 (11.6)	78.8 (12.7)
Gender: Female [n, (%)]	44,913 (64.3%)	5675 (61.8%)
Race/Ethnicity [n, (%)]		
Asian	3925 (5.62%)	411 (4.48%)
Black	11,708 (16.8%)	1989 (21.7%)
Hispanic	9007 (12.9%)	1498 (16.3%)
White	44,936 (64.3%)	5246 (57.1%)
Type of insurance [n, (%)]		
Dual eligibility	4009 (5.7%)	753 (8.2%)
Medicare/Medicaid fee-for-service only	61,362 (87.8%)	7659 (83.4%)
Any managed care	3056 (4.4%)	595 (6.5%)
Other (e.g., private)	1446 (2.1%)	175 (1.9%)
Living Condition: Living alone [n, (%)]	26,979 (38.5%)	3599 (39.2%)
Structured data (OASIS Item): Medical conditions—Active diagnoses [n, (%)]		
Acute myocardial infarction	12,618 (18.1%)	1957 (21.3%)
Arthritis	17,880 (25.6%)	1361 (14.8%)
Cardiac dysrhythmias	10,505 (15.0%)	1716 (18.7%)
Cancer	1000 (1.43%)	395 (4.30%)
Diabetes	19,325 (27.6%)	3421 (37.3%)
Dementia	8894 (12.7%)	1336 (14.6%)
Heart failure	9019 (12.9%)	2198 (23.9%)
Hypertension	45,574 (65.2%)	6129 (66.8%)
Pulmonary disease	10,262 (14.7%)	1813 (19.7%)
Renal failure	2277 (3.26%)	729 (7.94%)
Skin ulcer	6681 (9.56%)	1737 (18.9%)
Structured data (OASIS Item): Risk for hospitalization [n, (%)]		
History of falls in the past 12 months	14,904 (21.3%)	2087 (22.7%)
Multiple hospitalizations in the past 6 months	15,654 (22.4%)	3658 (39.8%)
Currently taking 5 or more medications	55,108 (78.8%)	7698 (83.8%)
Decline in mental, emotional, or behavioural status in the past 3 months	9850 (14.1%)	1686 (18.4%)
Structured data (OASIS Item): Sensory status [n, (%)]		
Vision impaired	13,306 (19%)	2141 (23.3%)
Hearing impaired	16,195 (23.2%)	2417 (26.3%)
Difficulty in understanding verbal content	19,729 (28.3%)	3058 (33.3%)
Difficulty in verbal expression	20,724 (29.7%)	3424 (37.3%)
Having Pain	53,891 (77.1%)	6813 (74.2%)
Structured data (OASIS item): Integumentary status [n, (%)]		
Having a risk of developing pressure ulcers	26,833 (38.4%)	4486 (48.9%)
Having at least one Unhealed Pressure Ulcer at Stage II or Higher	4169 (6%)	1013 (11%)
Having stasis wound	1255 (1.8%)	318 (3.46%)

TABLE 1 (Continued)

	Patients without hospitalizations/ED visits (N = 69,897)	Patients with hospitalizations/ED visits (N = 9182)
Having surgical wounds	20,176 (28.9%)	1670 (18.2%)
Having skin lesion or open wound	13,015 (18.6%)	2416 (26.3%)
Structured data (OASIS Item): Elimination [n, (%)]		
Urinary tract infection in the past 14 days	4457 (6.4%)	875 (9.5%)
Structured data (OASIS item): Neuro, emotional, and behavioural status [n, (%)]		
Cognitive functioning (i.e., required prompting, assistance or totally dependent)	8370 (12%)	1490 (16.2%)
Structured data (OASIS Item): Overall status [n, (%)]		
Stable	4849 (6.94%)	542 (5.90%)
Likely to be stable	55,260 (79.1%)	6726 (73.3%)
Fragile	9439 (13.5%)	1820 (19.8%)
Serious	349 (0.50%)	94 (1.02%)
Structured data (OASIS item): ADLs/IADLs		
ADL Needed [mean, (SD)] <sup>a</sup>	8.05 (1.52)	8.24 (1.36)
ADL Severity [mean, (SD)] <sup>b</sup>	15.5 (6.74)	17.2 (7.51)
Unstructured clinical notes: Using the Omaha system as a risk factor (Identified through NLP approaches) [n, (%)]		
Abuse	1375 (1.97%)	322 (3.51%)
Bowel function	2759 (3.95%)	831 (9.05%)
Circulation	23,108 (33.1%)	3842 (41.8%)
Cognition	10,654 (15.2%)	1828 (19.9%)
Infectious condition	15,422 (22.1%)	3070 (33.4%)
Consciousness	1492 (2.13%)	554 (6.03%)
Digestion/hydration	4798 (6.86%)	1097 (11.9%)
Genitourinary function	1684 (2.41%)	460 (5.01%)
Health care supervision	6017 (8.61%)	864 (9.41%)
Medication regimen	3311 (4.74%)	582 (6.34%)
Mental health	21,029 (30.1%)	3585 (39.0%)
Neglect	2153 (3.08%)	471 (5.13%)
Nutrition	4674 (6.69%)	1092 (11.9%)
Neuro musculoskeletal function	32,143 (46.0%)	4112 (44.8%)
Pain	32,414 (46.4%)	4595 (50.0%)
Respiration	13,455 (19.2%)	2990 (32.6%)
Skin	12,804 (18.3%)	2535 (27.6%)
Social contact	12,828 (18.4%)	1573 (17.1%)
Speech and language	2730 (3.91%)	472 (5.14%)
Substance use	376 (0.54%)	71 (0.77%)

Abbreviations: ADLs/IADLs, Activities of Daily Livings/Instrumental Activities of Daily Livings; NLP, natural language processing; OASIS, Outcome and Assessment Information Set; SD, standard deviation.

<sup>a</sup>“ADL Needed” which is defined as the summed binary ADL/IADL items (ranging from 0 to 9) derived from ADL items such as grooming, dressing upper and lower, bathing, toileting, transferring, ambulating, and eating, as well as IADL items such as meal preparation. Binary indicator 0 was given if response 0 was given (no issue); otherwise, 1 was given (moderate or significant issue).

<sup>b</sup>“ADLs Severity” was calculated by totalling the response categories of the dependency level in ADL/IADL items (total ranged from 0 to 38).

logistic regression analysis (Song, Woo, et al., 2021). In contrast, the current study showed that clusters of risk factors related to high comorbidities burden or cognitive/psychological or skin issues increases the risk of hospitalizations or ED visits. In addition, certain combinations of risk factors were associated with earlier hospitalizations or

ED visits. Perhaps, acute pain, a demonstrable cognitive/psychological impairment, or integumentary issues demand immediate attention, therefore, patients with those conditions may have been hospitalized earlier than those with chronic conditions that are comparatively not as urgent unless there are exacerbations (Green et al., 2018). Further



**TABLE 2** Clinical characteristics by clusters. Consequently, *cluster 1* is characterized by the combination of risk factors associated with “impaired physical comfort with pain,” *cluster 2* by the combination of risk factors associated with “high comorbidity burden,” and *cluster 3* by the combination of risk factors associated with “impaired cognitive/psychological and skin integrity.” we conducted analysis of variance (ANOVA) tests to examine the differences in clinical characteristics between each cluster (all *p*-values <.05)

	Cluster 1 (N = 37,678)	Cluster 2 (N = 30,999)	Cluster 3 (N = 10,402)
Hospitalization or ED visits [n, (%)]	3032 (8%)	4521 (14.6%)	1629 (15.7%)
Length of episode [mean: days, (SD)]	28.3 (14.3)	35.1 (14.6)	33.8 (15.2)
Structured data (OASIS Item): Socio-demographic factor			
Age [mean: years, (SD)]	73.9 (11.2)	82.9 (9.91)	85.1 (10.8) <sup>e</sup>
Gender: Female [n, (%)]	21,706 (57.6%)	21,869 (70.5%) <sup>d</sup>	7013 (67.4%)
Race/Ethnicity: Black [n, (%)]	6455 (17.1%)	5595 (18.0%) <sup>d</sup>	1647 (15.8%)
Race/Ethnicity: Hispanic [n, (%)]	4519 (12.0%)	4251 (13.7%)	1735 (16.7%) <sup>e</sup>
Race/Ethnicity: White [n, (%)]	24,777 (65.8%) <sup>c</sup>	19,185 (61.9%)	6220 (59.8%)
Living Condition: Living alone [n, (%)]	14,467 (38.4%)	13,606 (43.9%) <sup>d</sup>	2505 (24.1%)
Structured data (OASIS item): Medical conditions—Active diagnoses [n, (%)]			
Acute myocardial infarction	6049 (16.1%)	7018 (22.6%) <sup>d</sup>	1508 (14.5%)
Arthritis	12,102 (32.1%) <sup>c</sup>	5660 (18.3%)	1479 (14.2%)
Cardiac dysrhythmias	4293 (11.4%)	6550 (21.1%) <sup>d</sup>	1378 (13.2%)
Diabetes	9463 (25.1%)	10,511 (33.9%) <sup>d</sup>	2772 (26.6%)
Dementia	1070 (2.8%)	3448 (11.1%)	5712 (54.9%) <sup>e</sup>
Heart failure	2642 (7.01%)	7271 (23.5%) <sup>d</sup>	1304 (12.5%)
Pulmonary disease	4795 (12.7%)	6342 (20.5%) <sup>d</sup>	938 (9.02%)
Skin ulcer	1688 (4.48%)	3886 (12.5%)	2844 (27.3%) <sup>e</sup>
Structured data (OASIS Item): Prior medical conditions in the past 14 days [n, (%)]			
Urinary incontinent	4818 (12.8%)	23,523 (75.9%)	8898 (85.5%) <sup>e</sup>
Urinary tract infection	1329 (3.5%)	11,821 (38.1%)	5135 (49.4%) <sup>e</sup>
Impaired decision-making	654 (1.74%)	1914 (6.17%)	4582 (44.0%) <sup>e</sup>
Structured data (OASIS Item): Risk factors that may affect current health status [n, (%)]			
Obesity	4687 (12.4%)	4948 (16%) <sup>d</sup>	790 (7.6%)
Structured data (OASIS Item): Risk for hospitalization [n, (%)]			
History of falls in the past 12 months	5013 (13.3%)	9252 (29.8%) <sup>d</sup>	2726 (26.2%)
Multiple hospitalizations in the past 6 months	7013 (18.6%)	9686 (31.2%) <sup>d</sup>	2613 (25.1%)
Currently taking 5 or more medications	28,684 (76.1%)	26,020 (83.9%) <sup>d</sup>	8102 (77.9%)
Decline in mental, emotional, or behavioural status in the past 3 months	1837 (4.9%)	4994 (16.1%)	4705 (45.2%) <sup>e</sup>
Structured data (OASIS item): Sensory status [n, (%)]			
Vision impaired	3415 (9.1%)	8307 (26.8%)	3725 (35.8%) <sup>e</sup>
Hearing impaired	2523 (6.7%)	11,318 (36.5%)	4771 (45.9%) <sup>e</sup>
Difficulty in understanding verbal content	2832 (7.5%)	12,647 (40.8%)	7308 (70.3%) <sup>e</sup>
Difficulty in verbal expression	3451 (9.2%)	11,360 (36.7%)	9337 (89.8%) <sup>e</sup>
Having Pain	30,274 (80.4%) <sup>c</sup>	23,976 (77.3%)	6454 (62%)
Structured data (OASIS item): Integumentary status [n, (%)]			
Having a risk of developing pressure ulcers	5263 (14.0%)	17,933 (57.9%)	8123 (78.1%) <sup>e</sup>
Having surgical wounds	18,573 (49.3%) <sup>c</sup>	2718 (8.8%)	555 (5.3%)
Having skin lesion or open wound	6565 (17.4%)	6511 (21%)	2355 (22.6%) <sup>e</sup>
Structured data (OASIS item): Neuro, emotional, and behavioural status [n, (%)]			
Cognitive functioning (i.e., required prompting, assistance or totally dependent)	303 (0.8%)	474 (1.5%)	9083 (87.3%) <sup>e</sup>

TABLE 2 (Continued)

	Cluster 1 (N = 37,678)	Cluster 2 (N = 30,999)	Cluster 3 (N = 10,402)
Confusion	9122 (24.2%)	19,224 (62.1%)	9896 (95.1%) <sup>e</sup>
Anxiety	9243 (24.5%)	11,207 (36.2%)	4131 (39.7%) <sup>e</sup>
Structured data (OASIS item): Overall status [n, (%)]			
Stable	3586 (9.5%)	1304 (4.2%)	501 (4.8%)
Likely to be stable	31,631 (84%)	23,731 (76.6%)	6624 (63.7%)
Fragile	2414 (6.4%)	5789 (18.7%)	3056 (29.4%) <sup>e</sup>
Serious	47 (0.1%)	175 (0.6%)	221 (2.1%) <sup>e</sup>
Structured data (OASIS item): ADLs/IADLs			
ADL Needed [mean (SD)] <sup>a</sup>	7.4 (1.8)	8.5 (0.9)	8.9 (0.6) <sup>e</sup>
ADL Severity [mean (SD)] <sup>b</sup>	12 (4.0)	16.4 (5.5)	24.6 (7.6) <sup>e</sup>
Unstructured clinical notes: Using the Omaha system as a risk factor (identified through NLP approaches) [n, (%)]			
Circulation	11,750 (31.2%)	12,423 (40.1%) <sup>d</sup>	2777 (26.7%)
Cognition	1863 (4.94%)	5303 (17.1%)	5316 (51.1%) <sup>e</sup>
Infectious condition	9566 (25.4%) <sup>e</sup>	6545 (21.1%)	2381 (22.9%)
Neuro musculoskeletal function	16,721 (44.4%)	15,710 (50.7%) <sup>d</sup>	3824 (36.7%)
Mental health	9065 (24.1%)	11,035 (35.6%)	3973 (38.2%) <sup>e</sup>
Pain	19,373 (51.4%) <sup>c</sup>	14,500 (46.8%)	3136 (30.1%)
Respiration	5448 (14.5%)	9248 (29.8%) <sup>d</sup>	1749 (16.8%)
Skin	6274 (16.7%)	5806 (18.7%)	3259 (31.3%) <sup>e</sup>
Social contact	6293 (16.7%)	7192 (23.2%) <sup>d</sup>	9,16 (8.81%)

Abbreviations: ADLs/IADLs, Activities of Daily Livings/Instrumental Activities of Daily Livings; NLP, natural language processing; OASIS, Outcome and Assessment Information Set; SD, standard deviation.

<sup>a</sup>“ADL Needed” which was defined as the summed binary ADL/IADL items (ranging from 0 to 9) derived from ADL items such as grooming, dressing upper and lower, bathing, toileting, transferring, ambulating, and eating, as well as IADL items such as meal preparation. Binary indicator 0 was given if response 0 was given (no issue); otherwise, 1 was given (moderate or significant issue).

<sup>b</sup>“ADLs Severity” is calculated by totalling the response categories of the dependency level in ADL/IADL items (total ranged from 0 to 38).

<sup>c</sup>Denotes the representative risk factors for grouping in Cluster 1.

<sup>d</sup>Denotes the representative risk factors for grouping in Cluster 2.

<sup>e</sup>Denotes the representative risk factors for grouping in Cluster 3.

research is needed to determine whether trajectories of risk factors are associated with earlier hospitalizations or ED visits.

This study is also innovative because it leveraged various types of data streams, such as structured data and unstructured data (e.g., clinical notes) to perform cluster analysis and leveraged the problem and symptom terms within a standardized nursing terminology to facilitate the NLP (Martin, 2005). Our findings indicated that data retrieved from clinical notes and structured assessments have homogeneity in terms of content. For example, pain recorded in structured data was captured in the clinical notes as well. Thus, information extracted from these convergent data sources can be leveraged as valid indicators to determine the risk of hospitalization or ED visit, increasing the possibility of capturing the hidden combinations of risk factors and identifying patients' risk profiles. A comprehensive set of symptoms that were documented in the unstructured clinical note could be identified by using the Omaha System problem which included broad signs and symptoms (e.g., ‘does not follow recommended dosage/schedule’ under the problem of ‘Medication regimen’, or ‘fails to obtain routine/preventive health care’ under the problem of ‘Health care supervision’).

Structured data, on the other hand, has not been available for such data. From this perspective, along with highlighting the utilization of clinical notes in identifying risk factors for hospitalizations or ED visits, future efforts may include adding signs/symptoms that could be used to populate a structured symptom checklist in the HHC EHR to reduce the burden of narrative documentation.

#### 4.1 | Future clinical implications

Considering these results, developing cluster-based risk prediction models may be feasible in HHC. These models could be incorporated into early warning systems for identifying HHC patients at risk for hospitalizations or ED visits. Ultimately, the integration of such early warning systems into HHC clinical workflows would alert nurses about patients at risk, enabling them to intervene to reduce risks and improve outcomes. Although it has been demonstrated that early warning systems are effective in improving clinical outcomes in hospital settings (Gerry et al., 2020), little is known about their effectiveness in HHC.

Therefore, further research is needed to develop such early warning systems and evaluate their effectiveness in HHC settings to improve patient outcomes, such as reducing hospitalizations and ED visits.

## 4.2 | Limitations

There are several notable limitations to this study. First, this investigation was conducted at a single HHC organization located in an urban area in the northeastern U.S. This limits its generalizability to other geographic locations, which require external validation. Since data collected from 2015 to 2017 were utilized in the analysis, results should be replicated in more recent patient cohorts. Also, several clinical characteristics, even though they were associated with hospitalizations or ED visits, were not included in the cluster analysis because they were not selected in the initial variable selection stage due to their low prevalence; some information might have been lost as a result. Given we used unstructured clinical notes based on the English language, the current developed NLP approach is not available to the international nursing community, but structured data might be useful without language restrictions. Future work should also examine whether using structured data alone (e.g., OASIS) can produce similar clustering results. Moreover, the present study was based on retrospective data which limits our ability to infer causal relationships. Lastly, survival analysis in this study has a limitation in that information about hospitalization or ED visits was not available after discharge from HHC, leading us to underestimate these outcomes in some cases.

## 5 | CONCLUSIONS

This study identified three distinct clusters of risk factors associated with hospitalizations or ED visits. Our findings demonstrate the heterogeneity of the combination of risk factors and clearly show that every cluster had its own characteristics. The different combinations of risk factors showed different effects on the likelihood of hospitalizations or ED visits, and the timing of such visits. Our findings suggest that patients who experience 'impaired cognitive/psychological and skin integrity,' more frequently be hospitalized or visit the ED, have many unmet risk management needs, and may require the highest level of supportive care need and intervention during HHC. Future studies should explore the use of risk cluster-based early warning systems to prevent hospitalizations or ED visits in HHC.

### AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE): (1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content. The specific contribution is as follows: Study concept and design: J Song, S Chae, K Bowles, M Margaret, Y Barron, S Rossetti, M Topaz; Acquisition of

data: J Song, S Chae, M Hobensack, S Sridevi, L Evans, A Davoudi; Analysis and interpretation of data: J Song, S Chae, K Bowles, M Margaret, Y Barron, K Cato, S Rossetti, M Topaz; Drafting of the manuscript: J Song, S Chae, K Bowles, M Margaret, Y Barron, M Topaz; Critical revision of the manuscript of important intellectual content: All authors.

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### CONFLICT OF INTEREST

All authors report no conflicts of interest relevant to this article.

### PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15498>.

### DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions: The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

### ETHICS STATEMENT

This study was approved by the VNS Health Institutional Review Boards (IRB# 120-003).

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### ENDNOTE

<sup>1</sup> In 2020, the length of CMS-reimbursable HHC episode was reduced from 60 days to 30 days (Centers for Medicare and Medicaid Services, 2019). Data for this study were collected between 1/1/2015 and 12/31/17, hence we used an episode length of 60 days.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - QUANTITATIVE**

# Daily triage audit can improve nurses' triage stratification: A pre-post study

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**Abstract**

**Aims:** The objective was to evaluate whether the error rate in the application of the triage system decreased after the introduction of daily auditing, and it was also evaluated if the agreement rate between physician and nurse on triage priority levels increased after the introduction of daily auditing and if the error-related variables in the pre-intervention period changed in the post-intervention period.

**Design:** A quasi-experimental study was performed with a pre-post design, between June 2019 and June 2021 in one emergency department.

**Methods:** The accuracy and error rate of triage in the pre- and post-intervention period were compared. Univariate and multivariate logistic regression analyses were performed to explore the relationships between the variables related to the error. The comparison between the priority level assigned by the physician and the triage nurse was analysed using Cohen's K.

**Results:** Nine hundred four patients were enrolled in the pre-intervention period and 869 in the post-intervention period. The error rate in the pre-intervention period was 23.3% and in the post-intervention period was 9.7%.

The concordance between the degree of priority expressed by the physician and the nurse varied from a quadratically weighted Cohen's K of 0.447 in the pre-intervention period to 0.881 in the post-intervention period.

**Conclusion:** Daily auditing is a clinical procedure that improves the nurse's application of the triage system. Daily auditing has reduced errors by the nurse, improving performance and concordance with the physician.

**Impact:** Triage systems are a key point for the stratification of the priority level of patients and it is therefore evident that they maintain high-quality standards. Through the practice of daily auditing, not only a reduction in the error rate, which ensures patient safety, but also an improvement in triage performance has been demonstrated.

**No Patient or Public Contribution:** The study did not involve any patients during its conduction.

**KEYWORDS**

audit, clinical nursing, emergency department, emergency nurse, feedback, nurse, Manchester triage system, triage



## 1 | INTRODUCTION

Triage is the first evaluation point for patients admitted to the emergency department (Hinson et al., 2019). Triage aims to assign a level of priority to the multitude of patients who daily enter the emergency department, prioritizing those who need immediate medical management over those who can safely wait (Hinson et al., 2019). An incorrect stratification of the urgency can cause damage not only to the health of the patient but also to the structure of the emergency department itself (Hinson et al., 2019; Lentz et al., 2017). Undertriage (underestimation of patient severity) may lead to increased patient morbidity and mortality, while overtriage (overestimation of patient urgency) may have consequences in terms of spending limited resources on patients who are not really in need (Lee et al., 2019; Lentz et al., 2017; Vassallo et al., 2019). It is therefore essential that triage systems maintain high-quality standards (Tam et al., 2018).

Different studies in the literature have attempted to evaluate the accuracy of triage systems, both globally and when comparing time-dependent pathologies, by studying the correct stratification of patients (Azeredo et al., 2015; Brigo et al., 2022; Zaboli, Ausserhofer, Sibilio, Paulmichl, Toccolini, Losi, et al., 2022). In such studies, the triage priority code was always correlated with the patient's clinical outcome; unfortunately, only a few and limited studies have performed subsequent evaluations about the type of error to understand whether it was depending on a wrong application of the triage system or whether it was a problem present within the triage system itself (Brigo et al., 2022; Zaboli et al., 2020).

### 1.1 | Background

Many authors tried to investigate the reliability of triage systems in terms of their stratification ability, such as Gräff et al. (2014) who in their study on the validation of the Manchester Triage System assessed the inter-rater agreement between triage nurse and an Manchester Triage System expert across 167 cases and reported a Cohen's Kappa of 0.95. Göransson et al, using preformed charts, investigated the inter-rater agreement between different triage nurses and demonstrated a Cohen's Kappa of 0.71 in an emergency department using the Canadian Triage and Acuity Scale system (Göransson et al., 2005). All studies currently available in the literature analyse the correctness of risk stratification by triage nurses, but little is known about the correct methodological application of different triage systems. Although several triage systems indicate the need for a regular auditing process for this crucial component, limited data are available on this type of accuracy process (Tam et al., 2018). It is currently not known in the literature whether an auditing strategy is beneficial for triage performance, and the frequency with which to implement this strategy is unclear. This information could be crucial for the development and improvement of triage systems.

## 2 | THE STUDY

### 2.1 | Aims

The objectives of this quasi-experimental pre-post study were (1) to assess whether performing daily triage audits changed the error rate in the application of the triage system; (2) to evaluate whether the concordance between the nurse triage priority and the urgency expressed by the emergency department physician was improved by the daily triage audit; (3) to assess whether variables found to be associated with error in the pre-intervention period were also found to be associated with error in the post-intervention period.

### 2.2 | Design

A quasi-experimental pre-post study was performed between June 2019 and June 2021 at the emergency department of Merano Hospital, Italy (70,000 emergency department visits, 300 acute care beds), where triage activities are conducted in a standardized manner using the Manchester Triage System methodology (Mackway-Jones et al., 2014). Since 2018, all triage activities have been performed by two dedicated nurses during the day shift (08:00h–20:00h) and by one nurse during the night shift (20:00h–08:00h). All triage nurses have a minimum of 2 years of experience in a critical care setting, have completed a dedicated 2-day course, and have undergone a 3-month coaching period with an experienced clinical triage nurse.

All triage nurses have a minimum of 2 years of experience in a critical care area, have completed a dedicated 2-day course, and have received a 3-month coaching period from an experienced clinical triage nurse.

All triage activity performed for patients entering the emergency department (e.g., flow-chart used, vital parameters recorded and code assigned) is recorded in the department's database. The quality of the triage process is monitored through the audit procedure described in the Manchester Triage System manual (Mackway-Jones et al., 2014), and triage errors (yes/no) are determined based on the criteria described therein. According to the Manchester Triage System group, nurse-led triage quality should be assessed according to seven criteria: (a) correct use of presentational flow chart; (b) specific discriminators correctly selected; (c) pain score recorded; (d) correct triage category assigned (based on presentation and discriminators); (e) ability to navigate the computerized triage system demonstrated; (f) triage record legible and named; and (g) patient re-triaged where necessary. Criteria (c), (e), (f) and (g) refer to the "completeness" of the triage process, while criteria (a), (b), and (d) refer to its "accuracy." In the evaluation of randomly selected patient records, a triage error was considered to have occurred if any of the seven criteria were not adequately fulfilled or were not correctly selected, or priority levels were not correctly assigned (Mackway-Jones et al., 2014).

On a daily basis, the nurses dedicated to the auditing process printed the file documenting the previous day's admissions in

chronological order and performed the audit, excluding 33% of the eligible patient charts. The exclusion of this 33% was achieved by rejecting every third patient, without considering colour code, reasons for access or other details, so that the selection process was random and was based only on the chronological order of patient admission.

In addition, as of 2019, every emergency department physician must report the degree of urgency for each patient at their initial assessment (for which they do not have access to any of the diagnostic tools available at subsequent assessments). A five-level scale is used, and each level corresponds to a triage priority code, where level 5 is equivalent to a non-urgent patient (with a maximum waiting time of 240 min) and level 1 to a patient with a life-threatening illness or injury who is in need of immediate care (a waiting time of 0 min). Priority levels are assigned by the emergency department physician without the use of a standardized system, and thus the assessment of priority is subjective.

During the pre-intervention period (until December 2019), the correctness of the triage and thus the error rate for the triage activity of each nurse was assessed by performing 20 annual audits per nurse, which were randomly drawn from all triages performed during the previous year. The clinical intervention of the study from 1 January 2020 until 31 December 2020 included an expansion of the auditing procedures, with daily audits and direct feedback to the nurses on the days immediately following the audits.

Since the intervention, the files of all patients triaged on the previous day have been extracted from the computer database on a daily basis, and audits are carried out according to the specific Manchester Triage System procedure for patients not included in "fast-track" pathways (e.g., those with urological problems, dental problems and minor orthopaedic problems) and patients who have accessed an emergency department pathway other than the general emergency department (e.g., direct access to the paediatric emergency department or the gynaecological emergency department). An average of 50 triages were audited per day. The results of the audits (i.e., whether the triages were deemed to be correct or incorrect) were communicated the following day through a brief discussion or via email. When the nurse was present in the department on the following day, the results were communicated in person workload permitting—and he or she was provided with a focused presentation of all evaluated cases. If the nurse was not present in the department, a file with the assessed cases was sent via email the following day. Both discussions were performed according to the Manchester Triage System methodology, assessing the strengths and weaknesses of the triage under discussion. Only the triage nurse under analysis and the auditor nurses were aware of the feedback given.

In the pre- and post-intervention periods, audits were performed by a group of auditors consisting of three nurses, all of whom had more than 5 years of experience in triage; all auditors took a dedicated course and performed a period of auditing alongside an experienced colleague. Daily audits were performed by auditor nurses during times outside of normal clinical practice.

Daily auditing continued throughout 2020, except during the first 2 weeks of March 2020 due to the outbreak of the COVID-19 pandemic and the reorganization of the emergency department. The intervention, therefore, lasted for 11 months and 2 weeks. Thereafter, daily auditing was maintained during the post-intervention period.

Throughout the intervention period, nurses also had to adjust to the changes in the emergency department resulting from the COVID-19 pandemic, but in the pre- and post-intervention periods, the facilities remained basically unchanged, with the only difference being a dedicated pathway for COVID-19 patients. There was no change in the level of nursing resources between the pre- and post-intervention periods.

## 2.3 | Sample

A formal sample size calculation was not possible due to the absence of previous studies on the effect of the auditing procedure. Utilizing a randomized draw, 5% of patients accessed in 2019 and 5% of patients accessed in 2021 were selected. The emergency department records of the randomly selected patients were used to perform the auditing procedure as outlined in the Manchester Triage System methodology. Two groups of patients were thus identified, the pre-intervention group versus the post-intervention group. The following criteria were used for patient eligibility: (1) age over 18 years; (2) access to the emergency department for an acute medical or surgical problem; (3) not on fast-track paths; (4) resident in the district. For the pre-intervention study group, patients triaged from 1 June 2019 to 31 December 2019 and for the post-intervention study group, patients triaged from 1 January 2021 to 31 June 2021 were considered.

## 2.4 | Data collection

The baseline characteristics and triage data of the extracted and audited patients were recorded by manual re-evaluation of the emergency department records. In particular, the following clinical patient variables were identified: saturation, temperature, heart rate, respiratory rate, age and blood pressure. In addition, some characteristics of the nurses who triaged the selected patients were recorded. The following were included: The years of work in the emergency department under investigation; Whether the nurse worked in another department previously; Whether the nurse had previously worked with a different triage system.

The primary outcome of the study was the triage error identified according to the auditing procedure described in the Manchester Triage System manual. The secondary outcome was the rate of agreement between physician and nurse on the patient's degree of urgency. The tertiary outcome was to assess whether the variables most associated with triage error changed with the implementation of daily auditing.

## 2.5 | Ethical considerations

The study was conducted in accordance with the relative local ethical committees (Comitato etico per la sperimentazione clinica, Azienda Sanitaria dell'Alto Adige, Bolzano, Italia, approval number 95-2019) and was conducted according to the Declaration of Helsinki regarding the Ethical Principles for Medical Research Involving Human Subjects.

## 2.6 | Data analysis

Continuous variables were described as mean and standard deviation or as median and interquartile ranges depending on the underlying distribution. Relationship variables were described as the percentage and number of events in the total. Differences between categorical variables were tested using Fisher's exact tests or the Chi-square test, and using t-tests or the Mann-Whitney test for continuous variables. Variables found to be significant in the univariate analysis with a significance level of 0.05 were proposed to the multivariate model. The multivariate model was run with multivariate logistic regression to test the association between variables recorded in triage and the error.

The concordance between the triage priority and the priority assigned by the emergency department physician was evaluated with Cohen's Kappa coefficient, with 95% confidence intervals (95% CI) reported. Cohen's Kappa was calculated unweighted and then squared-weighted, as preferred for ordinal scales.

All tests with a  $p$  of  $<.05$  were considered statistically significant. Statistical analyses were performed with STATA® version 16.0 (StataCorp, College Station, Texas, USA).

## 3 | RESULTS

1773 patients were considered (Figure 1). 904 patients were enrolled in the pre-intervention period (1 June 2019–31 December 2019) and 869 in the post-intervention period (1 January 2021 to 31 June 2021). The error rate in the pre-intervention period was 23.2% (210/904) of the triages considered, while the error rate in the post-intervention period was 9.7% (84/869),  $p < .001$  (Table 1).

The clinical, anamnestic and triage nurse characteristics divided between the pre-intervention period and the post-intervention period are reported in Tables 2 and 3.

In the pre-intervention period, the triage error was associated with the priority defined in triage ( $p < .001$ ) and the essential parameters in triage according to the Manchester Triage System method ( $p = .021$ ) (Table 2). In addition, the mode of arrival in the emergency department was associated with the error ( $p = .016$ ), indicating a higher error rate in patients brought to the emergency department by the emergency medical services, as well as the time of arrival was also associated with the error ( $p = .021$ ), with a higher error rate during the day (Table 2). The emergency department physician's indication of a non-time-dependent condition at his first assessment was found to be associated with the error ( $p = .041$ ) (Table 2). The nurse with more years of work in the emergency department under analysis was also associated with the error ( $p < .001$ ), the triage nurse who had previously worked in another department was also associated with the error ( $p < .001$ ), and the triage nurse who had worked with another triage system in his career was also associated with the error ( $p < .001$ ) (Table 2).

Multivariate analysis indicated that in the pre-intervention period, the characteristics found to be significant risk factors for the

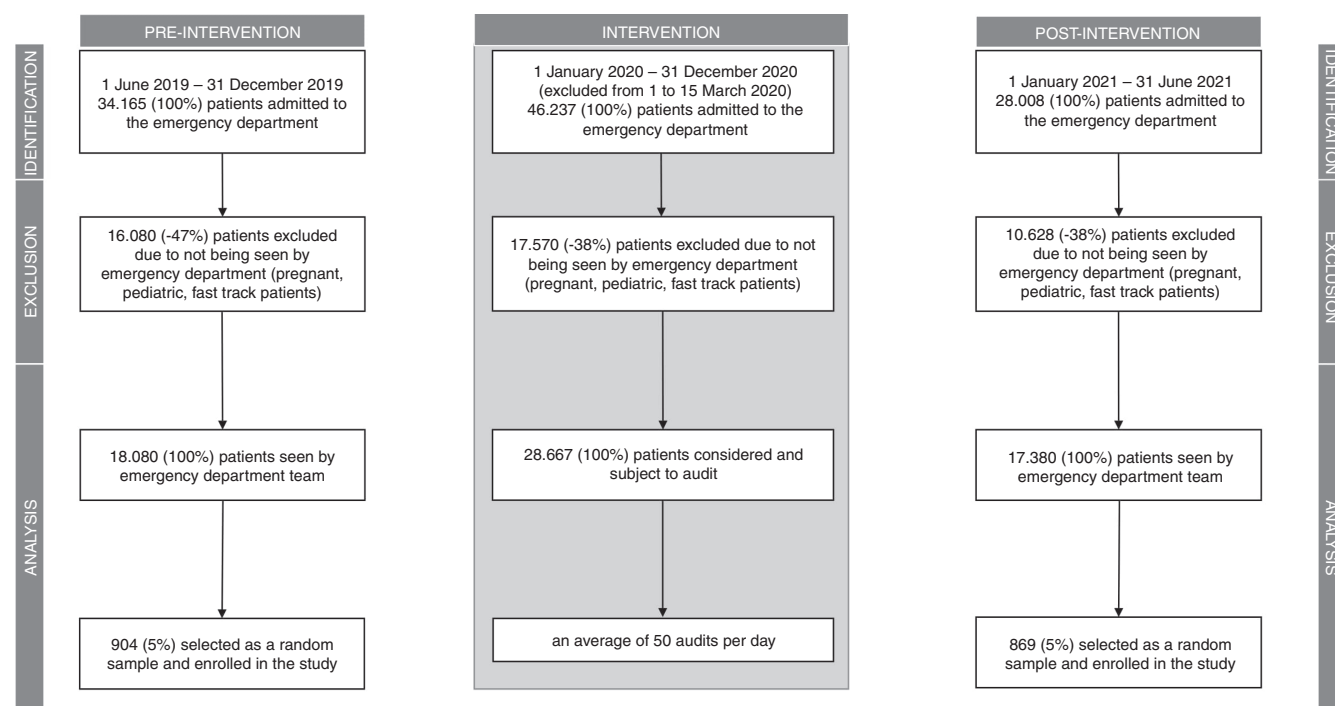


FIGURE 1 Flow-chart of patients enrolled in the study

**TABLE 1** Errors in triage distributed among patients in the pre- and post-intervention period

	2019	2021
Correct triage	694 (76.8)	785 (90.3)
Incorrect triage	210 (23.2)	84 (9.7)

error were the priority defined in triage with an odds ratio (OR) of 1.57 ( $p = .039$ ), nurse who had previously worked in another department with an OR of 0.24 ( $p < .001$ ) and the indication of a time-dependent pathology according to the emergency department physician with an OR of 0.16 ( $p = .008$ ) (Table 4).

In the post-intervention period, the univariate analysis only indicated the age of the patient ( $p = .010$ ), the years of work of the nurse in the emergency department ( $p = .026$ ), whether the nurse had worked in another department previously ( $p < .001$ ), and whether the nurse had used another triage system previously ( $p < .001$ ) as variables associated with error (Table 3). The multivariate analysis performed in the post-intervention period identified only the nurse who had previously worked with another triage system as significant risk factors with an OR of 2.46 ( $p = .007$ ) and the nurse who had previously worked in another department with an OR of 0.105 ( $p < .001$ ) (Table 4).

The comparison demonstrates that many variables associated with an error in the pre-intervention period have lost their association due to the intervention. These were the triage priority ( $p < .001$  vs.  $p = .292$ ), the presence of the parameters necessary for code assignment in triage ( $p = 0.021$  vs.  $p = .243$ ), the mode of arrival in the emergency department ( $p = .016$  vs.  $p = .175$ ), the time of arrival ( $p = .021$  vs.  $p = .126$ ) and the indication of a time-dependent pathology by the physician ( $p = .041$  vs.  $p = .723$ ) (Tables 2 and 3).

The agreement between the severity expressed by the emergency department physician and that expressed by the nurse is shown in Table 4. In the pre-intervention period, the interrater agreement reported a Cohen's Kappa of 0.447 while in the post-intervention period the interrater agreement reported a Cohen's Kappa of 0.881 (Table 5).

## 4 | DISCUSSION

Triage, by first estimating the severity of the patient and providing the urgency for medical treatment, is essential for modern emergency departments (Hinson et al., 2019). The correct application of the triage system by the triage nurses, therefore, becomes crucial not only for the outcome of the critical patient, but for the correct functioning of the whole emergency department structure (Christ et al., 2010; Tam et al., 2018). Although the importance of continuous training of triage nurses has been widely highlighted, no clinical tools are available to ensure progressive improvement in the daily clinical application of triage systems (Tam et al., 2018).

This quasi-experimental study demonstrated how the daily triage audit reduced the triage error rates made by nurses and improves

**TABLE 2** Variables recorded and distributed between correct and incorrect triage in pre-intervention period

	Univariate analysis 2019		
	Correct	Incorrect	<i>p</i> -value
Patients	694	210	
Sex, <i>n</i> (%)			.096 <sup>b</sup>
Male	389 (78.9)	104 (21.1)	
Female	305 (74.2)	106 (25.8)	
Age in years, mean (SD)	55.8 (21.4)	57.1 (20.5)	.467 <sup>c</sup>
Triage priority, <i>n</i> (%)			<.001 <sup>d</sup>
Blue	6 (100.0)	0 (0.0)	
Green	353 (89.1)	43 (10.9)	
Yellow	239 (64.1)	134 (35.9)	
Orange	95 (74.2)	33 (25.8)	
Red	1 (100.0)	0 (0.0)	
Vital parameters			
RR (breaths per minute), mean (SD)	17 (4)	18 (6)	.209 <sup>e</sup>
HR (bpm), mean (SD)	87 (19)	83 (16)	.138 <sup>e</sup>
Oxygen saturation (%), median (IQR)	97 (95–98)	97 (95–98)	.685 <sup>f</sup>
Systolic BP (mmHg), mean (SD)	144 (25)	143 (24)	.799 <sup>e</sup>
Diastolic BP (mmHg), mean (SD)	85 (15)	83 (14)	.421 <sup>e</sup>
Temperature (°C), median (IQR)	37.4 (36–37)	36.3 (36–36.8)	.206 <sup>f</sup>
Essential parameters in triage according to the Manchester Triage System method <sup>a</sup> , <i>n</i> (%)			.021 <sup>d</sup>
Yes	363 (73.8)	129 (26.2)	
No	330 (80.3)	81 (19.3)	
Arrival mode, <i>n</i> (%)			.016 <sup>d</sup>
Autonomous	460 (74.7)	156 (25.3)	
Ambulance	186 (83.8)	36 (16.2)	
Emergency medical services	48 (72.7)	18 (27.3)	
Day of arrival, <i>n</i> (%)			.065 <sup>d</sup>
During the week	483 (75.1)	160 (24.9)	
Weekend	211 (80.8)	50 (19.2)	
Time of arrival, <i>n</i> (%)			.021 <sup>d</sup>
Day (08:00–19:59)	500 (74.9)	168 (25.1)	
Night (20:00–07:59)	194 (82.2)	42 (17.8)	
Time-dependent pathology according to emergency department physician at first assessment, <i>n</i> (%)			.041 <sup>d</sup>

(Continues)

TABLE 2 (Continued)

	Univariate analysis 2019		
	Correct	Incorrect	p-value
Yes	41 (89.1)	5 (10.9)	
No	652 (76.1)	205 (23.9)	
Nurse who worked in another department, n (%)	43 (8.6)	456 (91.4)	<.001 <sup>b</sup>
Nurse who worked with a different triage system, n (%)	43 (14.1)	262 (85.9)	<.001 <sup>b</sup>
Years of work of the nurse in the emergency department, mean (SD)	9.5 (7.5)	11.8 (6.6)	<.001 <sup>d</sup>

<sup>a</sup>Intended as the parameters that would be needed by the nurse to define the selected triage priority.

<sup>b</sup>Fisher's exact test.

<sup>c</sup>Mann-Whitney *U*-test.

<sup>d</sup>Chi-square test.

<sup>e</sup>Student's *t*-test.

<sup>f</sup>Kruskal-Wallis test.

the concordance of the patient's estimated priority between emergency department nurse and physician. To the best of our knowledge, this is the first time that a clinical improvement technique, the daily triage audit, has been directly tested in daily clinical practice, advancing from previous simulation techniques. The daily triage audit appears to be a simple clinical tool available to the emergency department that can easily be incorporated into daily clinical practice and can simply improve triage performance.

In fact, previous simulation studies exploring nurses' concordance in the application of the triage system on selected clinical cases have reported inconsistent accuracy, reliability and inter-rater reliability values (De Magalhães-Barbosa et al., 2017; Parenti et al., 2014; Zachariasse et al., 2019). Van der Wulp et al. (2008) analysed the nurses' ability to stratify 50 scenarios and reported inter-rater reliability with a Cohen's Kappa of 0.49. van Veen et al. (2010) evaluated the ability of Manchester Triage System to stratify the paediatric population using 20 scenarios and reported a Cohen's Kappa of 0.65. Gräff et al. (2014) evaluated the performance of nurses in a general population of 167 cases and reported a Cohen's Kappa of 0.95.

The analysis of the studies seems to strongly suggest that despite the presence of triage systems that constantly aim at an objective standardization of patient assessment, different nurses using the same system may arrive at two different applications (Parenti et al., 2014; van der Wulp et al., 2008; van Veen et al., 2010). These observed discrepancies seem to amply justify the need to introduce continuous learning methods aimed at the constant improvement of system applications. According to Tam et al., given the increasingly crucial role of triage both for patient outcomes and for the entire functionality of the emergency department system, analysing and

TABLE 3 Variables recorded and distributed between correct and incorrect triage in post-intervention period

	Univariate analysis 2021		
	Correct	Incorrect	p-value
Patients	785	84	
Sex, n (%)			.252 <sup>b</sup>
Male	416 (91.4)	39 (8.6)	
Female	369 (89.1)	45 (10.9)	
Age in years, mean (SD)	64.3 (21.3)	69.1 (18.2)	.010 <sup>c</sup>
Triage priority, n (%)			.292 <sup>d</sup>
Blue	41 (97.6)	1 (2.4)	
Green	352 (89.8)	40 (10.2)	
Yellow	230 (89.5)	27 (10.5)	
Orange	143 (89.9)	16 (10.1)	
Red	19 (100.0)	0 (0.0)	
Vital parameters			
RR (breaths per minute), mean (SD)	17 (4)	18 (4)	.821 <sup>e</sup>
HR (bpm), mean (SD)	85 (18)	83 (18)	.725 <sup>e</sup>
Oxygen saturation (%), median (IQR)	97 (95–99)	97 (95–98)	.506 <sup>f</sup>
Systolic BP (mmHg), mean (SD)	135 (27)	134 (27)	.726 <sup>e</sup>
Diastolic BP (mmHg), mean (SD)	77 (13)	78 (12)	.588 <sup>e</sup>
Temperature (°C), median (IQR)	36.5 (36–37)	36.5 (36–37)	.615 <sup>f</sup>
Essential parameters in triage according to the Manchester Triage System method <sup>a</sup> , n (%)			.243 <sup>d</sup>
Yes	472 (89.4)	56 (10.6)	
No	313 (91.8)	28 (8.2)	
Arrival mode, n (%)			.175 <sup>d</sup>
Autonomous	417 (92.1)	36 (7.9)	
Ambulance	302 (88.8)	38 (11.2)	
Emergency medical services	66 (86.8)	10 (13.2)	
Day of arrival, n (%)			.160 <sup>d</sup>
During the week	560 (89.5)	66 (10.5)	
Weekend	225 (92.6)	18 (7.4)	
Time of arrival, n (%)			.126 <sup>d</sup>
Day (08:00–19:59)	575 (89.4)	68 (10.6)	
Night (20.00–07:59)	210 (92.9)	16 (19.0)	
Time-dependent pathology according to emergency department physician at first assessment, n (%)			.723 <sup>d</sup>
Yes	114 (91.2)	11 (8.8)	
No	671 (90.2)	73 (9.8)	

TABLE 3 (Continued)

	Univariate analysis 2021		
	Correct	Incorrect	p-value
Nurse who worked in another department, n (%)	472 (85.2)	82 (14.8)	<.001 <sup>b</sup>
Nurse who worked with a different triage system, n (%)	149 (70.6)	62 (29.4)	<.001 <sup>b</sup>
Years of work of the nurse in the emergency department, mean (SD)	11.1 (7.8)	13.1 (6.5)	.026 <sup>e</sup>

<sup>a</sup>Intended as the parameters that would be needed by the nurse to define the selected triage priority.

<sup>b</sup>Fisher's exact test.

<sup>c</sup>Mann-Whitney *U*-test.

<sup>d</sup>Chi-square test.

<sup>e</sup>Student's *t*-test.

<sup>f</sup>Kruskal-Wallis test.

improving the ability to correctly apply triage systems becomes a priority (Dong et al., 2007; Tam et al., 2018). Several authors agree that low inter-rater agreement between triage nurses affects the objectivity of triage by causing different prioritization of similar patients, which then affects both the safety of the individual patient and the safety of the facility in general (Buschhorn et al., 2013; Parenti et al., 2014). While the deficits in concordance may be partly due to an excessive attempt of the triage systems to aim at an exhausting

search for standardization and simplification even of heterogeneous and complex clinical presentations, the need to combine this strictly objective methodology of the triage systems with the advantage of the clinical experience of the individual nurse and his learning pathway in clinical practice may also emerge. Therefore, the daily triage audit could be part of the latter, stimulating continuous professional growth and the attainment of experience based on the comparison that could refine the schematic nature of triage systems even in those complex presentations that are difficult to harness within specific diagrams or flow-charts based on symptoms (Ausserhofer et al., 2020; Zaboli, Ausserhofer, Sibilio, Paulmichl, Toccolini, Pfeifer, et al., 2022).

Auditing procedures within triage systems (e.g., Manchester Triage System, Emergency Severity Index), designed to assess errors in the application of triage, appear to be natural tools for creating continuous clinical education, breaking down the current discordance between operators, and improving the fundamental action of triage (Mackway-Jones et al., 2014; Tanabe et al., 2005). The triage error analysis conducted in the study showed that the daily triage audit reduced the error rate from 23.2% in the pre-intervention period to 9.7% in the post-intervention period. Previous studies have reported triage error rates of between 15% and 30% of cases (Ausserhofer et al., 2021; Goldstein et al., 2017). Ausserhofer et al. (2021) in their study on errors in triage, evaluating Manchester Triage System, demonstrated that misapplication of the triage system occurred in 17% of the cohort considered. The error rate presented in the current study appears to be substantially in line with that presented in the literature and the small

TABLE 4 Multivariate analysis of variables found to be significant in the previous univariate analysis divided between pre- and post-intervention

Multivariate analysis 2019			
Variables	OR	CI 95%	p-value
Triage priority	1.574	1.024–2.410	.039
Essential parameters in triage according to the Manchester Triage System * method	1.722	0.942–3.148	.077
Time of arrival	0.727	0.416–1.268	.262
Years of work of the nurse in the emergency department	1.003	0.934–1.077	.920
Nurse who worked with a different triage system	0.592	0.225–1.559	.290
Nurse who worked in another department	0.243	0.145–0.405	<.001
Time-dependent pathology according to emergency department physician at first assessment	0.165	0.043–0.630	.008
Multivariate analysis 2021			
Variables	OR	CI 95%	p-value
Age	1.011	0.998–1.024	.080
Years of work of the nurse in the emergency department	1.039	1.000–1.080	.050
Nurse who worked with a different triage system	2.459	1.277–4.736	.007
Nurse who worked in another department	0.105	0.062–0.179	<.001

\*Intended as the parameters that would be needed by the nurse to define the selected triage priority.



	Kappa	95% confidence interval				
2019						
Unweighted	0.116	0.084–0.132				
Quadratically weighted	0.447	0.401–0.478				
2019						
	Nurse's priority code					
Physician's priority code	Blue	Green	Yellow	Orange	Red	
Blue	6	108	10	1	0	
Green	0	273	270	34	0	
Yellow	0	15	90	66	0	
Orange	0	0	3	26	1	
Red	0	0	0	1	0	
	Kappa	95% confidence interval				
2021						
Unweighted	0.771	0.757–0.789				
Quadratically weighted	0.881	0.855–0.907				
2021						
	Nurse's priority code					
Physician's priority code	Blue	Green	Yellow	Orange	Red	
Blue	37	10	1	0	0	
Green	5	338	35	4	0	
Yellow	0	37	204	16	0	
Orange	0	7	17	136	0	
Red	0	0	0	3	19	

TABLE 5 Agreement between emergency department physician and triage nurse calculated with unweighted and quadratically weighted Cohen's kappa

percentage gap could be explained by the stricter auditing methodology used, which is also considered 'incomplete' triage as errors as described in the Manchester Triage System auditing procedure (Mackway-Jones et al., 2014).

Unlike previous studies, inter-rater reliability was assessed between the triage nurse and the emergency department physician. The physician, thus taken as the gold standard, was asked to assign a priority code not by simulating the use of Manchester Triage System or any other triage system, but to express a degree of priority (among five available) based on his clinical experience at the first clinical evaluation, therefore without other diagnostic tools. Through the analysis of the results, it was shown that the agreement between the physician and the nurse increased exponentially after the introduction of the daily audit, with a quadratic weighted Cohen's Kappa of 0.447 before the intervention and one of 0.881 afterward. The result appears very significant and well above what is reported in the literature. Although the physician was not using the same scale as the nurse (Manchester Triage System) the impact of the audit shows that proper application of MTS also increases concordance with the ED physician.

Mirhaghi et al., in their study on the implementation of the emergency severity index in the clinical practice, reported a Cohen's Kappa between the emergency department physician applying the emergency severity index and the triage nurse of 0.45 (Mirhaghi

et al., 2015). emergency department physicians, who have been working closely with triage systems for many years, know the meaning of patient prioritization and are familiar with symptom presentations that can safely wait for those requiring rapid medical assessment. The decision to evaluate a possible benefit of daily triage auditing on the growth of concordance with the emergency department physician appears to be the best possible choice because it is considered to be the best possible comparison for the nurse's performance and because it is conducted during actual clinical practice and not through a reconstruction of the degree of urgency as was the case in previous studies (Dalwai et al., 2018; van der Wulp et al., 2008; van Veen et al., 2010).

Daily triage auditing, which is also based on the discussion of the clinical case with the medical records, seems to be able to develop and improve the clinical and medical knowledge of the nurse as well, and it can be assumed that daily triage auditing not only plays a role in the triage component but also in the overall education of the nurse. The strong reduction in the gap with the physician, the improvement in error in acute pathological conditions, and the reduction in clinical features related to error seem to suggest that daily triage auditing can develop the professional skills of the nurse by nurses themselves. Further studies could confirm this and allow daily triage auditing to be used as continuing education for emergency department nurses.

Some variables apparently associated with an increased possibility of triage error remained unchanged before and after the intervention, in particular those related to the triage nurse. Work experience in other departments or switching to another triage system were two factors, which had already been identified in other studies, on which auditing failed to decrease the error rate (Ausserhofer et al., 2021). As demonstrated by Giesbers et al. through their study on auditing and feedback to nurses, it was found that some nurses not only disliked undergoing these two methods but also showed no interest in modifying their behaviour. Although these nurses are in the minority as a proportion of the group studied (9%), they can still have an impact on the effects of auditing and feedback strategies (Giesbers et al., 2016). As reported by Whalen et al. in their review of the literature, although the effects of the use of auditing and feedback are unclear and further studies are needed to fully understand the advantages and disadvantages, two strategies remain strongly recommended in clinical practice (Whalen et al., 2021). The failure to change or improve nurse-related variables in the post-intervention period may therefore be attributable to the attitude of a proportion of nurses not wishing to receive feedback or audits on their triage performance. Nevertheless, this study indicates that most of the variables associated with an error in the pre-intervention period were found not to be associated with an error in the post-intervention period, such as a reduction in the incorrectness of patient stratification when delivered to triage directly by the out-of-hospital physician or a decrease in error during the day-time hours.

#### 4.1 | Limitations

The present study presents some limitations: First, no data were collected on the expenditure of resources and the time needed for daily auditing; Second, the timing of the triage was not recorded, although the intervention was performed at a different time from the triage and therefore should not have had an impact on its duration; Third, the monocentric nature of the study subjects it to all the biases attributable to this type of study; Fourth, there are no data available about the impact of the audit on nurses, their experiences and their feelings towards this intervention; Fifth, the sole consideration of patients seen in the emergency department and the exclusion of patients who were sent to fast-track may have altered the results, despite these limitations only a small portion of patients are sent to fast-track and with lower priority level. In addition, the consideration of the emergency department physician's classification based on their own experience may have limited the results of the study, despite that the objective of the study was to evaluate the audit and for that reason the use of such a method may have affected both pre-intervention and post-intervention results. In addition, the physicians considered are those from the emergency department and therefore are familiar with the meaning of each priority code.

## 5 | CONCLUSIONS

Daily auditing would appear to be a simple clinical technique that can significantly improve the fundamental activity of triage. Through daily monitoring and sharing with the triage nurse, daily auditing in triage has reduced error rates and improved triage performance. Moreover, although further experimental confirmation is needed, it would appear that daily auditing triage can increase the medical knowledge of the triage nurse which may open a new avenue towards the continuing education which is crucial for nurses in emergency departments.

#### AUTHOR CONTRIBUTIONS

Arian Zaboli and Gianni Turcato participated in the conception and initial design of the project. Arian Zaboli, Gabriele Magnarelli and Serena Sibilio collected the data. Arian Zaboli and Gianni Turcato undertook the statistical analysis. All the authors drafted the manuscript, revised and approved the final manuscript.

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#### CONFLICT OF INTEREST

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### PEER REVIEW

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#### DATA AVAILABILITY STATEMENT

Data available on request due to privacy restrictions.

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## APPENDIX A

### Information about nurses' training to become triage nurses

The nurses perform a 2-day MTS course. The course is performed for the whole province (seven different hospitals) within the major hospital.

Of the seven hospitals in the province, only the two largest hospitals have nurses who conduct the dedicated course.

During the course, the basic principles of triage, its usefulness and methodology are explained. Afterwards, the MTS methodology

is explained and several simulations are performed first in a single group and subsequently in smaller groups.

Each course accepts 12 to 16 nurses and the nurse instructor ratio is 1 to 4, so the courses are composed of 3/4 trainers.

Every 2 years there is a shorter retraining course (1 day) where only clinical cases are discussed and the basic theory part is avoided.

Each course (basic and retraining) is subject to a theoretical examination consisting of 30 questions, to obtain the triage nurse certificate the minimum possible score is 18.



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# Nurses' knowledge and confidence in recognizing and managing patients with sepsis: A multi-site cross-sectional study

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## Abstract

**Aims:** (1) To examine registered nurses' knowledge and confidence in recognizing and managing to patients with sepsis and (2) identify nurse and workplace factors that influence their knowledge on sepsis.

**Design:** A multi-site, cross-sectional survey.

**Methods:** An online survey was developed and content validated. Data was collected from registered nurses working in the inpatient wards and emergency departments of three hospitals of a single healthcare cluster in Singapore during August 2021. Statistical analyses of closed-ended responses and content analysis of open-ended responses were undertaken.

**Results:** A total of 709 nurses completed the survey. Nurses possessed moderate levels of knowledge about sepsis (mean score = 10.56/15; SD = 2.01) and confidence in recognizing and responding to patients with sepsis (mean score = 18.46/25; SD = 2.79). However, only 369 (52.0%) could correctly define sepsis. Nurses' job grade, nursing education level and clinical work area were significant predictors of nurses' sepsis knowledge. Specifically, nurses with higher job grade, higher nursing education level or those working in acute care areas (i.e. emergency department, high dependency units or intensive care units) were more likely to obtain higher total sepsis knowledge scores. A weak positive correlation was observed between sepsis knowledge test scores and self-confidence ( $r = .184$ ). Open comments revealed that participants desired for more sepsis education and training opportunities and the implementation of sepsis screening tool and sepsis care protocol.

**Conclusion:** A stronger foundation in sepsis education and training programs and the implementation of sepsis screening tools and care bundles are needed to enhance nurses' knowledge and confidence in recognizing and managing patients with sepsis.

**Impact:** The findings of this study are beneficial to administrators, educators and researchers in designing interventions to support nurses in their role in recognizing and responding to sepsis.

**KEYWORDS**

acute care, confidence, education, knowledge, management, nursing, recognition, registered nurse, sepsis, survey

## 1 | INTRODUCTION

Sepsis, a clinical syndrome of dysregulated host response to infection leading to life-threatening organ dysfunction, is a leading cause of global morbidity and mortality (Singer et al., 2016). It is a major challenge for healthcare systems worldwide because it leads to significant consumption of healthcare resources (Rudd et al., 2018). Sepsis imposes a large economic burden; for example, the annual cost on hospital care for patients with sepsis in the United States is estimated at more than US\$24 billion (Paoli et al., 2018). In addition, each year, there are approximately 14 million sepsis survivors who have an increased risk of recurrent infections and hospital readmissions, and this comes with grave physical and financial consequences (Prescott & Angus, 2018). At present, the estimated burden of sepsis is reported to be 48.9 million cases worldwide and 11 million of sepsis-related deaths, suggesting a 20% mortality rate for sepsis (Rudd et al., 2020). In Singapore alone—a high income country with 5.6 million population, close to 5000 deaths were attributed to sepsis from pneumonia and urinary tract infection in 2019 (Singapore Ministry of Health, 2020). This was an approximate 13% increment from those reported in 2012 (Singapore Ministry of Health, 2020). Incidence of sepsis will continue to rise with interplay of multiple factors including aging population with more predisposing comorbidities, use of immunosuppressive therapy, and emergence of multi-drug antimicrobial resistance (Rhee & Klompas, 2020). The considerable impact of sepsis highlights the importance of raising awareness to promote early recognition and treatment. Nurses play a pivotal role in the early recognition and management of sepsis because they are uniquely positioned to make the first crucial assessment in detecting sepsis and implementing timely intervention to prevent clinical deterioration.

### 1.1 | Background

Sepsis is recognized as a global health priority by the World Health Organization (WHO) which has adopted a resolution on improving the prevention, diagnosis and management of sepsis (Reinhart et al., 2017). As a time-critical medical emergency that is treatable and preventable, early recognition of sepsis with expeditious interventions is paramount in reducing the progression of sepsis and improving patient outcomes (See, 2022). Delays in sepsis recognition and treatment could lead to septic shock, a condition that

can result in multiorgan system failure and ultimately death (Singer et al., 2016). The International Surviving Sepsis Campaign (SSC), led by the Society of Critical Care Medicine and the European Society of Intensive Care Medicine, has provided evidence-based recommendations for clinicians to improve sepsis care (Dellinger et al., 2004).

Increased adherence to sepsis guideline bundles has led to better outcomes with reduced need for ICU admission, shorter hospital length of stay and lower mortality (Levy et al., 2015; Milano et al., 2018). Compelling evidence has shown that delay in executing each intervention and completing the bundle was associated with higher mortality (Pruinelli et al., 2018; Seymour et al., 2017). Nevertheless, it is noteworthy that management of sepsis can only commence after appropriate assessment and diagnosis have been made. Yet, identifying patients, especially in the earlier stages of sepsis continuum, poses a significant challenge due to its highly variable and non-specific clinical manifestations (Vincent, 2016). As such, the need to recognize sepsis accurately and quickly has led to development of sepsis screening tools which is an important element of sepsis performance improvement programs (Evans et al., 2021).

In the healthcare system, nurses play a pivotal role in identifying patients with sepsis and promptly escalate care for commencing diagnostic work and initiating treatment (See, 2022). In the emergency department (ED), triage nurses are often the first point of contact for assessing patients with community-acquired sepsis. In the ward settings, nurses are in a privileged position to identify hospital-onset sepsis at its earliest possible time because they spend the most contact hours doing routine bedside monitoring of patients. Nurse-led sepsis screening interventions have demonstrated positive impact on reducing mortality and improving process measures of sepsis care bundles (McDonald et al., 2018; Torsvik et al., 2016). It is therefore crucial that nurses understand the importance of their role in sepsis recognition, are trained to identify possible sepsis and have the self-confidence to respond and intervene with appropriate actions.

Internationally, there are several papers that published on nurses' level of knowledge on sepsis (Nucera et al., 2018; Rahman et al., 2019; Stamatakis et al., 2014; Storozuk et al., 2019; van den Hengel et al., 2016). The findings were consistent and revealed knowledge deficits on systemic inflammatory response syndrome, signs and symptoms of sepsis, and its initial management. However, these studies often asked lower order questions that relied on participants' factual recall of sepsis knowledge instead of higher order application and analytical questions that simulate real sepsis scenarios. Furthermore, it is important to note that the questions asked in a few of the earlier



studies were no longer in line with the updated sepsis-3 definitions and management guidelines (Nucera et al., 2018; Stamatakis et al., 2014; van den Hengel et al., 2016). With improved research leading to better understanding of sepsis pathophysiology, the Sepsis Task Force published *The Third International Consensus Definitions for Sepsis and Septic Shock (Sepsis-3)* was published in 2016 (Singer et al., 2016). Sepsis-3 encompasses organ dysfunction resulting from the patient's response to an infection (Singer et al., 2016). This was significantly different from Sepsis-2, which emphasized on the presence of two or more systemic inflammatory response syndrome criteria with a concomitant infection to define sepsis. With the new definitions of sepsis, the SSC recommended the initiation of a set of sepsis care bundle upon recognition of sepsis, which includes obtaining blood cultures followed by administration of antimicrobials, measuring lactate levels, initiating at least 30ml/kg intravenous crystalloids in sepsis-induced hypoperfusion or septic shock and starting vasopressors to maintain mean arterial pressure  $\geq 65$  mmHg during or after fluid resuscitation (Evans et al., 2021).

In addition to sepsis knowledge, nurses' level of self-confidence—one's beliefs about their capability and skills—has been identified as an important factor contributing to the recognition, escalation and management of paediatric sepsis (Harley, Schlapbach, et al., 2021). However, research on nurses' self-confidence in recognizing and managing adult sepsis is lacking. Thus, the interest in undertaking this study arose with the intent to assess if nurses are in keeping with the sepsis-3 definitions and guidelines using applied knowledge test and to examine their confidence levels in recognizing and managing sepsis. The findings from this study will help identify gaps in nurses' knowledge and competencies, thereby providing insights into developing future sepsis education and practice interventions to improve clinical outcomes.

## 2 | THE STUDY

### 2.1 | Aims

This study aimed to explore registered nurses' (RN) knowledge and confidence in recognizing and managing patients with sepsis. The specific objectives were to: (1) examine RNs' knowledge of sepsis and level of self-confidence in recognizing and managing patients with sepsis and (2) identify nurse and workplace factors that influence their knowledge on sepsis.

### 2.2 | Design

A multi-site, cross-sectional design using an anonymous online survey was conducted.

### 2.3 | Participants and setting

This study was conducted in three hospitals of one public healthcare cluster in the western region of Singapore. Hospital A is a 326-bed

integrated general hospital that provides holistic and seamless care from acute, subacute to rehabilitative settings, catering to the needs of residents living in the oldest housing estate in Singapore and Southwest of Singapore. The hospital has a 24-h urgent care centre (UCC) that provides immediate medical attention to walk-in patients and patients conveyed via private ambulance with acute and urgent medical conditions. Hospital B is a 700-bed acute hospital offering a range of comprehensive medical services, except obstetrics and gynaecology, paediatrics and transplant medicine. Hospital C is a 1200-bed university-affiliated tertiary referral hospital with more than 50 medical, surgical and dental specialties, offering a comprehensive range of specialist care for adults, women and children. At the point of study, none of the hospitals had a hospital sepsis protocol or care bundle in place. Except for the ED of Hospital B, the rest of the study sites and clinical areas do not have a sepsis screening tool in place. The ED of Hospital B adopts the national early warning score 2 (NEWS2), which predicts risk of clinical deterioration and in-hospital mortality based on a patient's physiological parameters (Royal College of Physicians, 2017). A cut-off point of NEWS2  $\geq 5$  serves as a trigger to alert clinicians to attend to these patients immediately and initiate evaluation for possible sepsis.

In Singapore, the basic preparatory education for RNs can be attained through either a 3-year nursing diploma programme or a 3-year nursing bachelor's degree programme (Chua et al., 2019). Following the basic nursing preparatory education, RNs can choose to acquire further in-depth speciality-specific skills and knowledge through advanced diplomas, graduate diplomas and post-graduation education (Woo et al., 2020). A convenience sample of RNs, including advanced practice nurses (APNs), involved in the clinical care of patients in inpatient wards, including intensive care units (ICUs) and high dependency units (HDUs), ED or UCC of the three hospitals was recruited for the study. RNs who were working in the paediatrics settings, operating theatres or ambulatory surgery and outpatient clinics were excluded from the study.

### 2.4 | Data collection

Data collection was conducted over a one-month period starting in early August 2021. Participants were recruited through a three-step process: (1) An email invitation to the study, comprising a letter to invite all RNs to participate, an electronic recruitment poster, the survey's hyperlink and a quick response (QR) code to access the survey, was first sent to the nursing leaders overseeing nursing research activities of the three hospitals. (2) The nursing leaders disseminated the study invitation to the nursing officers (i.e. nurse managers and nurse clinicians) and APNs of their respective hospitals. (3) Subsequently, the nursing officers of inpatient settings and ED/UCC circulated the study information face-to-face during roll calls and virtually via announcement portals to the ground nurses. The hard-copy recruitment poster was also pinned on the wards' noticeboard. To gather a higher response rate, the email invitation to the nursing leaders was re-sent at 2 and 4 weeks after the first email and 3 days

prior to closure of data collection. Participants were compensated S\$5 (≈US\$3.55) as remuneration for the time and effort they have provided in participating in the research.

The online survey was collected using Qualtrics and piloted to ensure user friendliness, ease of electronic interface and effective response collection. The survey was developed by the study team and designed to evaluate RNs' knowledge about sepsis and their perceived confidence in recognizing and managing patients with sepsis. The survey instrument comprised four sections (Supplementary file 1). Section one, consisting of 10 items, gathered demographic and workplace data. Section two consisted of five items, which asked the participants to rate their perceived confidence in recognizing and managing patients with sepsis, on a 5-point Likert scale. The total confidence scores ranged from 1 to 25, with higher scores indicating higher confidence in caring for patients with sepsis. Section three assessed RNs' knowledge about sepsis. It comprised 15 multiple choice questions (MCQs), of which four questions were on general knowledge of sepsis and 11 questions were scenario based MCQs. There were three short case scenarios (diabetic foot sepsis, urosepsis and catheter-related sepsis) and the questions covered four domains: early clinical manifestations of sepsis, sepsis laboratory investigations, patient monitoring and management of sepsis. The last section has an open-ended component to allow participants to provide free texts to comment on organizational support to improve nurses' roles in early recognition and management of patients with sepsis.

## 2.5 | Ethical considerations

Ethical approval was obtained from the National Healthcare Group Domain Specific Review Board (Ref No.: 2020/01480). Participation in the survey occurred on a voluntary basis and the completion and submission of the online survey implied the participant's consent. No personal identifiable data was collected. Confidentiality and anonymity about the survey responses were assured for all the participants.

## 2.6 | Data analysis

For all statistical analyses, the IBM SPSS Statistics for Windows Version 26.0 was used (IBM Corp., 2019). Descriptive statistics (mean and standard deviations (SD), medians and interquartile ranges (IQR), proportions and percentages) were computed to summarize the participants' demographic characteristics, workplace data, sepsis knowledge scores and self-confidence scores. Independent sample *t*-test and one-way analysis of variance (ANOVA) with Bonferroni correction were used to examine the differences in nurses' total sepsis knowledge and total self-confidence scores among the various categorical demographic and workplace subgroups. To explore the factors influencing nurses' sepsis knowledge (dependent variable), the variables (years of nursing experience, job grade, clinical

work area, education level, sepsis education and training in the last 1 year, and presence of sepsis screening tool) found to be statistically significant at  $p \leq .1$  in the univariate linear regression analyses were used as independent variables in the subsequent multiple linear regression analysis.

Pearson product-moment correlation coefficients were calculated to examine the association between sepsis knowledge and level of self-confidence. Chi-square test was used to compare the item-level responses in their level of self-confidence towards recognizing and managing patients with sepsis grouped according to the presence of sepsis screening tool and clinical work area. In all other analyses, the level of statistical significance was set at .05.

A content analysis of the open-ended responses collected in Section four of the survey was conducted. Line-by-line open coding of the short free-texts was performed. Codes with similar meanings were grouped into the same categories and related categories were clustered into themes (Graneheim & Lundman, 2004). Regular discussions were held among the authors to finalize the themes derived from the content analysis process.

## 2.7 | Validity, reliability and rigour

The survey instrument was assessed for content and face validity by a panel of seven content experts, who were APNs, a nursing academic, and an intensive care specialist. Each content expert was asked to independently rate the relevance of each item using a 4-point Likert scale (1 = not relevant to 4 = very relevant) and was also asked to provide comments. The item-level content validity index of the confidence scale and sepsis knowledge MCQs ranged between 0.86 and 1.00, with a scale-level content validity index of 1.00. Based on the results of the content validation assessments and comments from the content experts, minor revisions were made for the final version of the survey. The international consistency of the confidence scale estimated by Cronbach's alpha was .870.

## 3 | RESULTS

### 3.1 | Nurse and workplace characteristics

A total of 709 RNs (response rate: 23.1%) across the three study sites completed the questionnaire. The demographic characteristics and workplace data of the participants are presented in Table 1. Over 80% of the participants held the job grade of staff nurse and senior staff nurse, and close to one-third ( $n = 217$ , 30.6%) had between 6 and 10 years of nursing experience. Almost one-fifth ( $n = 136$ , 18.1%) of the respondents had attained a specialization within their field of practice. Twenty-five of the 29 participants with a master's degree had attained master's degree in nursing and were either APN or APN interns.

For workplace data, most participants worked in the general ward settings ( $n = 380$ , 53.6%). Ninety-six respondents (13.5%)

TABLE 1 Demographics and workplace characteristics of participants (n = 709)

Characteristics	Total, n (%) n = 709 (100%)	Hospital A, n (%) n = 130 (18.3%)	Hospital B, n (%) n = 252 (35.6%)	Hospital C, n (%) n = 327 (46.1%)
<b>Age</b>				
25 and below	131 (18.5)	21 (16.2)	46 (18.3)	64 (19.6)
26–30	228 (32.2)	38 (29.2)	98 (38.9)	92 (28.1)
31–35	186 (26.2)	26 (20.0)	69 (27.4)	91 (27.8)
36–40	79 (11.1)	16 (12.3)	19 (7.5)	44 (13.5)
41 and above	85 (12.0)	29 (22.3)	20 (7.9)	36 (11.0)
<b>Job grade</b>				
Staff nurse	311 (43.9)	57 (43.8)	126 (50.0)	128 (39.1)
Senior staff nurse	284 (40.1)	45 (34.6)	105 (41.7)	134 (41.0)
Assistant nurse clinician	48 (6.8)	9 (6.9)	7 (2.8)	32 (9.8)
Nursing officer	66 (9.3)	19 (14.6)	14 (5.6)	33 (10.1)
APN or APN Intern	25 (3.5)	3 (2.3)	7 (2.8)	15 (4.6)
<b>Years of nursing practice</b>				
Less than 1 year	38 (5.4)	10 (7.7)	12 (4.8)	16 (4.9)
1–2 years	92 (13.0)	13 (10.0)	31 (12.3)	48 (14.7)
3–5 years	156 (22.0)	32 (24.6)	61 (24.2)	63 (19.3)
6–10 years	217 (30.6)	26 (20.0)	94 (37.3)	97 (29.7)
More than 10 years	206 (29.1)	49 (37.7)	54 (21.4)	103 (31.5)
<b>Nursing education level</b>				
Diploma in nursing/ Basic nursing training certification	333 (47.0)	50 (38.5)	155 (61.5)	128 (39.1)
Advanced/graduate/specialist diploma in nursing	136 (18.1)	17 (13.1)	61 (24.2)	47 (14.4)
Bachelor of Nursing	473 (66.7)	103 (79.2)	133 (52.8)	237 (72.5)
Master's degree	29 (4.1) <sup>a</sup>	4 (3.1)	7 (2.78)	18 (5.5)
<b>Area of practice</b>				
ED/UCC	155 (21.9)	29 (22.3)	67 (26.6)	59 (18.0)
ICU/HDU	174 (25.4)	16 (12.3)	56 (22.2)	102 (31.2)
General ward	380 (53.6)	85 (65.4)	129 (51.2)	166 (50.8)
Received sepsis education/ training in the last 1 year	96 (13.5)	11 (8.5)	38 (15.1)	47 (14.4)
<b>Sepsis screening tool in area of practice<sup>b</sup></b>				
Yes	100 (14.1)	15 (11.5)	65 (25.8)	20 (6.1)
No	280 (39.5)	53 (40.8)	68 (27.0)	159 (48.6)
Unsure	329 (46.4)	62 (47.7)	119 (47.2)	148 (45.3)

Abbreviations: APN, advanced practice nurse; ED, emergency department; HDU, high dependency unit; ICU, intensive care unit; UCC, urgent care centre.

<sup>a</sup>25 attained Master's degree in nursing.

<sup>b</sup>Only ED of Hospital B has sepsis screening tool.

attended sepsis education or training in the last 1 year from the time of data collection. One hundred participants indicated the presence of sepsis screening tool in their area of practice. However, only the ED of study Hospital B has implemented a sepsis screening tool. Yet, only 50 (74.6%) out of the 67 participants were aware of the presence of a sepsis screening tool, while 14 were unsure and three were oblivious to it.

### 3.2 | Nurses' sepsis knowledge

The total sepsis knowledge score ranged from 3 to 15, with a mean score of  $10.56 \pm 2.01$  out of a maximum score of 15. The greatest proportion of participants ( $n = 135, 19.0\%$ ) answered 12 questions correctly and only 6 participants (0.8%) correctly answered all the

questions in the sepsis knowledge test. Table 2 summarizes the participants' sepsis knowledge performance at item level.

The correct responses for the four questions related to general knowledge of sepsis ranged between 52.0% (definition of sepsis) and 91.0% (risk factors of sepsis). Most selected "bacteria in blood" ( $n = 167$ , 23.6%) and "infection" ( $n = 140$ , 19.7%) as the definition of sepsis. About half responded incorrectly to the question on the cause of sepsis ( $n = 378$ , 53.3%) and close to one-third responded incorrectly to the question about epidemiological data of sepsis ( $n = 246$ , 34.7%).

In the short case scenarios section, the four questions (Q9, Q10, Q13 and Q14) that addressed the treatment of sepsis were answered correctly by between 66.0% (Q13. vasopressors therapy for septic-shock induced hypotension) and 91.1% (Q14. blood culture prior to starting intravenous antibiotics) of the participants. On the questions related to sepsis laboratory investigations, close to two-thirds correctly identified blood culture as the most essential septic workup ( $n = 456$ , 64.3%) and about half of the participants were able to identify serum lactate level of 4.0mmol/L as a concern for patients with sepsis ( $n = 376$ , 53.0%). However, of concern, only

8.3% ( $n = 59$ ) could identify high respiratory rate as an early clinical manifestation of sepsis.

As presented in Table 2, chi-squared tests showed that nurses working in acute care areas such as ED/UCC and ICU/HDU had greater knowledge than general ward nurses in questions related to the immediate management of sepsis and septic shock. Nurses working in the ICU/HDU were shown to fare significantly better in their assessment and evaluation of septic shock treatment (Q15) compared to nurses working in ED/UCC and general wards.

### 3.3 | Differences in sepsis knowledge among different groups of nurses

The total sepsis knowledge scores by nurses' and workplace characteristics are presented in Table 3. Significant differences in nurses' sepsis knowledge scores were observed between nurses of different years of nursing experience, clinical work area, nursing job grade and education level. Nurses with more than 10 years of nursing experience scored significantly higher in sepsis knowledge test

TABLE 2 Nurses' sepsis knowledge item-level performance, based on numbers of correct answers ( $n = 709$ )

Items/Topic	Overall $n$ (%)	ED/UCC $n$ (%)	ICU/HDU $n$ (%)	General ward $n$ (%)	$\chi^2$	$p$ -value
General sepsis knowledge						
Q1. Definition of sepsis	369 (52.0)	84 (54.2)	108 (62.1)	177 (46.6)	11.84	.003
Q2. Risk factors of sepsis	645 (91.0)	135 (87.1)	162 (93.1)	348 (91.6)	3.97	.138
Q3. Cause of sepsis	378 (53.3)	77 (49.7)	107 (61.5)	194 (51.1)	6.28	.043
Q4. Epidemiological data of sepsis	463 (65.3)	120 (77.4)	110 (63.2)	233 (61.2)	13.04	.001
Case scenario 1						
Q5. Predisposing factor of sepsis	669 (94.4)	142 (91.6)	168 (96.6)	359 (94.5)	3.78	.151
Q6. Early manifestation of sepsis	59 (8.3)	26 (16.8)	8 (4.6)	59 (8.3)	19.19	<.001
Q7. Blood culture as most essential septic workup	456 (64.3)	105 (67.7)	91 (52.3)	456 (64.3)	14.53	.001
Q8. Serum lactate as a biomarker of sepsis	376 (53.0)	105 (67.7)	104 (59.8)	167 (43.9)	29.23	<.001
Case scenario 2						
Q9. Prioritized immediate management of sepsis	556 (78.4)	139 (89.7)	134 (77.0)	283 (74.5)	15.31	<.001
Q10. Antibiotics administration as key to improve sepsis clinical outcome	591 (83.4)	130 (83.9)	151 (86.8)	591 (83.4)	2.37	.306
Q11. Monitoring of patient with sepsis	587 (82.8)	136 (87.7)	144 (82.8)	307 (80.8)	3.74	.154
Case scenario 3						
Q12. Source of infection leading to sepsis	675 (95.2)	146 (94.2)	169 (97.1)	360 (94.7)	1.94	.380
Q13. Vasopressors therapy for septic-shock induced hypotension	468 (66.0)	117 (75.5)	130 (74.7)	221 (58.2)	22.52	<.001
Q14. Blood culture prior to starting intravenous antibiotics	646 (91.1)	137 (88.4)	167 (96.0)	342 (90.0)	7.09	.029
Q15. Assessment and evaluation of septic shock treatment	549 (77.4)	111 (71.6)	158 (90.8)	280 (73.7)	23.87	<.001

Abbreviation: ED, emergency department; HDU, high dependency unit; ICU, intensive care unit; UCC, urgent care centre.

TABLE 3 Differences in sepsis knowledge and self-reported confidence scores among different group of RNs ( $n = 709$ )

Variables	<i>n</i>	Total sepsis knowledge score Mean (SD)	Total self-confidence score Mean (SD)
<b>Years of nursing experience<sup>a</sup></b>			
2 years and below	130	10.02 (2.00)	16.96 (2.89)
3–5 years	156	10.21 (1.96)	18.27 (2.61)
6–10 years	217	10.73 (1.85)	18.76 (2.75)
More than 10 years	206	10.99 (2.10)	19.23 (2.51)
F-value (p-value)		8.630 (<0.001 <sup>c</sup> )	19.041 (<0.001 <sup>d</sup> )
<b>Job grade<sup>a</sup></b>			
Staff nurse	311	9.95 (2.02)	17.71 (2.91)
Senior staff nurse	284	10.88 (1.79)	18.87 (2.62)
Assistant nurse clinician/nursing officer	114	18.87 (2.62)	19.49 (2.27)
F-value (p-value)		31.291 (<0.001 <sup>e</sup> )	23.656 (<0.001 <sup>f</sup> )
<b>Area of practice<sup>a</sup></b>			
ED/UCC	155	11.03 (1.94)	18.52 (2.69)
ICU/HDU	174	10.98 (1.71)	18.83 (2.65)
General Ward	380	10.17 (2.09)	18.27 (2.79)
F-value (p-value)		15.787 (<0.001 <sup>g</sup> )	2.488 (0.084)
<b>Nursing education level<sup>a</sup></b>			
Group I: Without any nursing specialization	557	10.32 (1.95)	18.22 (2.75)
Group II: With nursing advanced/graduate/specialist diploma	123	11.24 (1.84)	19.15 (2.80)
Group III: With master's degree	29 <sup>i</sup>	12.34 (2.26)	20.14 (2.49)
F-value (p-value)		23.894 (<0.001 <sup>h</sup> )	11.498 (<0.001 <sup>i</sup> )
<b>Advanced nursing practice<sup>b</sup></b>			
APN/APN intern	25	12.92 (1.58)	20.56 (2.18)
Non-APN	684	10.47 (1.97)	18.38 (2.78)
t-statistic (p-value)		-7.535 (<0.001)	-4.849 (<0.001)
<b>Received sepsis education/training in the last 1 year<sup>b</sup></b>			
Yes	96	10.64 (2.23)	19.81 (2.26)
No	613	10.55 (1.97)	18.25 (2.80)
t-statistic (p-value)		-0.396 (0.693)	-6.082 (<0.001)
<b>Sepsis screening tool in area of practice<sup>b</sup></b>			
Yes	67 <sup>k</sup>	10.75 (1.89)	18.34 (3.13)
No	642	10.54 (2.02)	18.47 (2.75)
t-statistic (p-value)		0.797 (0.425)	-0.360 (0.719)

Abbreviations: APN, advanced practice nurse; ED, emergency department; HDU, high dependency unit; ICU, intensive care unit; UCC, urgent care centre.

<sup>a</sup>One-way ANOVA test.

<sup>b</sup>Independent sample t-test.

<sup>c</sup>Post-hoc test with Bonferroni correction: 0–2 years versus 6–10 years ( $p = .007$ ), 0–2 years versus >10 years ( $p < .001$ ), 3–5 years versus >10 years ( $p = .001$ ).

<sup>d</sup>Post-hoc test with Bonferroni correction: 0–2 years versus 3–5 years ( $p < .001$ ), 0–2 years versus 6–10 years ( $p < .001$ ), 0–2 years versus >10 years ( $p < .001$ ), 3–5 years versus >10 years ( $p = .005$ ).

<sup>e</sup>Post-hoc test with Bonferroni correction: staff nurse versus senior staff nurse ( $p < .001$ ), staff nurse versus assistant Nurse Clinician/nursing officer ( $p < .001$ ), senior staff nurse versus assistant Nurse Clinician/nursing officer ( $p = .009$ ).

<sup>f</sup>Welch ANOVA due to unequal variance assumed, post-hoc test with Bonferroni correction: staff nurse versus senior staff nurse ( $p < .001$ ), staff nurse versus assistant Nurse Clinician/nursing officer ( $p < .001$ ).

<sup>g</sup>Welch ANOVA due to unequal variance assumed, post-hoc test with Bonferroni correction: emergency department versus general ward ( $p < .001$ ), ICU/HDU versus general ward ( $p < .001$ ).

<sup>h</sup>Post-hoc test with Bonferroni correction: Group I versus Group II ( $p < .001$ ), Group I versus Group III ( $p < .001$ ), Group II versus Group III ( $p = .018$ ).

<sup>i</sup>Post-hoc test with Bonferroni correction: Group I versus Group II ( $p = .002$ ), Group I versus Group III ( $p = .001$ ).

<sup>j</sup>25 attained master's degree in nursing.

<sup>k</sup>Hospital B emergency department.

than those under 6 years of nursing experience ( $F = 8.63, p < .001$ ). Total sepsis knowledge scores differed significantly by clinical work area, with nurses working in ED/UCC (mean = 11.03, SD = 1.94) reporting higher scores compared to nurses working in ICU/HDU (mean = 10.98, SD = 1.71) and general wards (mean = 10.17, SD = 2.09). Total sepsis knowledge scores were also observed to be highest among assistant nurse clinicians and nursing officers ( $F = 31.29, p < .001$ ), master's-prepared nurses ( $F = 23.89, p < .001$ ) or APNs and APN interns ( $t = -7.54, p < .001$ ). No significant differences in total sepsis knowledge score were observed in relation to attendance in sepsis education and training in the last 1 year and the presence of sepsis screening tool subgroups.

### 3.4 | Factors affecting nurses' sepsis knowledge

Univariate linear regression analyses were done to examine the relationship between RNs' characteristics and their total sepsis knowledge score. Given post hoc test with Bonferroni correction did not demonstrate any significant difference between RNs with 0–2 years and 3–5 years of nursing experience as well as between RNs with 6–10 years and more than 10 years of nursing experience, RNs were regrouped into two groups: (1) 0–5 years of nursing experience and (2) more than 5 years of nursing experience.

Years of nursing experience, nursing job grade, clinical work area and education level were identified to be sufficient for inclusion ( $p \leq .1$ ) in the multiple linear regression analysis. Nurses' job grade ( $F = 10.82, p < .001$ ), nursing education level ( $F = 7.70, p < .001$ ) and clinical work area ( $F = 9.18, p < .001$ ) were found to be significant predictors of nurses' sepsis knowledge, which accounted for 12.6% variance ( $R^2 = .126$ ). A nursing specialization or master's level education, holding a higher job grade and working in acute care areas (i.e. ED/UCC/ICU/HDU) were predictors of higher sepsis total sepsis knowledge scores. Details of the univariate and multiple linear regression model are presented in Table 4.

### 3.5 | Nurses' self-reported confidence

The total self-confidence scores in recognizing and managing patients with sepsis ranged from 5 to 25, with a mean score of  $18.46 \pm 2.79$  out of a maximum score of 25. The greatest proportion of participants ( $n = 201, 28.3\%$ ) scored 20 for total self-confidence score. Overall, there was a weak positive correlation between nurses' sepsis knowledge and self-perceived confidence in the recognition and management of sepsis ( $r = .184, p < .001$ ).

The differences in self-reported confidence among different groups of nurses are presented in Table 3. Higher total self-confidence scores were observed among nurses with more than 10 years of nursing experience ( $F = 19.04, p < .001$ ), assistant nurse clinicians and nursing officers ( $F = 23.66$ ), master's-prepared nurses or APNs and APN interns ( $t = -4.85, p < .001$ ). Nurses who received sepsis education and training in the last 1 year also had significantly

higher total self-confidence scores ( $t = -6.08, p < .001$ ). There were no significant differences in total self-confidence scores among nurses based on their clinical work area as well as between the presence of sepsis screening tool subgroups.

Figure 1 summarizes the participants' item-level self-reported confidence. Of the five items, more than three-quarters of the nurses believed that they know when to escalate possible sepsis to the medical team and had knowledge in monitoring patients with sepsis. Conversely, slightly over half are confident in identifying and assessing patients for sepsis.

A further analysis was done to examine if there were significant differences in the level of self-confidence towards recognizing and managing patients with sepsis among nurses grouped according to clinical work area and presence of sepsis screening tool in their work area (i.e. nurses in ED of hospital B). At item level, no significant difference was found between nurses in ED of Hospital B (presence of sepsis screening tool) and nurses working in clinical areas without a sepsis screening tool in their confidence towards recognizing sepsis symptoms, monitoring and assessment of sepsis, escalation of sepsis to the medical team and initial management of sepsis.

### 3.6 | Organizational support for improving sepsis care: Open-ended results

Of the 709 participants, 591 (83.3%) provided their responses in the free text on the open-ended question regarding organizational support for improving sepsis care. Three main themes, each supported by subthemes, were derived from the content analysis of the 591 valid entries (Supplementary file 2). Participants indicated the need for more regular and formal "sepsis training and education" ( $n = 450$ ) on assessing patients with sepsis, sepsis management and sepsis prevention. The suggested mode of education delivery included regular in-service talks and seminars, e-learning, case sharing and discussions, clinical teaching by physicians, and simulation. To aid nurses in caring for patients with sepsis, many also suggested having a hospital "sepsis workflow and protocol" ( $n = 173$ ) which included a sepsis screening tool and escalation policy, and a sepsis management bundle or algorithm. Cue cards and posters could be placed in clinical areas to facilitate adherence to sepsis workflow and protocol. Lastly, some suggestions cited were associated with "nursing empowerment" ( $n = 26$ ). Participants reported the importance of physicians listening to nurses' inputs or concerns regarding a patient's condition, having workflows that empower ward nurses to initiate initial sepsis management within their capacity and having a sepsis resource or outreach nurse to raise the profile of sepsis recognition and management.

## 4 | DISCUSSION

This cross-sectional study sampled RNs from three hospitals of one public healthcare cluster in Singapore and explored their



TABLE 4 Univariate linear regression analysis and multiple linear regression examining factors affecting nurses' sepsis knowledge (n = 709)

Variables	n	Univariate analysis			Multiple linear regression		
		B (95% CI)	SE	p-value	B (95% CI)	SE	p-value
Years of nursing experience <sup>a</sup>							.161
0–5 years	286	Reference			Reference		
>5 years	423	0.733 (0.436, 1.031)	0.151	<.001			
Area of practice <sup>a</sup>							<.001
ED/UCC	155	0.859 (0.490, 1.227)	1.88	<.001	0.696 (0.337, 1.055)	0.183	<.001
ICU/HDU	174	0.809 (0.455, 1.163)	1.80	<.001	0.553 (0.203, 0.903)	0.178	.002
General Ward	380	Reference			Reference		
Job grade <sup>a</sup>							<.001
Staff nurse	311	Reference	0.211	<.001	Reference		
Senior staff nurse	284	0.928 (0.617, 1.239)	0.158	<.001	0.814 (0.403, 1.226)	0.210	<.001
Assistant nurse clinician/Nursing officer	114	1.490 (1.075, 1.905)	0.211	<.001	1.212 (0.671, 1.753)	0.276	<.001
Nursing education level <sup>a</sup>							.001
Without any nursing specialisation <sup>b</sup>	557	Reference			Reference		
With nursing advanced/graduate/specialist diploma <sup>c</sup>	123	0.918 (0.537, 1.299)	0.1.94	<.001	0.483 (0.083, 0.884)	0.204	.018
With Master's degree <sup>d</sup>	29	2.027 (1.299, 2.755)	0.371	<.001	1.366 (0.600, 2.132)	0.390	<.001
Received sepsis education/training in the last 1 year	96	0.087 (–0.346, 0.521)	0.221	.693	–	–	–
Presence of sepsis screening tool	67 <sup>e</sup>	0.206 (–0.301, 0.712)	0.258	.425	–	–	–

Abbreviations: ED, emergency department; HDU, high dependency unit; ICU, intensive care unit; UCC, urgent care centre.

<sup>a</sup>Included in the multiple linear regression.

<sup>b</sup>Nursing diploma only, nursing diploma and degree only, or nursing degree only.

<sup>c</sup>Nursing advanced/graduate/specialist diploma + <sup>a</sup>.

<sup>d</sup>Nurses with master's degree, 25 out of 29 had attained master's degree in nursing and were either advanced practice nurse or advanced practice nurse intern.

<sup>e</sup>Hospital B emergency department.

knowledge and confidence in recognizing and managing adult patients with sepsis. In contrast to previous studies that tended to ask lower order factual sepsis knowledge questions, the sepsis knowledge test developed for this study focused more on higher order thinking skills, involving the application and analysis of sepsis knowledge using case scenarios questions. The findings of this study provide meaningful evidence to suggest that RNs across different areas of practice have average knowledge on sepsis care and identify gaps in nurses' sepsis knowledge. The results are consistent with previous studies despite the difficulties in making direct comparisons due to the diverse sepsis knowledge quizzes used and differing ward settings where the studies were conducted (Nucera et al., 2018; Rahman et al., 2019; Stamataki et al., 2014; Storzuk et al., 2019; van den Hengel et al., 2016).

While our results showed that nurses displayed good awareness of sepsis risk factors, there is a significant lack of awareness of the updated sepsis-3 definitions and epidemiological data of sepsis.

This may suggest an underappreciation of the severity of sepsis as a life-threatening medical condition, which could have a negative impact on patient outcomes. The findings also suggest a significant knowledge gap among nurses in recognizing tachypnoea as an early manifestation of sepsis, and other aspects of sepsis bundle including collection of blood cultures, serum lactate's thresholds and management of septic shock. This knowledge gap was observed to correspond with the participants' lower confidence in identifying, performing clinical assessment and initiating initial management of sepsis. The limited knowledge on sepsis care and lack of confidence were not surprising given that less than 15% of the participants reported receiving any education or training activities about sepsis in the past 1 year. However, it is encouraging that majority of the participants indicated their desire for further sepsis education and training, suggesting they were well aware of their knowledge deficit and the need to renew and advance their knowledge.

Our study showed that while those nurses who received sepsis education and training in the past 1 year had significantly higher

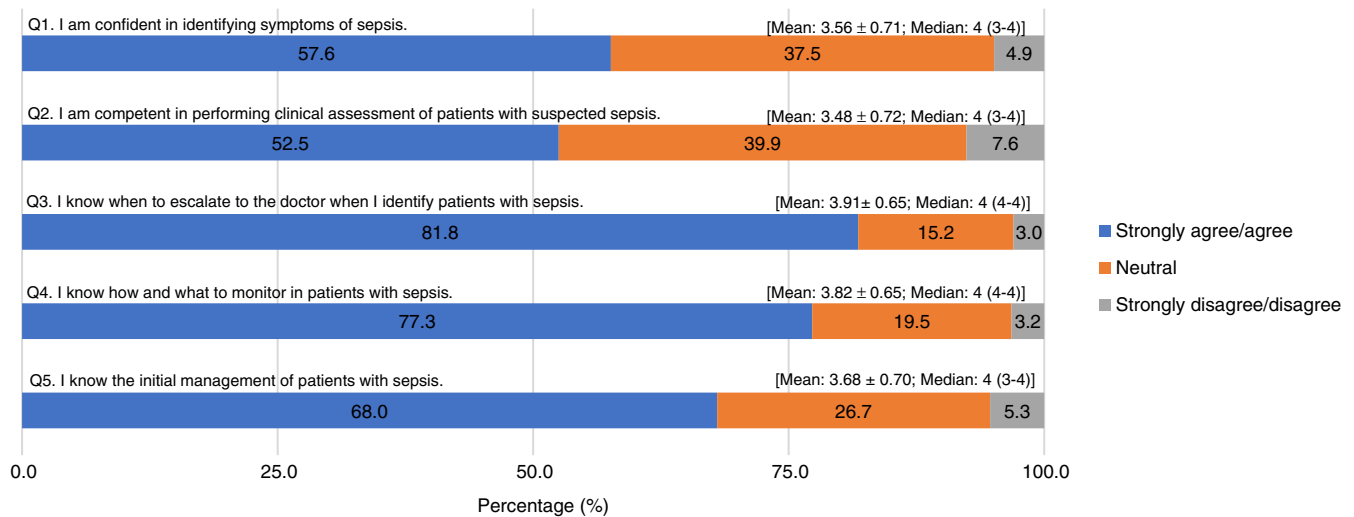


FIGURE 1 Nurses' self-reported confidence in recognizing and managing sepsis ( $n = 709$ ).

confidence scores than those who did not, their knowledge scores were only marginally higher. This contrasts with findings in studies that have demonstrated improvement in nurses' attitudes, knowledge and confidence in recognizing and managing sepsis with sepsis education and training (Delaney et al., 2015; Edwards & Jones, 2021; O'Shaughnessy, 2017), and even more so if it was done recently (van den Hengel et al., 2016). One plausible reason for this could be related to the characteristics of the sepsis education and training activities (i.e. learning content, educational delivery method and teaching approach) that the participants had recently attended, which unfortunately was not captured in our questionnaire. We postulate that the methods of education and training delivery may have played an integral part in the learner's learning. This is supported by a recent systematic review of 32 international studies demonstrating sepsis education and training that incorporated active learning strategies were shown to enhance learners' knowledge retention and transfer of learning to clinical practice than didactic teaching (Choy et al., 2022). Nurses should therefore be provided with experiential learning opportunities such as simulation training or rotations to critical care areas with higher sepsis caseload. This allows them to apply their theoretical knowledge in practice, which can strengthen their competence and build their confidence levels.

In this study, factors such as nursing education level, clinical work area and job grade in recognizing and managing sepsis were found to be predictors of nurses' sepsis knowledge. Nurses who had attained a nursing specialization or a master's level education, worked in acute clinical areas such as ED/UCC or ICU/HDU, and held a more senior nursing position were found more likely to have better sepsis knowledge scores. This result is expected because teachings on sepsis for nurses without a specialization qualification—RNs with a diploma and/or bachelor's degree only—would be lacking in depth compared to nursing specialization programs and master's degree in

nursing. For nurses without specialization, they would have limited exposure to sepsis education in their pre-licensure nursing education curriculum, and further sepsis education and training programs would be usually dependent on their workplace training. Similar to Australia (Harley, Massey, et al., 2021), the apparent deficit in sepsis content in the pre-licensure nursing curricula may be attributed to nursing curriculum planners being adaptable and responsive to the healthcare needs in Singapore. Key population health issues such as diabetes, stroke, mental health disorders and healthy aging have taken precedence. In addition, sepsis is a complex syndrome that may pose a challenge for educators to impart to nursing students who have limited clinical exposure. On the other hand, sepsis may have been given greater focus in the curriculum of higher nursing education. This may explain why nurses with higher educational levels have higher sepsis knowledge scores which was also found in Öztürk Birge et al. (2021).

Our findings show that nurses working in acute care areas such as the ED/UCC, HDU and ICU generally have higher sepsis knowledge and self-confidence scores than general ward nurses, a result that echoes those of Stamatakis et al. (2014). While there has been an observed increase in the prevalence of sepsis in general wards (Szakmany et al., 2016; Zaccone et al., 2017), nurses' exposure to sepsis is higher in ICU/HDU and ED. As patients with sepsis often develop multiple organ-system failure that requires aggressive management and close monitoring, they are usually treated in the ICUs or HDUs (Evans et al., 2021). Furthermore, patients in ICUs or HDUs have an increased risk of acquiring nosocomial infections due to various risk factors such as severity of illness, invasive procedures and multiple invasive catheters (Mayr et al., 2014). In the ED, the triage nurses are often the first-line responders to patients presenting with community-onset sepsis which accounted for almost 90% of hospitalized cases with sepsis (Rhee et al., 2019). The exposure to high volume caseload in their

daily clinical practice may have contributed to better knowledge on sepsis presentation and its initial management.

Our study observed a poor correlation between sepsis and knowledge test scores and self-confidence. A possible explanation for this outcome is that knowledge test does not allow for direct conclusion on participants' abilities and skills to provide sepsis care in their respective work environment (Liaw et al., 2012). Instead, the use of objective measures to evaluate nurses' clinical competencies and skills should be considered. This may include using a simulation test with an assessor checklist, workplace-based assessment or sepsis-related performance indicators. In addition, self-reported competence and confidence may be limited by a cognitive bias where participants may have reported themselves as being more capable than they really are (Kruger & Dunning, 1999).

There is a growing body of knowledge advocating the implementation of sepsis screening tools and sepsis care bundles, which have been demonstrated to improve the recognition and management of sepsis, and lead to better patient outcomes (Evans et al., 2021). In this study, almost 30% of the open comments were related to implementing a hospital sepsis screening tool and sepsis management bundle or algorithm and surrounded empowering ward nurses to initiate initial sepsis management within their capacity. This would be particularly helpful for nurses with little clinical experience or limited sepsis knowledge. However, it is noteworthy that this study found no association between sepsis screening tool and nurses' knowledge and confidence in recognizing sepsis symptoms and performing clinical assessment of patients with suspected sepsis. This is contrary to previous studies that found improved confidence among nurses in the identification of patients with sepsis with the implementation of a sepsis screening tool (Edwards & Jones, 2021). Our finding may be explained by 25% of the nurses lacking awareness of the sepsis screening tool; which prompted us to pay attention to the implementation and dissemination process of clinical protocols. It also underlines the importance of continuous education and sepsis training of ground staff so as to improve compliance with sepsis clinical protocols and achieve a synergistic effect (Damiani et al., 2015; Roberts et al., 2017).

#### 4.1 | Limitations

This study had a few limitations. First, the low response rate of 23.1% limits the generalisability of the study to a wider population of RNs working in acute-tertiary hospitals and to community nurses. The study was conducted during the coronavirus disease (COVID-19) pandemic period where nurses' low morale and fatigue might have influenced participation rate. Second, even though we attempted to test the application and analysis of sepsis knowledge using case scenarios questions, MCQs may not be an accurate representation of participants' sepsis knowledge and clinical competencies and skills. Third, an in-depth exploration of nurses' experiences

and perceptions around recognizing and managing patients with sepsis was not elicited through the survey, in which these insights may be valuable to inform local policies and enrich nursing educational packages.

## 5 | CONCLUSION

Nurses are placed in an opportunistic position to recognize and manage patients with sepsis. In congruent with previous studies, this multi-site study revealed gaps in nurses' clinical knowledge of sepsis recognition and management, albeit nurses working in the acute clinical areas such as ED/UCC, HDU and ICU had higher knowledge and confidence than general ward nurses. Sepsis screening tools and sepsis bundles have been identified by participants as useful adjuncts in clinical practice to facilitate nurses in timely recognition and management of patients with sepsis. This study augments the need for a stronger foundation in sepsis education and training programs for nurses and the implementation of systems improve nurses' knowledge and confidence in recognizing and managing sepsis.

With the ongoing research to understand the pathophysiology and immunological mechanisms of sepsis and approach in managing sepsis, nurse educators and academics are responsible to ensure that sepsis education content are in keeping with the latest evidence-based knowledge and best practices. There is a need to review the current pre-licensure nursing curriculum and the delivery of current sepsis educational programs in workplace-based nursing education. In addition, we should consider adopting a multidisciplinary approach involving nurses, physicians and pharmacists to formulate nurse-driven sepsis screening algorithms and sepsis care protocols that are specific to different clinical areas. Efforts should also be aimed at continuous education, regular reviews of clinical processes, clinical audits and feedback to ensure sustainability.

#### AUTHOR CONTRIBUTIONS

All the listed authors have (1) made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; (2) been involved in drafting the manuscript or revising it critically for important intellectual content and (3) given final approval of the version to be published.

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## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

## PEER REVIEW

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## DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# Assessment, diagnosis and treatment of peristomal skin lesions by remote imaging: An expert validation study

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## Abstract

**Background:** Prevention and treatment of peristomal skin problems should be a priority for nurses caring for ostomates, even when the assessment of lesions must be done remotely.

**Objective:** To measure the level of agreement on assessment, diagnosis and care indications for peristomal skin lesions using remote imaging among nurses in Spain.

**Design:** Prospective observational multicentre study to assess the diagnostic validity and inter- and intraobserver agreement between nurses in peristomal skin lesions. Data were collected between March and October 2019.

**Settings and Participants:** The research sample consisted of a group of 39 nurses with expertise in the care of ostomates.

**Methods:** A panel of experts established a list of 24 common signs/findings, 15 diagnostic options and 35 treatment approaches for peristomal skin lesions. Three expert stoma therapy nurses compiled the clinical cases, which they described thoroughly and documented with photographs. The 39 participating nurses evaluated the cases in two rounds to measure inter and intraobserver agreement.

**Results:** A high or very high level of agreement ( $\kappa > 0.61$ ) was observed for the following signs: encrustation, nodules, mucocutaneous separation and varicose veins; for the following diagnoses: mucocutaneous dehiscence, allergic contact dermatitis, encrustation and varicose veins (caput medusae); for the following treatments: recommending a diet rich in vitamin C/blueberries, applying acetic acid dressings, applying cold and topical tacrolimus treatment.

**Conclusions:** The most easily identifiable lesions were those most prevalent and with visible signs. There was a lower level of agreement in identifying lesions for which photographs required additional information (laboratory data, description of signs and symptoms, type of diet and level of self-care). It is important to train nurses caring for ostomates to correctly describe ostomy-related lesions, which is important for nursing records, continuity of care and telehealth care.

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## KEYWORDS

continuity of care, digital health, eHealth, nurse education, nursing care, ostomy, peristomal skin, remote consultation, remote diagnostic imaging, selfcare, telehealth

## 1 | INTRODUCTION

Surgical treatment of some intestinal or urinary tract pathologies may require an ostomy, which is a surgical procedure in which an opening (stoma) is created in the abdominal wall through which a viscera is passed to the outside to expel faeces, urine, or other secretions (Registered Nurses' Association of Ontario, 2019). Depending on the organ exteriorized, the stoma is referred to as a colostomy, ileostomy or urostomy (McGee, 2016).

The estimated incidence in Western countries is 2–4 ostomized patients per 1000 adults, with colostomy being the most frequent surgery (Smeltzer et al., 2016) and colorectal cancer the main cause (Violin et al., 2017).

Ostomy surgery can have a significant impact on quality of life (QoL), as it generates important physiological, emotional, and relational changes in those who undergo it, also requiring the learning of new self-care habits (Díaz et al., 2019; Moya-Muñoz et al., 2019). Furthermore, the creation of a stoma is not a risk-free procedure, and its performance is associated with a high rate of complications including Peristomal Skin Lesions (PSL) (Ruiz-de-la-Hermosa-García-Pardo et al., 2019).

It is essential for ostomy patients to keep the peristomal skin healthy and intact, but despite advances in care, peristomal skin issues remain frequent among patients. The incidence of these issues can be up to 75%, depending on the type of stoma. (Almutairi et al., 2018; Malik et al., 2018). Skin conditions can vary from mild abrasions to serious wounds requiring complex treatment and care (Murken & Bleier, 2019; Steinhagen et al., 2017).

A systematic review of the literature (Szymanski et al., 2010) concluded that impaired integrity of the peristomal skin may be related to chemical damage, mechanical destruction, infectious disease, immunological reactions and disease-related conditions.

Subsequently, the term peristomal moisture-associated skin damage (P-MASD) defined by Colwell et al. (2011) as 'inflammation and erosion of the skin caused by prolonged exposure to various sources of moisture' was incorporated. If the exposure to moisture is due to contact with faeces, the problem is referred to as irritant contact dermatitis (Colwell et al., 2017). Another term currently used to describe peristomal skin lesions is Peristomal medical adhesive-related skin injury (P-MARSI) defined as 'erythema, epidermal stripping or skin tears, erosion, bulla, or vesicle observed after removal of an adhesive ostomy pouching system' (LeBlanc et al., 2019).

Irrespective of the cause, peristomal skin issues have a significant impact on patients' lives and can cause pain, discomfort, self-care difficulties, low mood, reduced social interaction, and increased healthcare costs (Nichols et al., 2018).

### Impact Statement

- The assessment of peristomal skin lesions (PSLs) is complex and requires specific expertise and knowledge in the nursing staff caring for ostomates.
- Remote assessment using photographs opens up a new opportunity in the care of PSLs, but requires that the images are accompanied by additional information such as
  - Laboratory data
  - Description of signs and symptoms
  - Type of diet
  - Level of self-care
- The use of standardized tools for peristomal skin assessment would facilitate consensus among professionals and continuity of care, helping to facilitate telehealth and healthcare savings.

## 1.1 | Background

During the COVID-19 pandemic, many ostomates were unable to receive their usual level of care due to the restructuring of healthcare resources and limited face-to-face visits. This prompted teleconsultations (Pata et al., 2020), a healthcare resource that is increasingly used. Experiences of teleconsultation of ostomy nurses with ostomy patients have been published (Sims & Wilson, 2020; Weinstein et al., 2021) but not of the use of teleconsultation counselling between professionals for the management of ostomy-related problems.

In daily practice, it is common for ostomy nurses to consult each other on complex cases of stoma and peristomal skin complications via emailed images or mobile apps, but is the advice reliable after remote assessment of these lesions?

Therefore, it is important to carry out research to determine the degree of proficiency among nurses in assessing and diagnosing PSL when patients are not physically present using clinical information and images of the lesions exclusively.

This study will help to understand the limitations of remote visits to address gaps and improve outcomes in the care of ostomized patients.

## 2 | THE STUDY

### 2.1 | Aim

The aim of the study was to measure the level of agreement in the assessment, diagnosis and care indications for PSL using remote imaging among Spanish nurses with expertise in ostomy care.

## 2.2 | Design

This is a multicentre prospective observational study assessing diagnostic validity and inter- and intraobserver agreement among nurses about a sample of ostomy patients with PSL.

The study centred around the participation of three stoma therapy nurses with extensive training and experience from two hospitals in Madrid with many PSL cases.

These three nurses recruited cases for the study and collected information on an electronic data collection form (DCF). The first part of the DCF collected socio-demographic data of the ostomized patient, personal history, aspects of the disease necessitating the ostomy, the surgery itself and the stoma. Also included were up to three photographs of each PSL taken by these three nurses with a state-of-the-art mobile phone camera according to a set of pre-identified specifications. Complications were framed with two small rulers to measure the size of the lesion.

The second part of the DCF covered the assessment of the signs observed (24 signs/findings), diagnosis of the lesion or lesions present (15 diagnostic options) and the appropriate treatment prescribed (35 treatment approaches).

All items were compulsory and a list of response items, which had been agreed in advance with a panel of experts, was provided. There was also the option to add an alternative in free text form. The panel of experts was made up of 4 stoma therapy nurses, three colorectal surgeons, two urologists and two dermatologists.

The list of diagnostic options, signs/findings and treatments/care indications described by the group of experts can be viewed in [Table 1](#).

During their first visit to the data collection platform, the nurses filled in a questionnaire about their training and experience in the care of ostomates.

To facilitate consensus on the naming of signs/findings and diagnoses, the participating nurses were provided with a glossary of terms previously developed by the expert group.

To determine the level of agreement, the kappa index (Cohen, 1960) was used, interpreting the results according to the scale proposed by Landis and Koch (1977) in which a value of  $k$  equal to or greater than 0.61 indicates a degree of agreement of 'substantial' to 'near perfect'.

## 2.3 | Sample/participants

The reference population was nurses providing clinical care to ostomates in Spanish hospitals.

Opportunity sampling was performed, including in the study nurses who worked with ostomized patients, with ostomy training at expert or master's level and who agreed to participate in the study on a voluntary basis.

**TABLE 1** List of diagnostic options, signs/findings, and treatments and care indications defined by experts

<b>Diagnoses</b>	
Candidiasis	Pseudoverrucous lesion
Atopic dermatitis	Neoplasm
Mechanical dermatitis	Pyoderma gangrenosum
Allergic contact dermatitis	Psoriasis
Contact irritant dermatitis	Bacterial superinfection
Mucocutaneous dehiscence	Friction/pressure ulcer
Granuloma	Varicose veins
Encrustation	
<b>Signs and findings</b>	
Cellulitis	Maceration
Crust	Nodules
Scaling	Erythematous plaques
Blockage	Lichenified plaques
Erythema	Pustules centred on hair follicles
Erosion	Haemorrhage
Purulent exudate	Mucocutaneous separation
Serous exudate	Necrotic tissue
Fistula	Tumour
Hive	Ulcer
Overgranulation	Varicose veins
Calcium encrustations	Vesicles, blisters, bullae
<b>Care and treatment</b>	
Adjusting the diameter of the faceplate	Belt
Diet rich in vitamin C / blueberries	Barrier paste
Antidiarrhoeals	Hydrocolloid paste
Topical antifungals	Convex faceplates
Emollient products	Hydrocolloid powder
Foam dressing	Mouldable resin strips
Extra thin hydrocolloid dressing	Applying cold
Hydrofibre dressing with silver	Topical haemostatic agents
Hydrofibre dressing without silver	Acetic acid dressings
Hydrogel dressing	Reducing soluble fibre intake
Silicone dressing	Reducing insoluble fibre intake
Increasing soluble fibre intake	Skin barrier spray
Increasing insoluble fibre intake	Adhesive remover spray
Increasing water intake	Replacing the device
Topical corticosteroids	Topical tacrolimus
Two-piece device	Negative pressure therapy
Hydrocolloid rings	Oral/topical antibiotic treatment

## 2.4 | Data collection

The designated hospitals recruited patients when they attended their appointments for PSL. Once they had been informed of the study purpose, agreed voluntarily to participate and signed the informed consent form, the nurses completed the first part of the DCF, took photographs and attached them to the file.

On the second part of the DCF, the nurses marked 'yes', 'no', or 'I don't know' to indicate the presence or absence of each of the 24 possible signs/findings used to assess the lesion, the 15 diagnostic options and the 35 treatment/care indications based on their own judgement.

The responses of the stoma therapy nurse from the recruiting hospitals represented the gold standard. The nurses received support from the group of experts where necessary.

The images and the first part of the DCF were blinded and sent to the assessing nurses online. The complete cases were sent to the research team in the same manner.

To measure interobserver agreement between the assessing nurses, they were asked to complete the second part of the DCF based on their own judgement, in the same manner, marking 'yes', 'no', or 'I don't know' to indicate the presence or absence of each of the signs, diagnoses, and care indications after viewing the images and reading the patients' clinical characteristics.

The assessing nurses carried out their assessments individually without help from other experts in a maximum of 15 days.

To measure intraobserver agreement, another round of assessments was conducted in the same way after 30 days. On this occasion, the cases were presented in a different order than in Round 1 to reduce recall bias as much as possible.

Once all the information had been collected on the DCF, the assessing hospitals sent it to the research team for analysis.

## 2.5 | Ethical and legal considerations

This observational study using anonymous data adhered to the ethical principles established by the World Medical Association's Helsinki Declaration and was approved by the Clinical Research Ethics Committee at the recruitment hospitals (San Carlos Clinical University Hospital (18/503-E) and 12 de Octubre University Hospital (18/479), in Madrid) in December 2018.

Patients were invited to participate in the study on a voluntary basis, were given oral and written information and signed an informed consent form guaranteeing the anonymity and confidentiality of their data.

In legal terms, Spanish Organic Law 5/2018 on Personal Data Protection guaranteed the anonymity of the participants (patients and nurses) and the database, with no personal data that can be used to identify them.

## 2.6 | Data analysis

The variables were described using absolute and relative frequencies. The level of agreement (the proportion of agreement observed) between the responses given by the assessing nurses and the recruiting nurses, as well as between the assessing nurses' first and second assessments, was calculated for the various diagnoses, signs, and care indications. To test for agreement, McNemar's test and Bowker's symmetry test were performed to check the equality of classification measurements and Cohen's  $\kappa$  coefficient and the 95% confidence intervals were calculated.

All analyses were performed using SAS statistical software (Copyright © 2002–2012 by SAS Institute Inc., Cary, NC, USA). The statistical significance threshold for all analyses was set at 5%.

## 2.7 | Validity and reliability/rigour

We adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines in reporting this study (Vandenbroucke et al., 2014).

## 3 | RESULTS

From March to October 2019, 32 patients were recruited. Their mean age was 69.2 years old ( $\pm 15.09$ ). 53.1% (17) were men, 71.9% (23) were able to care for their ostomy themselves and only 5 patients took no medication. The diagnosis leading to the stoma surgery was oncological in 56.3% (18) of the cases, the main surgical procedure was sigmoidectomy, with 25.2% (8) of cases, and the most common type of stoma was end colostomy, with 62.5% (20) of cases.

Thirty-nine nurses participated in the validation and agreement study based on their availability and consent to participate. About the profile of the participating nurses, 59% (23) had specific training in stoma therapy at the expert level and 41% (16) at the master's degree level. A total of 56.4% (22) had been working as stoma therapy nurses for more than 5 years and 89.7% (35) had participated in a refresher course on stoma therapy in the last year (Table 2).

### 3.1 | Level of agreement

About signs/findings, from the list of 24 signs/findings initially established by the expert panel, a high or very high level of agreement ( $\kappa$ -value  $>0.61$ ) was obtained for four signs, which were encrustation, nodules, mucocutaneous separation and varicose veins. The level of agreement was low ( $\kappa$ -value  $<0.61$ ) for the identification of signs such as obstruction, purulent exudate, maceration and blisters.

About diagnosis, of the 15 diagnostic options initially established by the expert panel, a high or very high level of agreement ( $\kappa$ -value

TABLE 2 Experience and training among nurses

Characteristics of the sample	N = 39
Professional experience as a nurse, n (%)	
<5 years	1 (2.6)
6–10 years	2 (5.1)
11–20 years	7 (17.8)
>21 years	29 (74.4)
Professional experience as a stoma therapy nurse, n (%)	
<5 years	17 (43.6)
6–10 years	9 (23.1)
11–20 years	11 (28.2)
>21 years	2 (5.1)
Level of training in stoma therapy, n (%)	
Postgraduate diploma in stoma therapy	23 (59)
Master's degree in stoma therapy	16 (41)
When was the last time you participated in a refresher course on stoma therapy? n (%)	
<1 year ago	35 (89.7)
1–2 years ago	4 (10.3)

>0.61) was obtained for four of them, namely mucocutaneous dehiscence, allergic contact dermatitis, encrustation and varicose veins (caput medusae). The lowest level of agreement ( $\kappa$ -value <0.61) was observed for the diagnoses of candidiasis, psoriasis, bacterial superinfection and friction/pressure ulcer.

With reference to the treatment, of the 35 options initially established by the expert panel, a high or very high level of agreement ( $\kappa$ -value >0.61) was obtained for the four following indications for care: recommendation of a diet rich in vitamin C/ blueberries, application of acetic acid dressings, application of cold, topical treatment with tacrolimus. The lowest level of agreement ( $\kappa$ -value <0.61) was obtained for the application of a foam dressing, application of a silicone dressing, recommendation to increase water intake and recommendation to reduce soluble fibre intake.

About the intraobserver agreement, all the values for the signs, diagnoses and care indications were significant and the  $\kappa$ -value was 1 (perfect agreement).

All results with a non-zero  $\kappa$ -value in McNemar's test or Bowker's symmetry test are shown in Tables 3 (signs/findings), 4 (diagnoses) and 5 (indications for care).

Result	Round 1		Round 2	
	n	Cohen's $\kappa$ (95% CI)	n	Cohen's $\kappa$ (95% CI)
1. Cellulitis	9	0.43 (0.38 to 0.48)	9	0.43 (0.38 to 0.48)
2. Scaling	15	0.41 (0.34 to 0.49)	15	0.416 (0.34 to 0.49)
3. Blockage	2	0.37 (–0.77 to 1.52)	2	0.37 (–0.77 to 1.52)
4. Erythema	14	0.42 (0.37 to 0.47)	14	0.42 (0.37 to 0.47)
5. Erosion	17	0.42 (0.38 to 0.46)	17	0.42 (0.38 to 0.46)
6. Purulent exudate	9	0.36 (0.22 to 0.50)	9	0.36 (0.22 to 0.50)
7. Serous exudate	14	0.41 (0.37 to 0.44)	14	0.41 (0.37 to 0.45)
8. Fistula	7	0.42 (0.13 to 0.70)	7	0.42 (0.13 to 0.70)
9. Overgranulation	34	0.49 (0.45 to 0.53)	34	0.49 (0.45 to 0.53)
10. Encrustation	28	0.71 (0.63 to 0.79)	28	0.71 (0.63 to 0.79)
11. Maceration	5	0.38 (0.20 to 0.56)	5	0.38 (0.20 to 0.56)
12. Nodules	29	0.61 (0.51 to 0.72)	29	0.61 (0.51 to 0.72)
13. Erythematous plaques	17	0.41 (0.31 to 0.51)	17	0.41 (0.31 to 0.51)
14. Haemorrhage	5	0.36 (0.23 to 0.49)	5	0.36 (0.24 to 0.49)
15. Mucocutaneous separation	38	0.63 (0.58 to 0.68)	38	0.63 (0.58 to 0.68)
16. Necrotic tissue	24	0.51 (0.40 to 0.63)	24	0.51 (0.40 to 0.62)
17. Tumour	10	0.41 (0.17 to 0.65)	10	0.41 (0.17 to 0.65)
18. Varicose veins	18	0.80 (0.69 to 0.91)	18	0.80 (0.69 to 0.91)
19. Blister	7	0.32 (0.02 to 0.62)	7	0.32 (0.02 to 0.62)
20. Ulcer	35	0.55 (0.50 to 0.60)	35	0.55 (0.50 to 0.60)

TABLE 3 Interobserver agreement on signs. Significant  $\kappa$ -values. Rounds 1 and 2

**TABLE 4** Interobserver agreement on diagnoses. Significant  $\kappa$  values. Rounds 1 and 2

Result	Round 1		Round 2	
	<i>n</i>	Cohen's $\kappa$ (95% CI)	<i>n</i>	Cohen's $\kappa$ (95% CI)
1. Candidiasis	12	0.33 (0.10 to 0.55)	12	0.33 (0.10 to 0.55)
2. Mucocutaneous dehiscence	39	0.64 (0.59 to 0.69)	39	0.64 (0.59 to 0.69)
3. Mechanical dermatitis	13	0.55 (0.45 to 0.65)	13	0.55 (0.45 to 0.65)
4. Allergic contact dermatitis	37	0.72 (0.64 to 0.81)	37	0.72 (0.64 to 0.81)
5. Contact irritant dermatitis	21	0.46 (0.41 to 0.51)	21	0.46 (0.41 to 0.51)
6. Granuloma (overgranulation)	30	0.48 (0.42 to 0.53)	30	0.48 (0.42 to 0.53)
7. Encrustation	26	0.61 (0.53 to 0.68)	26	0.61 (0.53 to 0.68)
8. Pseudoverrucous lesion	17	0.46 (0.30 to 0.61)	17	0.46 (0.31 to 0.61)
9. Neoplasm	8	0.42 (0.25 to 0.59)	8	0.42 (0.25 to 0.59)
10. Pyoderma gangrenosum	24	0.57 (0.45 to 0.69)	24	0.57 (0.45 to 0.69)
11. Psoriasis	2	0.32 (-3.81 to 4.47)	2	0.32 (-3.81 to 4.47)
12. Bacterial superinfection	2	0.33 (-0.08 to 0.73)	2	0.33 (-0.08 to 0.73)
13. Varicose veins (caput medusae)	18	0.79 (0.70 to 0.88)	18	0.79 (0.70 to 0.88)
14. Friction/pressure ulcer	16	0.33 (0.23 to 0.44)	16	0.34 (0.23 to 0.44)

When relating the degree of agreement and the degree of uncertainty ('do not know' response) with the professional and educational factors, no statistically significant differences were found between the variables, neither with parametric nor with non-parametric tests (Table 6).

## 4 | DISCUSSION

Best practice guidelines recommend ongoing research into peristomal skin care and the prevention, detection and treatment of lesions that may appear in this area. (Association of Stoma Care Nurses UK, 2016; Registered Nurses' Association of Ontario (RNAO), 2009). This recommendation, together with the pandemic situation experienced by COVID-19 in which many ostomized patients had to be attended by teleconsultation, are the reasons that motivated this research.

In this study, a high level of agreement was found in the identification through images of lesions such as nodules, calcium encrustations and varicose veins, which are unmistakable lesions with striking colours and characteristics. The same may be said for mucocutaneous separation, a frequent and recognizable complication for expert nurses and allergic contact dermatitis, which takes the form of distinctive lesions covering the entire area beneath the device with erythema and, on some occasions, blisters.

Lesions that need to be palpated, such as blockage or maceration, or which cannot be assessed from an image, such as exudate, obtained a lower level of agreement among the nurses participating in the study, as did candidiasis and bacterial superinfection. The images of these lesions must be supplemented with the results of diagnostic tests and descriptions of the patient's signs and symptoms. These complications are relatively rare, making them harder to diagnose for nurses with more limited experience or who work

in hospitals with fewer cases (Nieves et al., 2017). However, pyoderma gangrenosum, a lesion with an estimated prevalence of 1% (Afifi et al., 2018) showed an adequate level of agreement. This may be due to the experience and up-to-date training of the participating nurses as several articles have recently been published that elaborate on the aetiopathogenesis and treatment of this lesion (Afifi et al., 2018; Cerdán-Santacruz et al., 2020; George et al., 2019; Le et al., 2019).

About care indications, indications related to urostomies were easily identifiable (recommending a diet rich in vitamin C/blueberries or applying acetic acid dressings), as were applying cold and topical tacrolimus. The use of foam or silicone dressings obtained a low level of agreement and so did nutritional recommendations. About the latter, it is important to remember that recommendations to address complications should not only focus on product application and/or device change but should also include indications related to self-care and diet/hydration, as recommended by Ratliff et al. (2021) in their consensus document. Accompanying images of a PSL with a description of the suitability of self-care routines would help increase the level of agreement in the identification of lesions such as mechanical dermatitis, which is related to sudden movements while handling the device, and lesions such as friction/pressure ulcers. Similarly, we believe that adding information about nutritional and intestinal habits (frequency, quantity and consistency/appearance) at the onset of the complication would help ensure that more holistic measures are recommended.

Research has shown that the care of ostomy patients by stoma therapy nurses is cost-effective and significantly reduces the occurrence and time required to cure PSL (Coca et al., 2015). Stoma therapy nurses are better equipped to manage skin complications caused by ostomy and to manage the devices used (Wound, Ostomy, and Continence Nursing: Scope and Standards of WOC Practice, 2nd Edition: An Executive Summary, 2018). Peristomal skin assessment is



TABLE 5 Interobserver agreement on care indications. Significant  $\kappa$ -values. Rounds 1 and 2

Result	Round 1		Round 2	
	n	Cohen's $\kappa$ (95% CI)	n	Cohen's $\kappa$ (95% CI)
1. Adjusting the opening diameter of the faceplate	3	0.32 (-0.50 to 1.13)	3	0.32 (-0.50 to 1.13)
2. Diet rich in vitamin C / blueberries	36	0.75 (0.70 to 0.81)	36	0.75 (0.70 to 0.81)
3. Antidiarrhoeals	23	0.56 (0.50 to 0.63)	23	0.56 (0.50 to 0.63)
4. Topical antifungals	12	0.30 (0.07 to 0.51)	12	0.30 (0.07 to 0.51)
5. Foam dressing	2	0.12 (-1.43 to 1.68)	2	0.12 (-1.43 to 1.68)
6. Extra thin hydrocolloid dressing	13	0.41 (0.33 to 0.48)	13	0.41 (0.33 to 0.48)
7. Hydrofibre dressing with silver	4	0.37 (0.27 to 0.48)	4	0.37 (0.27 to 0.48)
8. Silicone dressing	1	0	1	0
9. Increasing soluble fibre intake	2	0.29 (-0.55 to 1.13)	2	0.29 (-0.55 to 1.13)
10. Increasing water intake	1	-0.31	1	-0.31
11. Topical corticosteroids	2	0.46 (0.44 to 0.47)	2	0.46 (0.44 to 0.47)
12. Two-piece device	5	0.45 (0.32 to 0.59)	5	0.45 (0.32 to 0.59)
13. Using hydrocolloid rings	8	0.38 (0.33 to 0.43)	8	0.38 (0.33 to 0.43)
14. Using belts	21	0.43 (0.38 to 0.48)	21	0.43 (0.38 to 0.48)
15. Use of stoma paste to level skin	8	0.43 (0.34 to 0.52)	8	0.43 (0.34 to 0.52)
16. Use of convex faceplates	30	0.56 (0.51 to 0.61)	30	0.56 (0.51 to 0.61)
17. Use of hydrocolloid powder	16	0.39 (0.36 to 0.43)	16	0.39 (0.36 to 0.43)
18. Acetic acid dressings	24	0.61 (0.52 to 0.69)	24	0.61 (0.52 to 0.69)
19. Applying cold	9	0.67 (0.51 to 0.84)	9	0.67 (0.51 to 0.84)
20. Topical haemostatic agents	8	0.49 (0.30 to 0.68)	8	0.49 (0.30 to 0.68)
21. Silver nitrate	20	0.45 (0.41 to 0.49)	20	0.45 (0.41 to 0.49)
22. Reducing insoluble fibre intake	2	0.20 (-2.29 to 2.69)	2	0.20 (-2.29 to 2.69)
23. Skin barrier spray	1	0.33	1	0.33
24. Adhesive remover spray	1	0.49	1	0.49
25. Topical tacrolimus	15	0.61 (0.43 to 0.78)	15	0.61 (0.43 to 0.78)
26. Oral antibiotic treatment	11	0.51 (0.35 to 0.69)	11	0.51 (0.35 to 0.69)

complex and requires specific expertise and knowledge, even more so if this assessment is performed remotely. Recommendations for a nurse to perform telehealth include an expert level of knowledge and demonstrated experience in the application of evidence-based care (Cloyd & Thompson, 2020). In this study, the participating nurses had a high level of knowledge of ostomy care and kept their knowledge up to date by taking additional training courses. However, the level of agreement was not very high, perhaps due to the complexity of the remote assessment of stoma and peristomal skin lesions. Along the same lines show the results of their study by Colwell et al. (2017) describing the practices of North American ostomy nurses in relation to PSL. They did not find complete concordance in any of the practices, although they did observe general trends in the management of complications. The study concluded that further research was needed to define the epidemiology, type and severity of PSL, as well as to establish their management, care and treatment.

Remote imaging of stoma or peristomal skin lesions is a resource that allows stoma care nurses to act as consultants to other professionals or the patients themselves. But this resource requires that the images are of good quality, indicate the position in which they

are taken, are accompanied by information on lesion measurements using standardized tools (Shiraishi et al., 2020) and complementary information such as self-care habits, type and consistency of effluent, nutritional status, laboratory results (cultures, biopsies, etc.) and dressing or ostomy materials used (Beitz & Colwell, 2016). Other data, such as social support, physical activity level and emotional state, can also be useful in assessing the person and their injury in a holistic manner, allowing for an appropriate and individualized care plan to be developed.

## 5 | LIMITATIONS

The  $\kappa$ -value, used to determine the level of agreement in this study, is an indicator of strong agreement, but it depends on the complexity of the issue studied and the assessment of peristomal skin is certainly complex. The  $\kappa$ -value is affected by the prevalence of the aspect in question, so it is a useful statistic for description but not for making inferences. The study included several less prevalent lesions, which were difficult for nurses at hospitals with limited numbers of cases to assess.

TABLE 6 Relationship between occupational and educational factors and the degree of agreement and uncertainty

Variable	n (%)	Mean kappa values (DE)	p value*	p value**	Mean percentage uncertainty values (DE)	p value*	p value**
Professional experience as a nurse			.240	.245		.139	.125
<5 years	1 (2.6)	0.39 (NC)			35.9 (NC)		
Between 5 and 10 years	2 (5.1)	0.21 (0.11)			5.5 (7.73)		
Between 11 and 20 years	7 (17.8)	0.30 (0.14)			36.8 (13.6)		
>! 20 years	29 (74.4)	0.34(0.08)			26.5 (17.8)		
Professional experience as a stomatherapy nurse			.674	.591		.312	.258
<5 years	17 (43.6)	0.31 (0.11)			24.1 (17.7)		
Between 5 and 10 years	9 (23.1)	0.37 (0.09)			25.2 (17.0)		
Between 11 and 20 years	11 (28.2)	0.31 (0.10)			31.2 (17.9)		
>20 years	2 (5.1)	0.32 (0.03)			46.6 (9.9)		
Level of training in stomatherapy			.110	.061		.272	.247
Stomatherapy expert level (29–30 credits ECTS = 725–750 h theory/practice)	23 (59.0)	0.31 (0.10)			24.9 (18.4)		
Stomatherapy masters degree (60 credits ECTS = 1500 h theory/practice)	16 (41.0)	0.36 (0.09)			31.3 (16.2)		
Have you received any training during the last 5 years in Evidence-Based Clinical Practice (EBP)?			.509	.676		.776	.872
No	10 (25.6)	0.35 (0.08)			26.0 (11.4)		
Yes	29 (74.4)	0.32 (0.11)			28.0 (19.4)		
How long ago have you participated in a refresh course in stomatherapy?			.105	.105		.647	.563
<1 year	35 (89.7)	0.32 (0.10)			27.1 (18.1)		
Between 1 and 2 years	4 (10.3)	0.41 (0.08)			31.4 (13.7)		

\*t de Student-Fisher/Anova.; \*\*U de Mann Whitney/Kruskall Wallis.

The  $\kappa$ -value also depends on the number of categories. The more categories there are, the more difficult it is to correctly classify the subjects and very low  $\kappa$ -values are usually obtained. In this study, a total of 72 categories encompassing signs, diagnoses, and care indications were measured.

When the variables are classified, the  $\kappa$  value depends to a large extent on the definition assigned to each category. Although participants were provided with a glossary produced by the experts containing perfectly detailed definitions of each category, there is a degree of subjectivity involved in assessing skin lesions that would be controlled if validated tools for assessing peristomal skin such as care algorithms were used.

Limitations of the study include the small number of participants, which makes it difficult to detect statistical differences and generalize results.

Another limitation is the possible recall bias among the participating nurses that could account for the high level of intra-observer agreement obtained.

Despite having taken all the photographs in the case with the same type of mobile phone and having established guidelines for taking the photographs, it is possible that the lighting and focus used when taking the photographs may have influenced the results.

## 6 | CONCLUSIONS

There is significant variability among nurses in Spain when it comes to the level of agreement on assessments, diagnoses and care indications in PSL using digital images.

The most easily identifiable lesions were the most prevalent and those accompanied by visible signs. There was a lower level of agreement in identifying lesions for which photographs required additional information (laboratory data, description of signs and symptoms, type of diet and level of self-care).

It is important to train nurses caring for ostomates to correctly describe ostomy-related lesions, which is important for nursing

records, continuity of care and the remote care or telehealth that is so widely used today.

## AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE\*):

1. Substantial contributions to conception and design, acquisition of data or analysis and interpretation of data.
2. Drafting the article or revising it critically for important intellectual content.

\* <http://www.icmje.org/recommendations/>

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## DATA AVAILABILITY STATEMENT

Data available on request from the authors. The data that support the findings of this study are available from the corresponding author upon reasonable request.

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**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - QUANTITATIVE**

# Identifying the suicidal ideation risk group among older adults in rural areas: Developing a predictive model using machine learning methods

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**Abstract**

**Aims:** The aim of this study was to develop a predictive model that can identify the suicidal ideation risk group among older adults in rural areas using machine learning methods.

**Design:** This study applied an exploratory, descriptive and cross-sectional design.

**Methods:** The participants were older adults ( $N = 650$ ) aged over 65 living in rural areas of South Korea. Self-report questionnaires were used to collect the demographics, suicidal ideation, depression, socioeconomic information and basic health information from September to October 2020. The collected data were analysed using machine learning methods with R statistical software 4.1.0.

**Results:** The predictive models indicated that depression, pain, age and loneliness were significant factors of suicidal ideation. Good performance was observed based on the area under the receiver operating characteristic curve in the decision tree, random forest and logistic regression. Finally, the evaluation of model performance indicated moderate to high sensitivity and specificity.

**Conclusion:** The predictive models using machine learning methods may be useful to predict the risk of suicidal ideation. Furthermore, depression with pain, age and feelings of loneliness should be included in the initial screening to assess suicide risk among older adults in rural areas.

**Impact:** Identifying suicidal risk among older adults is challenging. Thus, employing predictive models that can assess depression, pain, age and loneliness can enable public healthcare providers to detect suicidal risk groups. Particularly, the presented models from this study can facilitate healthcare providers with initiating early interventions to prevent suicide among older adults in clinical and community nursing care settings.

**Reporting Method:** The reporting of this study (Observational, cross-sectional study) conforms to the STROBE statement.

**Patient or Public Contribution:** No patient or public contribution. This study did not involve patients, service users, caregivers or members of the public.

**Implication for the Profession and/or Patients Care:** Applying this model may help to prevent geriatric suicide because the nursing staff will have a greater awareness



regarding the suicide ideation risk of older adults, thereby reducing the possibility of their suicide.

#### KEYWORDS

aged, depression, loneliness, machine learning, nurses, pain, rural population, suicidal ideation

## 1 | INTRODUCTION

Globally, there are approximately 0.7 million annual deaths due to suicide, with the highest rate being among older adults (World Health Organization, 2021a). Suicide in older adults is considered a severe public health problem in South Korea and other Asian countries, where the older adult population is increasing rapidly. Furthermore, the rate of suicidal ideation is expected to increase further, particularly considering the increase and rapid ageing of the older adult population in rural areas. In contrast to urban areas, the rate of suicide or suicidal ideation in older adults is higher in rural areas (Chin et al., 2020; Ministry of Health & Welfare & Korea Foundation for Suicide Prevention, 2021; Statistics Korea, 2021). Moreover, South Korea has one of the highest suicide rates among older adults globally and is ranked first among the Organization for Economic Co-operation and Development (OECD) member countries (Ministry of Health & Welfare & Korea Foundation for Suicide Prevention, 2021; Statistics Korea, 2021).

It is well known that suicide occurs after suicidal ideation and plans. However, there is limited knowledge underscoring the association between suicidal ideation and suicide in older adults (Van Orden et al., 2010). Studies have suggested that reducing suicidal ideation can serve as an effective prevention strategy. Furthermore, recognizing suicidal ideation provides a crucial strategy for identifying potential suicide attempts or deaths (Jeon, 2011; Silverman & Berman, 2014). Therefore, it is necessary to explore the predictors of suicidal ideation in older adults.

Over 66% of individuals at high risk of suicide denied having suicidal ideation, of which 50% committed suicide within 2 days (Berman, 2018). Hence, it is important to explore the presence or absence of suicidal ideation and to observe and integrate specific individuals' characteristics related to suicidal ideation. Moreover, it is pertinent to determine how these characteristics interact with or predict suicidal ideation (Conwell, 2014).

Existing studies are limited as they only underscore fragmentary predictors for suicidal ideation among older adults. Particularly, available findings are based on Big Data, which apply secondary analysis using variables from an existing dataset. The dataset mainly comprises data collected from urban areas and uses an analytic method such as the logistic regression analysis.

Machine learning is an emerging analytical method used to predict outcomes or develop decision support systems based on clinical data (Iniesta et al., 2016). Machine learning methods have been used widely for risk stratification in acute contexts and approved for providing better prediction over logistic regressions such

as readmission and deteriorating conditions (Churpek et al., 2016; Mortazavi et al., 2016; Rojas et al., 2018). Furthermore, machine learning focuses on discovering hidden patterns among variables or exploring optimal models to explain data using algorithmic techniques. Particularly, it applies when the distribution of predictors is uneven or affected simultaneously by several factors (Long et al., 1993). Moreover, the decision tree generates a single decision tree, while the forests in the random forest consist of several decision trees, although complementary (Breiman, 2001). Thus, the meta-analysis validates the prediction performance between logistic regression and machine learning algorithms. Consequently, this study found that the random forest exhibited good performance and better acuity of prediction in contrast to the logistic regression (Miles et al., 2020; Sufriyana et al., 2020).

This study used machine learning methods to develop a highly accurate predictive model that can identify suicidal ideation among older adults living in rural areas. Particularly, it employed a predictive model to identify older adults with suicidal ideation based on the International Classification of Functioning, Disability and Health (ICF) model (Kim et al., 2019; World Health Organization, 2016). Consequently, the findings can serve as practical and specific directions for the early detection of suicidal ideation and suicide prevention among older adults in clinical and community nursing fields.

## 2 | BACKGROUND

Globally, the suicide rate of adults over the age of 65 years of age was 38.2–165.1 deaths per 100 thousand persons, exceeding other age groups (World Health Organization, 2021b). Likewise, the suicide rate in South Korea was the highest among older adult men aged at least 80 years, accounting for 118 deaths per 100,000 population (Statistics Korea, 2021). Furthermore, the suicide rate among older adults is four times higher than the average suicide rate of 25.7 for all ages in South Korea. (Statistics Korea, 2021).

Suicidal ideation is commonly referred to as 'waxing and waning suicidal thoughts', which refers to a desire for death and suicide (Harmer et al., 2020). Generally, it is among the most significant predictors of suicidal behaviour. Jeon (2011) reported that individuals attempt suicide approximately 1–2 years after their initial severe suicidal ideations. Furthermore, the rate of suicidal ideation reportedly comprised 84.0%–98.5% of suicide attempters. Therefore, most suicide attempts occur after thorough consideration as opposed to impulsively, especially in older adults.

Research has shown that 44% of individuals who committed suicide had contact with their primary and mental healthcare services during their last month of life (Stene-Larsen & Reneflot, 2019). It implies that health providers tend to overlook the significance of suicidal ideation. Consequently, there has been increased emphasis for communication regarding suicidal ideation in risk assessment in primary care (Silverman & Berman, 2014). Furthermore, older adults living in rural areas are more likely to neglect their care needs, thereby increasing their susceptibility to suicide due to social isolation and reduced access to mental health services (Chin et al., 2020; Reccord et al., 2021). Therefore, early detection of suicide risk groups and intervention is crucial in the prevention of suicide in older adults, especially individuals in rural settings (Berry et al., 2020; Chin et al., 2020).

Studies have suggested that suicidal ideation among old adults is significantly associated with several factors. They are (1) socio-demographic factors such as gender and region (Chin et al., 2020), age (i.e. under the age of 74 years), higher education and lower economic status, living alone (Kang et al., 2014; Ko et al., 2021), social disconnectedness (Kang et al., 2014) and loneliness (McClelland et al., 2020); (2) physical factors, including physical illness, pain, the activity of daily living (Kang et al., 2014; Kim, 2016; Ko et al., 2021), poor perceived health status (Choi et al., 2015) and sleep disturbance (Chin et al., 2020) and (3) psychological factors such as depression (Ge et al., 2017; Kang et al., 2014), perceived burdensomeness (Cukrowicz et al., 2011; Shim et al., 2021) and meaning of life (Heisel et al., 2016; Lutzman & Sommerfeld, 2021).

However, despite consistent results correlating multiple predictive factors with suicidal ideation among older adults, suicide prevention presents a challenge for healthcare providers because of the unknown interactions among suicidal risk factors. Thus, simultaneously assessing proven suicide risk factors while considering additional information about an individual may be useful to identify older adults who are at risk of suicide. Accordingly, this study used machine learning methods that consider the individual's information to develop a predictive model to identify suicidal ideation, particularly among older adults.

### 3 | THE STUDY

#### 3.1 | Aim and objectives

This study aimed to develop a predictive model using machine learning methods to identify suicidal ideation in older adults living in rural areas of South Korea.

## 4 | METHODS/METHODOLOGY

### 4.1 | Design

This study applied an exploratory, descriptive and cross-sectional design.

### 4.2 | Population and sample

The recruited participants consisted of 2839 older adults living alone registered at the Okcheon Public Health department. In total, 650 participants were recruited using the convenience sampling method. The inclusion criteria comprised participants who (1) were aged over 65 years in rural areas, (2) expressed typical cognitive functioning with a score higher than 18 on the Korean Mini-Mental State Examination (K-MMSE; Kim et al., 2003), (3) were able to understand and answer the questions in the study questionnaire and (4) were willing to participate in the study. Furthermore, participants diagnosed with neurocognitive disorders or acute psychiatric diseases and who had attempted suicide within a week prior to the study were excluded.

For the classification matrix research using data mining, the minimum sample size of 204 was calculated using  $6 \times$  the number of groups for the output variable  $\times$  the number of variables (Delmater & Hancock, 2001). Furthermore, a sample size of 519 was used for the logistic regression analysis which was calculated based on a two-tailed test. Moreover, the odds ratio (OR) = 1.49 (Choi et al., 2015), the probability ( $p$ ) = .20, the significance level of .05 and the power = .95 were determined using the G\*power 3.1.9.7 program. Accordingly, the sample size of 650 in this study met the two conditions.

### 4.3 | Validity, reliability and the questionnaire

To enhance the validity and reliability of the study, explanatory variables related to suicidal ideation were selected based on ICF models (World Health Organization, 2016) and evidence from a study conducted by Kim et al. (2019). The current study used home visits to collect data, thus increasing the reliability of obtained data from older adults with suicidal ideation throughout rural regions.

*Suicidal ideation* was assessed based on the following question: 'Have you thought about ending your life by any means in the past year'? The responses were scored using 'No = 0' and 'Yes = 1'.

*Depression* was assessed using the Korean version of the Geriatric Depression Scale Short Form (GDSSF-K) which was developed by Sheikh and Yesavage (1986) and modified by Kee (1996) for use in the Korean context. The scale consists of 15 items rated on a dichotomized scale using 'yes = 1' or 'no = 0'. The score ranged from 0 to 15, with higher scores indicating greater severity of depression. Furthermore, a cut-off point of five was used to indicate depression. Finally, the reliability for this scale had a Cronbach's alpha of .88 in Kee's (1996) study, and .87 in the present study.

*Social disconnectedness* was assessed using the scale of social networking from the 2017 Living Profiles of Older People Survey in South Korea (Jang et al., 2018). This scale contains seven items to measure the frequency of contact, namely, with family, friends, relatives, co-workers, neighbours, public officers and the welfare centre staff. Each item was scored on a 6-point Likert scale where 'None = 1', '1 to 2 times a year = 2', '1 to 2 times every 6 months = 3', '1 to 2 times per a month = 4', '1 to 2 times per week = 5', 'every day = 6'. Specifically, a lower score indicates a greater level of social

disconnectedness. The reliability of this scale in the present study comprised a Cronbach's alpha of .80.

The activity of daily living (ADL) was assessed using the Korean version of the Activities of Daily Living (K-ADL) developed using the Katz index (Wallace & Shelkey, 2007) and the Barthel index (Mahoney & Barthel, 1965) prior to being modified for use in Korean by Chang-Won et al. (2002). The scale comprises seven items of ADL (i.e. dressing, washing face and hands, bathing, eating, transfer, toileting and continence). Each item was scored on a 3-point Likert scale, with higher scores indicating a greater level of activity in daily living. Reliability for this scale had a Cronbach's alpha of .98 in Chang-Won et al.'s (2002) study and .80 in the present study.

The feeling of loneliness was assessed using the following question: 'In the past month, to what extent have you felt loneliness?' *Feelings of burdensome felt by a participant towards significant others (self-burden)* were assessed using the following question: 'In the past month, to what extent have you felt like a burden to significant others'?

The meaning of life was assessed using the following question: 'In the past month, to what extent have you felt your life is meaningful'?

The degree of sleep disturbance was assessed using the following question: 'In the past month, to what extent have you felt sleep disturbances'?

Pain was assessed using the following question: 'In the past month, to what extent have you felt physical pain'? To facilitate responses for older adults, all these questions were measured using a thermometer-shaped visual analog scale (Choinière & Amsel, 1996) marked from 'Not at all = 0' to 'Extremely = 10'.

Demographic data were collected and assessed using a demographic questionnaire including information such as age (years), gender, education level, marital status, comorbidities, physical disability (yes, no) and economic status.

#### 4.4 | Data collection

The study was conducted on the behalf of the Annual Geriatric Health Survey of the Okcheon Public Health Department. Data were collected from September to October 2020 through home visits to residents aged over 65 years living alone based in nine regions of rural Okcheon Province. A total of nine home-visiting nurses from the Okcheon Public Health Department visited the residents registered under each region's community health department. Consequently, 90 to 100 participants were recruited from each region. Thereafter, data were collected by trained visiting nurses through face-to-face interviews with participants in their homes or health centres located in the subdivision of Okcheon province. In total, 860 questionnaires were distributed, while 650 questionnaires were returned (response rate: 75.6%). Finally, data from 650 participants were analysed.

#### 4.5 | Ethical considerations

All study procedures were approved by the Institutional Review Board of Chosun University (2-7008161-A-N-01). The participants were

sufficiently informed about the study's objectives, procedure, the right to withdraw from the study, and its benefits before obtaining their written consent. The consent forms and questionnaires were stored in a locker and could only be accessed by authorized individuals.

#### 4.6 | Data analysis

The analysis was conducted using SPSS 26.0 program and R statistical software version 4.1.0 (2020-02-18), which includes the caret packages. The messiness was checked and the frequency, mean and standard deviation (SD) were computed. Thereafter, the differences in suicidal ideation according to demographic characteristics and study variables were analysed using a t-test and  $\chi^2$ -test.

The study applied machine learning algorithms that covered the decision tree and random forest to predict suicidal ideation. The machine learning methods are beneficial because they are not affected by the overfitting issue and are protected from the impact of collinearity. (Breiman, 2001; Matsuki et al., 2016; Strobl et al., 2009). Furthermore, the application of machine learning methods in mental health has been demonstrated in public health, clinical research and the diagnosis and prognosis of mental conditions (Shatte et al., 2019).

The models generated from the machine learning methods were compared with one generated from logistic regression. The caret package was applied to the decision tree and random forest (Kuhn, 2022). To perform the analysis, the original dataset was divided into the training (70% of the total dataset) and testing (30% of the total dataset) samples. Consequently, a predictive model was generated from the training dataset and tested using the testing dataset. To ensure an accurate estimation of the predictive validity, 10-fold cross-validation was performed (Hastie et al., 2008; Poldrack et al., 2020). Finally, to evaluate model performance, a receiver operating characteristic (ROC) curve was generated and the sensitivity and specificity of each model and area under the receiver operating characteristic (AUROC) curve were calculated.

### 5 | RESULTS

#### 5.1 | Sample characteristics

The demographic characteristics of the participants are presented in Table 1. In total, 26.6% ( $n = 173$ ) of the participants had suicidal ideation. Furthermore, 77.8% ( $n = 506$ ) were female and 42.0% ( $n = 273$ ) of them had elementary school-level education, with a mean age of 78.54 (SD = 6.71). The mean GDS was 4.04 (SD = 3.80) and the mean pain was 5.14 (SD = 3.06). A Predictive Model from the analysis of a decision tree, random forest and logistic regression.

The decision tree is presented in Figure 1. Particularly, GDS >5 (Node 1,  $p < .001$ ) and pain >7 (Node 5,  $p = .010$ ) comprised the factors predicting suicidal ideation. The calculation of the total decrease in node impurities from the plot resulting from the random forest (Figure 2), demonstrated that GDS was the most important

TABLE 1 Demographic characteristics and study variables by suicidal ideation (N = 650)

Characteristics	Categories	Total N (%) / M (SD)	Suicide ideation		$\chi^2/t$	p
			No (n = 477) N (%)	Yes (n = 173) N (%)		
Gender	Male	144 (22.2%)	105 (22.0%)	39 (22.5%)	0.021	.970
	Female	506 (77.8%)	372 (78.0%)	134 (77.5%)		
Education	None	233 (35.8%)	167 (35.0%)	66 (38.2%)	3.41	.637
	Elementary	273 (42.0%)	202 (42.4%)	71 (41.0%)		
	Middle school	56 (8.7%)	42 (8.8%)	14 (8.1%)		
	High school	64 (9.8%)	45 (9.4%)	19 (11.0%)		
	Undergraduate	22 (3.4%)	19 (4.0%)	3 (1.7%)		
	Graduate	2 (0.3%)	2 (0.4%)	0 (0.0%)		
Economic status	Less than 100% of MCL	53 (8.2%)	31 (6.5%)	22 (12.7%)	8.93	.030
	Less than 120% of MCL	42 (6.4%)	33 (6.9%)	9 (5.2%)		
	Standard median income	549 (84.5%)	407 (85.3%)	142 (82.1%)		
	More than standard median income	6 (0.9%)	6 (1.3%)	0 (0.0%)		
Marital status	Single	11 (1.7%)	10 (2.1%)	1 (0.6%)	13.64	.009
	Married	73 (11.2%)	64 (13.4%)	9 (5.2%)		
	Divorced	52 (8.0%)	32 (6.7%)	20 (11.5%)		
	Widowed	509 (78.3%)	367 (77%)	142 (82.1%)		
	Other	5 (0.8%)	4 (0.8%)	1 (0.6%)		
Diabetes mellitus	Yes	161 (24.8%)	115 (24.1%)	46 (26.6%)	0.42	.586
	No	489 (75.2%)	362 (75.9%)	127 (73.4%)		
Hypertension	Yes	426 (65.5%)	306 (64.2%)	120 (69.4%)	1.53	.253
	No	224 (34.5%)	171 (35.8%)	53 (30.6%)		
Arthritis	Yes	211 (32.5%)	137 (28.7%)	74 (42.8%)	11.44	.001
	No	439 (67.5%)	340 (71.3%)	99 (57.2%)		
Physical disability	Yes	84 (12.9%)	48 (10.1%)	36 (20.8%)	13.03	.001
	No	566 (87.1%)	429 (89.9%)	137 (79.2%)		
Age		78.54 (6.71)	78.05 (6.37)	79.90 (7.41)	-2.90	.004
Social disconnectedness		24.33 (6.02)	24.56 (5.99)	23.69 (6.07)	1.63	.104
Depression		4.04 (3.80)	2.96 (3.07)	7.01 (4.06)	-11.94	.001
Loneliness		3.83 (3.16)	3.23 (2.93)	5.50 (3.18)	-8.56	.001
Pain		5.14 (3.06)	4.75 (2.99)	6.23 (3.02)	-5.57	.001
Sleep disturbance		6.69 (3.20)	7.11 (2.99)	5.55 (3.48)	5.22	.001
Self-burden		2.27 (2.96)	1.97 (2.75)	3.10 (3.35)	-3.99	.001
Life meaning		6.46 (3.00)	6.92 (2.86)	5.17 (3.04)	6.76	.001
ADL		7.25 (0.88)	7.16 (0.73)	7.50 (1.16)	-4.49	.001

Abbreviations: ADL, activities of daily living; MCL, minimum cost of living.

predictor, followed by pain, age and loneliness. In contrast, logistic regression (see Figure 3) indicated that only GDS increased suicidal ideation (OR = 1.26 [95% CI: 1.17–1.35]), while the other scales were not associated with suicidal ideation.

## 5.2 | The performance of the models

The ROC of the decision tree, random forest and logistic regression are displayed in Figure 4, while the specificity, sensitivity and AUROC of each predictive model are illustrated in Table 2.

This study found that the evaluation of model performance demonstrated moderate to high sensitivity (decision tree, 0.78; random forest, 0.76; logistic regression, 0.80) and specificity (decision tree, 0.64; random forest, 0.73; logistic regression, 0.76). The AUROC indicated the probability that a randomly selected patient who has experienced an event will have a higher predicted risk score than a randomly selected patient who did not experience an event (D'Agostino et al., 2013). Finally, the AUROC of the decision tree, random forest and logistic regression in this study was 0.77 (95% CI: 0.70–0.84), 0.78 (95% CI: 0.72–0.87) and 0.82 (95% CI: 0.75–0.88) respectively.

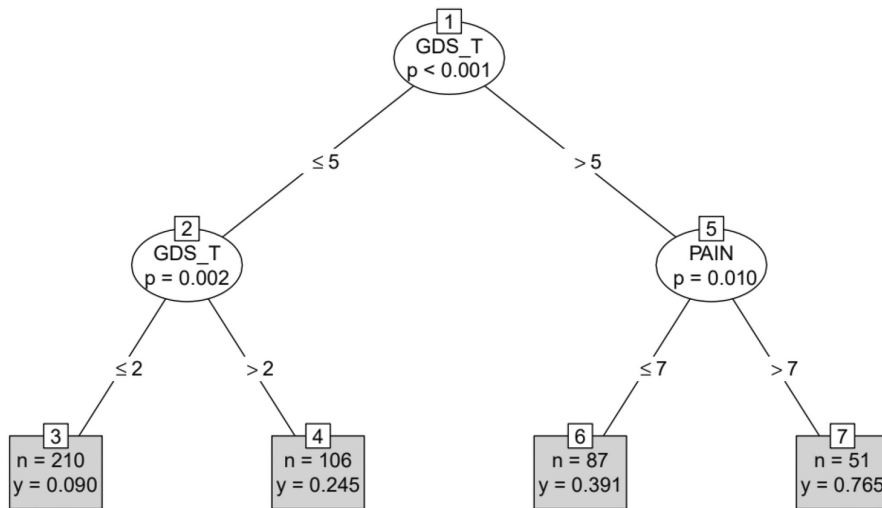


FIGURE 1 A decision tree generated by Ctree. GDS\_T, depression.

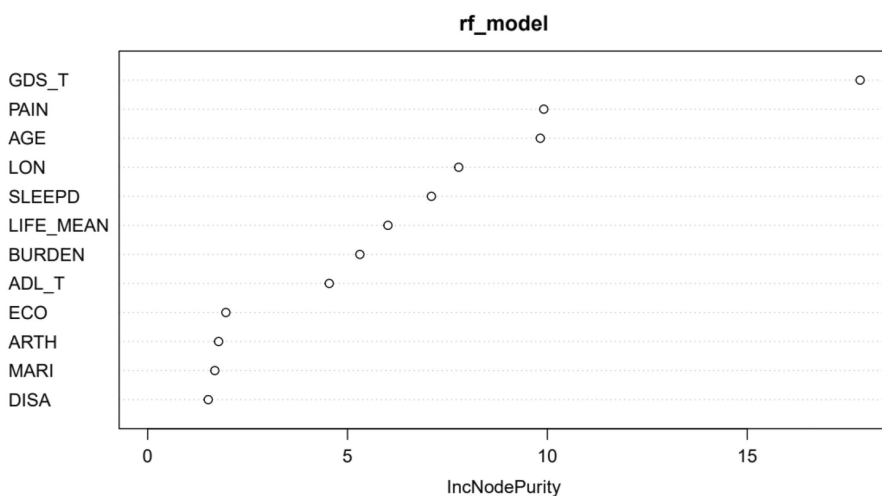


FIGURE 2 The predictive factors generated by random forest. ADL\_T, activity of daily living; ARTH, arthritis; BURDEN, the feeling of a participant as a burden to significant others; DISA, physical disability; ECO, economic status; GDS\_T, depression; IncNodePurity, the total decrease in node impurities; LIFE\_MEAN, the life meaning; LON, the feeling of loneliness; MARI, marital status; rf, logistic regression; SLEEPD, the degree of sleep disturbance.

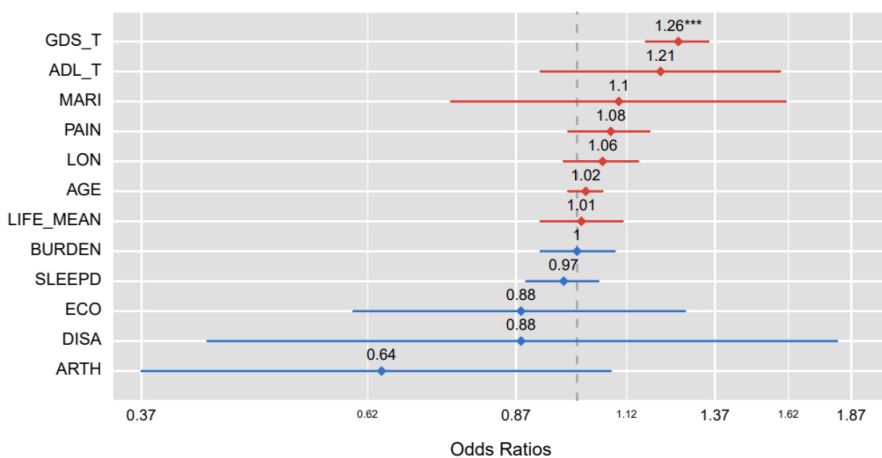


FIGURE 3 Odds ratios of each variables. GDS\_T, depression; LON, the feeling of loneliness; SLEEPD, the degree of sleep disturbance; LIFE\_MEAN, the life meaning; BURDEN, the feeling of a participant as a burden to significant others; ADL\_T, activity of daily living; ECO, economic status; ARTH, arthritis; MARI, marital status; DISA, physical disability. \*\*\* $p < .001$ .

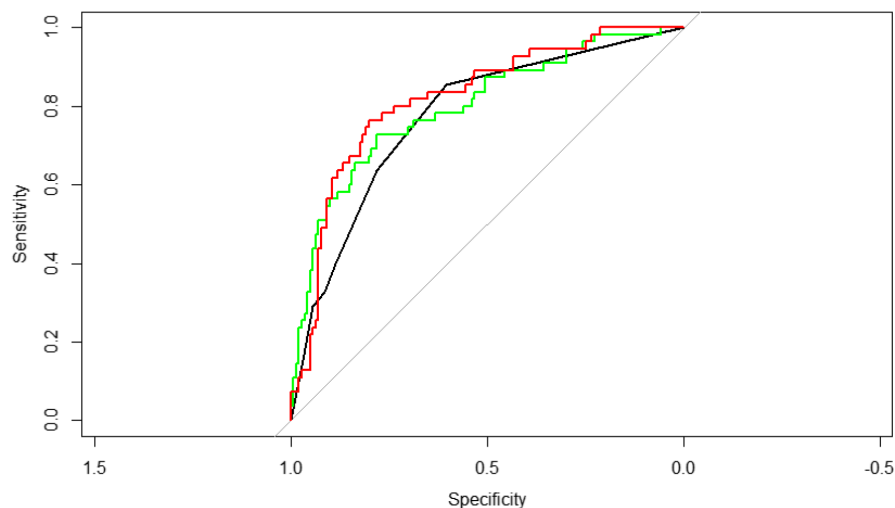
## 6 | DISCUSSION

This study is the first to develop predictive models using machine learning based on data collected from healthy older adults living in rural areas to identify individuals with suicidal ideation. Machine learning tools such as the decision tree and the random forest have been recognized for their advantages in the advancement of clinical

decision support systems because of their ability to analyse complex and large data. Thus, these tools are useful tools for predicting outcomes (Inieta et al., 2016; Navarro et al., 2021).

The Geriatric Health Survey used in this study was designed by the Public Health Department. Consequently, the survey comprises many binary variables to increase the completion of the questionnaires and the feasibility of data collection from older adults. While

**FIGURE 4** Receiver operating characteristic. Black = decision tree; Green = random forest; Red = logistic regression.



**TABLE 2** Evaluation of predictive models ( $N = 650$ )

Estimates	Decision tree	Random forest	Logistic regression
AUROC	0.77 (95% CI: 0.70–0.84)	0.78 (95% CI: 0.72–0.87)	0.82 (95% CI: 0.75–0.88)
Accuracy	0.74 (95% CI: 0.67–0.80)	0.75 (95% CI: 0.68–0.8)	0.79 (95% CI: 0.73–0.85)
Sensitivity	0.78	0.76	0.80
Specificity	0.64	0.73	0.76
Predict value			
Positive	0.85	0.88	0.90
Negative	0.53	0.54	0.60

Abbreviation: AUROC, area under the receiver operating characteristic curve.

logistic regression is suitable to determine the binary outcome that generated the best AUROC in this study, this tool only effectively identified depression as the most influential factor to predict suicidal ideation. The factors influencing suicide among older adults in this study are multi-dimensional. Therefore, it is necessary to select an analysis method that can determine the risk factors of suicidal ideation. Particularly, this method should consider the complex interaction among predictors as opposed to using a traditional linear model such as logistic regression. Furthermore, random forest is a machine learning method that identifies predictors of suicidal ideation from the data. In addition to using depression, calculating the total reduction of node impurities (see Figure 2) suggested that pain, age and loneliness were risk factors underlying the prediction of suicidal ideation in this model. Moreover, machine learning methods capture the predictors without assumption, misspecification or bias as would a logistic model (Dasgupta et al., 2014). In addition, a random forest provides a more stable and important ranking of a variable than logistic regression. (Rossi et al., 2005; Strobl et al., 2009). Therefore, predictive models generated from machine learning methods enhance the effective prediction of a risk group with suicidal ideation.

Several studies have found that the risk of suicidal ideation is induced by factors such as depression, loneliness, age and pain (Dong et al., 2015; Kang et al., 2014; Kim, 2016; McClelland et al., 2020; Okolie et al., 2017), which is consistent with the present study results. Furthermore, research shows that depression screening and management are effective

in reducing suicidal ideation (Okolie et al., 2017). However, the use of a cut-off for the severity of depression to initiate preventive management has not been suggested. Moreover, most studies identified participants as depressed or not depressed. From the decision tree analysis, a criterion (5 points) measured by GDSSF-K was identified as a cut-off to imply a more accurate assessment determining whether older adults experience suicidal ideation.

Previous studies have identified pain as a risk factor and current evidence has shown that moderate to severe pain can increase suicidal ideation (Kang et al., 2014; Kim, 2016; Santos et al., 2020). These findings are consistent with the results of this study. From this study, older adults having depressive symptoms with moderate to severe pain are a risk group who potentially have suicidal ideation.

In terms of the random forest tool, age was determined as a meaningful predictor. In contrast, this finding is inconsistent with the current meta-analysis, which reveals that increasing age lowers the odds of suicidal ideation (OR = 0.5, 0.39–0.65) in adults over 65 (Carrasco-Barrios et al., 2020). However, previous studies support a higher suicidal ideation rate among older adults in rural areas (Berry et al., 2020; Chin et al., 2020). The current finding indicates that older adults over 65 globally have the highest suicide rate (Naghavi, 2019). Nonetheless, studies exploring the specific characteristics and accurate predictors of suicidal ideation in older adults are limited (Conwell, 2014). Therefore, further studies are required to clarify whether age is a predictor of suicidal ideation.



The present study showed that there was no significant difference in suicidal ideation rate based on gender. However, the current results contradict previous studies, which reported that women have a higher suicide rate than men (Chin et al., 2020; Choi et al., 2015). Furthermore, these results perhaps differ from previous studies as the composition of the sample was predominantly female. Thus, further repeated investigations are should be conducted to explore various mediating or moderating factors on the relationship between gender and suicidal ideation among older adults.

The current study developed a predictive model of suicidal ideation in healthy older adults living in rural areas using a machine learning method. Consequently, the study found that the early detection of suicide risk groups and initiation of early preventive interventions are crucial in the prevention of suicide in older adults, especially in community settings. Previous research indicated that suicidal older adults reported physical and cognitive functional decline, low social support, high levels of depression and loneliness (Conejero et al., 2018). While the current study participants demonstrated relatively high functional levels, low depression levels and normal cognitive function, the prevalence of the rate of suicidal ideation was 26.6%, higher than in previous studies conducted in South Korea and China. Respectively, these studies exhibited a rate of 11.5%, 25.2% and 23.6% (Chin et al., 2020; Choi et al., 2015; Hu et al., 2020). Furthermore, this study demonstrated that the vulnerability of residents living in rural areas to physical and social isolation decreased access to mental health services (Chin et al., 2020; Reccord et al., 2021). Consequently, it resulted in a high prevalence of suicidal ideation.

Future studies ought to evaluate the effects and predictability of the current model in suicidal plans and attempts among older adults. The current results could contribute to the development of an assessment tool and intervention program for the early detection and prevention of suicide through early detection. Furthermore, future research should develop an assessment pathway or intervention program based on the factors stated in the current predictive model. Moreover, it is necessary to conduct a longitudinal study that includes various factors such as culture, resilience, social safety and reasons for living as they can contribute to suicidal ideation in older adults living in rural areas. Particularly, these studies should evaluate the usefulness of the proposed model by applying it to multiple practical fields in the community.

## 6.1 | Limitations

This study had several limitations. First, it has limited generalizability based on the relatively small sample size of healthy older adults living in rural areas. However, using tree-based machine learning methods, the random forest served as both a non-parametric classification and regression method which can overcome the validity of statistical issues, especially overfitting issues emerging from hierarchical or simultaneous regression (Breiman, 2001; Strobl et al., 2009). Second, this study did not include habits such as the consumption of alcohol or smoking. Thus, their impact on the study results was not discussed. Third, perceived burdensomeness comprised one of the

dimensions of suicidal ideation based on the Interpersonal Theory of Suicide (Van Orden et al., 2010). However, the feeling of a participant as a burden to significant others (self-burden) showed relatively low IncNodePurity. Furthermore, a study presented the low importance of perceived burdensomeness in predicting suicide (Forkmann et al., 2020). In addition, the significance of this feeling to suicidal ideation is associated with the interaction with thwarted belongingness rather than a significant predictor alone (Chu et al., 2017). Therefore, further research is required to evaluate the importance of burdensome as a risk factor and validate the results of this study with a dataset that is more representative. Fourth, the data included many binominal measurements through self-reporting likely contributing to the bias in the results. Fifth, the study used a cross-sectional design which is limited in terms of explaining the causal relationship among variables. Thus, further studies are needed to validate the predictive model using longitudinal observation.

## 7 | CONCLUSION

Early detection of suicidal ideation is crucial in the prevention of suicide and could serve as the best strategy to initiate intervention in risk groups of older adults living in rural areas. Furthermore, it is highly feasible to screen for depressive symptoms and collect information regarding pain levels, loneliness and the feeling of being a burden to significant others from community healthcare settings. Therefore, the current predictive model utilizing this information, which is generated by machine learning methods to ascertain suicidal ideation, may be useful in preventing suicide in older adults in community care settings. Consequently, further research ought to be conducted to validate the identified factors from this study that can predict suicidal risk groups in diverse care settings.

## AUTHOR CONTRIBUTIONS

Junglyun Kim and Moonhee Gang developed idea and concepts for the study, analysed and interpreted data and wrote a draft. DongHyeon Gwak and Seonhee Kim participated in investigation, data curation, analysing data and writing—reviewing & editing. All authors have agreed on the final version and meet at least one of the following criteria: (1) substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content.

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## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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## DATA AVAILABILITY STATEMENT

Research data are not shared.

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# Psychosocial factors associated with career success among nurses: A latent profile analysis

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## Abstract

**Aim:** In this study, a person-centred approach was used to analyse career success profiles and explore the associated psychosocial factors among nurses.

**Design:** A cross-sectional study was conducted from 15 April to 15 October 2019.

**Methods:** A total of 1155 registered Chinese nurses were recruited from two general hospitals using convenience sampling. Participants completed a printed questionnaire, including the Maslach Burnout Inventory, Stress of Conscience Questionnaire, Practice Environment Scale, and Career Success Scale. Latent profile analysis and multinomial logistic regression were performed. The data were analysed with Mplus 8.3 and SPSS version 26.0.

**Results:** Three latent profiles of career success were identified: high, moderate and low. Nurses with lower educational levels, more years of work experience, lower emotional exhaustion, higher personal achievement, lower stress of conscience and higher participation in hospital affairs were more likely to have higher career success than the other profiles.

**Conclusions:** Burnout, stress of conscience, practice environment, educational level and years of work experience were associated with career success among nurses. Targeting interventions may help enhance nurses' career success. Future research should combine subjective and objective indicators (salary, title and so on) to assess career success and explore other determinants for formulating interventions to enhance nurses' career success.

**Impact:** The heterogeneity and psychosocial factors associated with nurses' career success provide valuable evidence for the formulation of individualized interventions. Nursing managers should understand the importance of career success, develop interventions to reduce nurses' burnout and stress of conscience, and improve the practice environment to enhance their career success.

**No Patient or Public Contributions:** This study was designed to examine the psychosocial factors associated with nurses' career success. The study was not conducted using suggestions from the patient groups or the public.

## KEYWORDS

achievement, burnout, environment, nurses, stress



## 1 | INTRODUCTION

The nursing shortage is a global problem, particularly in China. At the end of 2019, mainland China had a total population of approximately 1.40 billion, but only 4.43 million were registered nurses (National Bureau of Statistics of China, 2020). As a result, the number of nurses per 1000 people was only 3.16, much lower than that in developed countries, such as the US and Canada (9 nurses or more per 1000 people; Liu et al., 2012). Moreover, turnover intention is prevalent, and the turnover rate among nurses is high (Li et al., 2020). According to previous surveys, 9.82% of nurses reported a strong intention to leave their jobs, and the turnover rate was 49.7% (Cao et al., 2021; Park & Ko, 2020). In recent years, despite significant advances in nursing science, the nursing workforce has remained unstable (Liu et al., 2018). Nurses' career success is accompanied by strong work motivation, secured well-being and low turnover intention (Liu & Liu, 2016; Liu et al., 2015; Spurk, Hirschi, et al., 2019). However, research on nurses' career success remains in its infancy (Xu et al., 2022). Therefore, promoting nurses' career success, increasing their sense of achievement and reducing their turnover rate are crucial to solve nursing shortage problems.

## 2 | BACKGROUND

Career success refers to positive work-related or psychological outcomes or achievements arising from accumulated work experiences (Li et al., 2014). Career satisfaction and perceived marketability in internal and external marketplaces have been used to describe career success (Zamanzadeh et al., 2019). Career satisfaction refers to a psychological form of success in which one is satisfied with their work objectives and accomplishments. Perceived marketability refers to the belief that one is valuable to one's current employer. High career success among nurses benefits nursing staff stability. Career success undoubtedly contributes to individuals and organizations (Drewery et al., 2020). Although studies have explored the factors related to employees' career success in the field of enterprise (Haenggli & Hirschi, 2020), only a few have examined nurses' career success (Sonmez et al., 2021). Therefore, this matter must be further investigated.

Chinese nurses have reported moderate levels of career success (Wang et al., 2019; Xue et al., 2022), which measured career success with total scores or average scores on the Career Success Scale (CSS). However, the above studies did not exhibit cut-off scores for differentiating various levels of career success. Furthermore, one of the few studies adopted a variable-centred approach focusing on the relationships between individual variables (e.g. career success and related factors; Wu et al., 2022). This approach is limited to reflecting various aspects of career success and restricts appropriate interventions. Moreover, the traditional approach assumes that all individuals react to events homogeneously. However, hypothesizing that individuals from heterogeneous subgroups react differently to events is reasonable (Watanabe & Yamauchi, 2019). Therefore, it is essential to analyse intergroup differences in career success. Person-centred approaches

enable us to understand how variables work between and within people and explore subgroups with heterogeneous characteristics, which can provide helpful insights into the development of targeted interventions. In latent profile analysis, researchers classify individuals on the basis of the measured career success and identify subgroups according to these characteristics (Vermunt & Magidson, 2002). Thus, the purpose of present study was to identify career success profiles in nurses using latent profile analysis and to explore the psychosocial factors related to career success profiles.

The basic principle of the conservation of resources theory is that 'individuals strive to obtain, retain, foster, and protect those things they centrally value' (Hobfoll et al., 2018). Resources are defined as anything that helps individuals attain their goals (Chu et al., 2022). Given that career success is seen as a valuable state and resources exist in individual and environmental fields, the conservation of resources theory provides theoretical support for examining factors associated with career success (Spurk, Keller, et al., 2019). Moreover, Hirschi et al. (2022) proposed a career resource model showing that human capital (such as experiences), social (such as available environmental support) and psychological resources are vital for successful career management. On the basis of these two theories, we investigated the psychosocial factors related to nurses' career success.

### 2.1 | Burnout

Burnout is a psychological syndrome characterized by emotional exhaustion, depersonalization and reduced personal accomplishment that occur in situations with long-term emotional demands (Maslach & Leiter, 2017). Emotional exhaustion refers to physical and emotional fatigue caused by continuous interaction between employees and service users. Depersonalization refers to negative, callous or cynical attitudes and feelings resulting from difficulties encountered while serving clients. Lessened personal accomplishment entails negative self-perception, particularly because of services that involve clients (Ramirez-Baena et al., 2019). Thus, burnout, which reduces cognitive and emotional resources, may be regarded as a loss of psychological resources. Professional practice requires significant emotional engagement, and nurses are particularly vulnerable to burnout. However, no study has explored the relationship between burnout and career success among nurses. Burnout is positively related to nurses' turnover intention, and turnover intention is negatively related to career success (Barthauer et al., 2020; Talluri & Uppal, 2022). Moreover, job burnout negatively affects construction professionals' success (Cao et al., 2020). Similarly, burnout is negatively correlated with academic success among nursing students (Bulfone et al., 2022). Thus, we hypothesize that burnout is negatively associated with career success among nurses.

### 2.2 | Stress of conscience

Nurses consider conscience an important factor in the performance of their nursing duties, and they behave in accordance with their



conscience and moral values (Nilsson et al., 2022). However, nurses may be troubled by their conscience when they do not perform according to the expected standards in healthcare settings (e.g. they are unable to support high-quality care; Heikkilä et al., 2022). The stress of conscience refers to the pressure caused by the uneasiness felt when failing to comply with one's conscience (Nilsson et al., 2022). Healthcare personnel sometimes mention their consciousness when discussing ethically difficult situations. Thus, the stress of conscience can be viewed as an ethical issue and a loss of psychological resources. However, studies on the relationship between stress of conscience and career success among nurses remain scant. A previous study treated the stress of conscience as an ethically challenging situation and found it to be negatively associated with job satisfaction among nursing home staff (Vassbo et al., 2019), which is a subjective criterion for describing career success (Xu et al., 2022). Furthermore, stress of conscience is associated with negative outcomes among healthcare personnel (Lamiani et al., 2017; Van Diepen et al., 2022). Therefore, we hypothesize that stress of conscience is negatively associated with career success among nurses.

### 2.3 | Practice environment

The nursing practice environment is a complex construct comprising multiple organizational components that affect professional nursing practice, including nurse participation and valued status in hospital settings, nursing foundations for high-quality care, the role of nurse managers, adequate staff and support resources and working relationships between nurses and physicians (Al Sabei et al., 2020; Ogata et al., 2022). Therefore, the nursing practice environment can be perceived as a social resource. The practice environment has a positive impact on job satisfaction, which also affects turnover intention (Ambani et al., 2020; Wu et al., 2022; Zelenikova et al., 2020). Moreover, a favourable practice environment can improve the quality of patient care (Falguera et al., 2021). A meta-analysis revealed that a better practice environment is related to lower negative nurse outcomes (e.g. job dissatisfaction and intention to leave), fewer negative patient outcomes (e.g. 30-day inpatient mortality and adverse patient events), better quality of care and safety and higher patient satisfaction (Lake et al., 2019). In addition, the practice environment was positively correlated with career success in nurses with master's or doctoral degrees (Wang et al., 2019). Similarly, a study among Turkish nurses revealed that practice environment dimensions—participation in hospital affairs, staffing and resource adequacy, and collegial nurse–physician relations—positively affected nurses' career success (Sonmez et al., 2021). Hence, we hypothesize that the practice environment is positively correlated with nurses' career success.

### 2.4 | Sociodemographic characteristics

Drawing on the human capital theory, professional experience (e.g. years of work experience) can be regarded as human capital.

Professional experiences may affect nurses' career success, given that nursing is a practical occupation. For example, more years of work experience can lead to enhanced nursing skills (Joho et al., 2020). Therefore, the researchers expected that years of work experience would be related to nurses' career success. Data on other sociodemographic factors (i.e. age, sex and education) were also collected on the basis of previous studies (Wang et al., 2019; Wu et al., 2022).

## 3 | THE STUDY

### 3.1 | Aims

The purpose of this study was to use a person-centred approach to identify career success subgroups among nurses and examine the associated psychosocial factors, including burnout, stress of conscience and practice environment.

### 3.2 | Design

A descriptive cross-sectional design was adopted.

### 3.3 | Participants

Researchers recruited 1155 registered nurses from two tertiary general hospitals in Shandong Province, China. The inclusion criteria were as follows: (1) registered nurses, (2) officially employed by the hospital and (3) consent to participate. Participants who had 1 day off were excluded. The participants were surveyed using self-report questionnaires.

### 3.4 | Sample size

The sample size was based on a large project. Based on the rule of latent profile analysis, a sample size of 500 was suitable for determining the number of profiles. Moreover, larger sample sizes may result in stronger statistical power for detecting the 'true' number of latent classes (Bagby et al., 2021; Nylund et al., 2007). Therefore, the sample size of 1155 in this study met this requirement.

### 3.5 | Data collection

Nurses were recruited from two general hospitals using convenience sampling between 15 April and 15 October 2019. After securing the head nurses' approval of the sample departments, the research objectives and significance were explained to the nurses by researchers, and informed consent was obtained. The paper-based questionnaires were administered face-to-face in a meeting room. Of the 1272 questionnaires, 1155 were valid, with a response rate

of 90.80% (Figure 1). Data input was performed separately by two researchers using the EpiData software.

### 3.6 | Instruments

#### 3.6.1 | Sociodemographic characteristics

Sociodemographic data included age, gender, education and years of work experience.

#### 3.6.2 | Job burnout

The Maslach Burnout Inventory (MBI) developed by Maslach and Jackson (1981) was used to measure nurses' burnout. The scale consists of emotional exhaustion, depersonalization and personal accomplishment subscales. Participants responded to 22 items on a 7-point Likert scale ranging from 0 (never) to 6 (every day). The subscale scores ranged from 0 to 54 (emotional exhaustion), 0 to 30 (depersonalisation) and 0 to 48 (personal accomplishment). For emotional exhaustion and depersonalization, higher scores indicated a higher level of burnout, whereas, for personal accomplishment, higher scores indicated more favourable outcomes. The MBI has good reliability and validity in the Chinese population (Li & Liu, 2000; Zhang et al., 2014). In the present study, Cronbach's alphas for the three subscales were .885, .757 and .866, respectively.

#### 3.6.3 | Stress of conscience

The Stress of Conscience Questionnaire (SCQ), comprising nine items, was used to assess nurses' stress and how troubled they were by their conscience (Glasberg et al., 2006). Each item of the scale comprised Questions A and B. Question A determines how often a selected stressful situation occurs (or happened in the past), whereas Question B establishes how troubled one feels/felt based on the situation

described in answer to Question A. Question A was rated on a 6-point Likert scale ranging from 0 (never) to 5 (every day). Question B: 'Does this give you troubled conscience?' is rated on a 6-point Likert scale ranging from 0 (no, not at all) to 5 (yes, it gives me a very troubled conscience). The total 'stress of conscience' score for an item was determined by multiplying the scores of Questions A and B. A higher score indicates serious stress of conscience. The SCQ has good reliability and validity among registered nurses in China (Huang et al., 2019). In the current study, Cronbach's alpha for the scale was .921.

#### 3.6.4 | Practice environment

The Practice Environment Scale was used to measure the hospital nursing practice environment (Lake, 2002). The Chinese version of the scale comprises 28 items, with three items deleted from the original version (Wang & Li, 2011). The five subscales are nurse participation in hospital affairs, nursing foundations for quality of care, nurse manager ability, leadership and support of nurses, staffing and resource adequacy, and collegial nurse-physician relations. The participants responded on a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). A higher score indicated a better practice environment. In the present study, Cronbach's alpha for the entire scale was .967, and the Cronbach's alphas for the five subscales were .888, .920, .790, .846 and .839, respectively.

#### 3.6.5 | Career success

The CSS of 11 items, developed by Eby et al. (2003), was used to measure career success. It measures three criteria for career success: perceived career satisfaction, internal marketability and external marketability. The ratings ranged from 1 (strongly disagree) to 5 (strongly agree) on a 5-point Likert scale. A higher score indicates greater career success. The Chinese version of the CSS has good reliability and validity among medical staff (Li et al., 2013). In this study, Cronbach's alpha for the scale was .936.

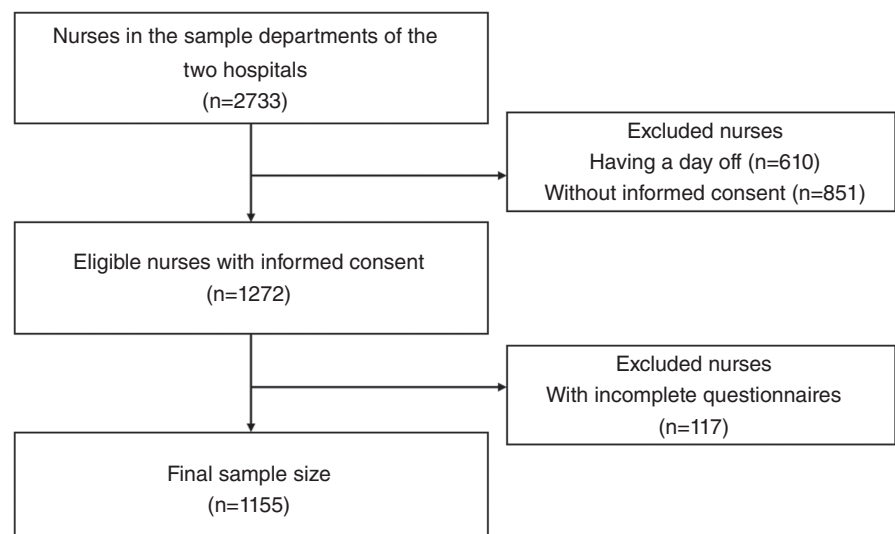


FIGURE 1 Flow chart showing nurses screening and recruitment process

### 3.7 | Ethical considerations

This study was approved by the Institutional Review Board, where the first author is affiliated (no. 2018-R-026, date: 30 November 2018), and all participants were informed about the purpose of the study and signed a written informed consent form prior to the survey. Furthermore, the anonymity of the participants was maintained by assigning code numbers to each survey questionnaire, and confidentiality of the information was assured. All data were stored on the computer of the research team, and only the research team had access to the data.

### 3.8 | Data analyses

Descriptive statistics were used for all the variables. Latent profile analysis was conducted to identify subgroups of career success on the basis of the responses to each item of CSS. First, model fit indices referring to Akaike's information criterion (AIC) and Bayesian information criterion (BIC) were used to determine the best option or number of clusters (profiles). The lower these values, the better the model fit. Entropy refers to individual classification accuracy (values close to 1 are preferred). The bootstrapped parametric likelihood ratio test (BLRT) was used to compare the  $k$  class model with the  $k - 1$  class model, and significant  $p$ -values suggest that the  $k$  class model has a better fit. Second, the researchers classified nurses according to the number of profiles determined in the previous step based on the mean scores for each item of career success. Third, multinomial logistic regression was employed with career success subgroups as dependent variables; sociodemographic characteristics, job burnout, stress of conscience and practice environment were used as independent variables to enter the regression. Researchers performed regressions twice, each with low and moderate career success as the reference groups, and the 95% confidence interval (95% CI) did not contain 1, suggesting that the difference was statistically significant. Data were analysed using SPSS (version 26.0) and Mplus (version 8.3).

### 3.9 | Validity and reliability

The psychometric properties of the measurement instruments have been described above.

## 4 | RESULTS

### 4.1 | Participant characteristics

As shown in Table 1, most of the participants (97.1%) were female nurses. Nearly half (43.5%) of the patients were younger than 30 years of age. The majority (88.2%) had a bachelor's degree, and 20.7% had been working as nurses for 11–15 years.

### 4.2 | Latent profiles of career success

The number of subgroups was determined based on the model fit indices (Figure 2). As the number of profiles increased from two to five, the AIC and BIC values gradually decreased. When the number of profiles in the fitting model reached five, the  $p$ -value of BLRT was not significant. These results indicate that five or more potential classes cannot produce representative classes. Compared with the other models, the three-class model had the highest entropy and relatively low BIC and AIC scores. Taking interpretability and parsimony into consideration, researchers judged that the three-class model fit the current study most effectively. The model-fitting indices are listed in Table 2.

The first profile, containing 14.2% of the nurses, scored the highest in all items of career success and was labelled the 'high career success' subgroup. The second profile included 66.0% of the nurses who scored in the middle for each item and were labelled as the 'moderate career success' subgroup. The third profile, involving 19.8% of the nurses, had the lowest score for all items and was labelled the 'low career success' subgroup.

### 4.3 | Psychosocial factors associated with nurses' career success

Multinomial logistic regression analysis was used to examine psychosocial factors associated with nurses' career success. The results are shown in Table 3. First, nurses who had lower educational levels (a. OR = 0.147, 95% CI: 0.035–0.614; b. OR = 0.110, 95% CI: 0.022–0.550), more years of work experience (mainly between 11 and 15 years, OR = 3.756, 95% CI: 1.315–10.732), lower emotional exhaustion (OR = 0.952, 95% CI: 0.920–0.986), higher personal accomplishment (OR = 1.073, 95% CI: 1.044–1.103), lower stress of conscience (OR = 0.974, 95% CI: 0.964–0.985) and higher participation in hospital affairs (OR = 1.392, 95% CI: 1.239–1.563) were more likely to appear in the 'high career success' subgroup than in the 'low career success' subgroup. Second, nurses who had lower educational levels (a. OR = 0.150, 95% CI: 0.052–0.436; b. OR = 0.120, 95% CI: 0.035–0.405), lower stress of conscience (OR = 0.977, 95% CI: 0.968–0.987) and higher participation in hospital affairs (OR = 1.174, 95% CI: 1.063–1.297) were more likely to belong to the 'high career success' subgroup than the 'moderate career success' subgroup. Third, those with lower emotional exhaustion (OR = 0.964, 95% CI: 0.942–0.985), higher personal accomplishment (OR = 1.059, 95% CI: 1.039–1.079) and higher participation in hospital affairs (OR = 1.185, 95% CI: 1.105–1.271) were more likely to be in the 'moderate career success' subgroup than the 'low career success' subgroup.

## 5 | DISCUSSION

Career success plays an important role in maintaining the stability of hospital human resources and improving the quality of patient care.

TABLE 1 Participant characteristics

Variables	Total (N = 1155, 100%)	Low CS (N = 229, 19.8%)	Moderate CS (N = 762, 66%)	High CS (N = 164, 14.2%)
<b>Gender</b>				
Male	34 (2.9%)	5 (2.2%)	27 (3.5%)	2 (1.2%)
Female	1121 (97.1%)	224 (97.8%)	735 (96.5%)	162 (98.8%)
<b>Age</b>				
20–29	503 (43.5%)	115 (50.2%)	337 (44.2%)	51 (31.1%)
30–39	560 (48.5%)	104 (45.4%)	360 (47.2%)	96 (58.5%)
≥40	92 (8%)	10 (4.4%)	65 (8.5%)	17 (10.4%)
<b>Education</b>				
Below bachelor's degree	25 (2.2%)	5 (2.2%)	11 (1.4%)	9 (5.5%)
Bachelor's degree	1019 (88.2%)	202 (88.2%)	677 (88.9%)	140 (85.4%)
Above bachelor's degree	111 (9.6%)	22 (9.6%)	74 (9.7%)	15 (9.1%)
<b>Years of work experience</b>				
≤5	259 (22.4%)	57 (24.9%)	180 (23.6%)	22 (13.4%)
6–10	448 (38.8%)	111 (48.5%)	284 (37.3%)	53 (32.3%)
11–15	239 (20.7%)	33 (14.4%)	160 (21%)	46 (28%)
≥16	209 (18.1%)	28 (12.2%)	138 (18.1%)	43 (26.2%)
<b>Burnout, M (SD)</b>				
Emotional exhaustion	16.77 (9.54)	22.08 (9.66)	16.38 (8.83)	11.17 (8.85)
Depersonalization	4.62 (4.43)	6.42 (4.73)	4.54 (4.28)	2.47 (3.58)
Personal accomplishment	35.57 (9.52)	30.19 (9.57)	36.31 (8.69)	39.67 (10.00)
Stress of conscience M (SD)	31.16 (31.56)	42.15 (33.37)	31.62 (31.45)	13.70 (19.05)
<b>Practice environment, M (SD)</b>				
Nurse participation in hospital affairs	24.50 (3.88)	22.06 (3.82)	24.57 (3.37)	27.60 (3.88)
Nursing foundations for quality of care	29.63 (3.77)	27.78 (3.34)	29.58 (3.52)	32.40 (3.84)
Nurse manager ability, leadership, and support of nurses	13.21 (1.78)	12.29 (1.71)	13.24 (1.67)	14.33 (1.70)
Staffing and resource adequacy	12.38 (2.25)	11.15 (2.27)	12.43 (2.04)	13.90 (2.16)
Collegial nurse-physician relations	9.87 (1.42)	9.21 (1.37)	9.88 (1.31)	10.75 (1.47)

Abbreviations: CS, career success; M, mean; SD, standard deviation.

The current study provides additional evidence about nurses' career success, identifying three subgroups—high, moderate and low—using a person-centred approach. In the current study, most nurses (66%) had a moderate level of career success, which is consistent with a previous study of nurses (Dan et al., 2018). This suggests that nurses' career success should be further improved and that nursing managers should pay more attention to and take reliable steps to enhance their career success. One-fifth of the nurses were in the low-career success subgroup. Managers should attach particular importance to these nurses and encourage them to utilize resources and opportunities to increase their career success (Sonmez et al., 2021).

In terms of sociodemographic characteristics, lower educational levels were associated with higher career success among nurses in this study, which is similar to the findings of a previous study (Osuji et al., 2014). Nurses with higher educational levels usually have a higher standard of requesting themselves, and they may

perceive lower career success relative to their expectations (Zuo & Wang, 2020). Consequently, they reported lower career success. Moreover, years of work experience was associated with career success. Nurses' career success varies with their years of work experience; the longer they work, the higher their career success. This may partly be because nurses feel more confident and fulfilled in their current jobs when they have more years of work experience. Therefore, nursing managers should attach greater importance to helping nurses with less work experience and provide platforms or opportunities to enhance their skills to achieve greater career success (Xin et al., 2020).

Our findings underscore that burnout (emotional exhaustion and personal accomplishment but not depersonalization) is related to nurses' career success. Higher career success was accompanied by lower emotional exhaustion and higher personal accomplishment. Nurses continually confront the needs, problems and suffering of

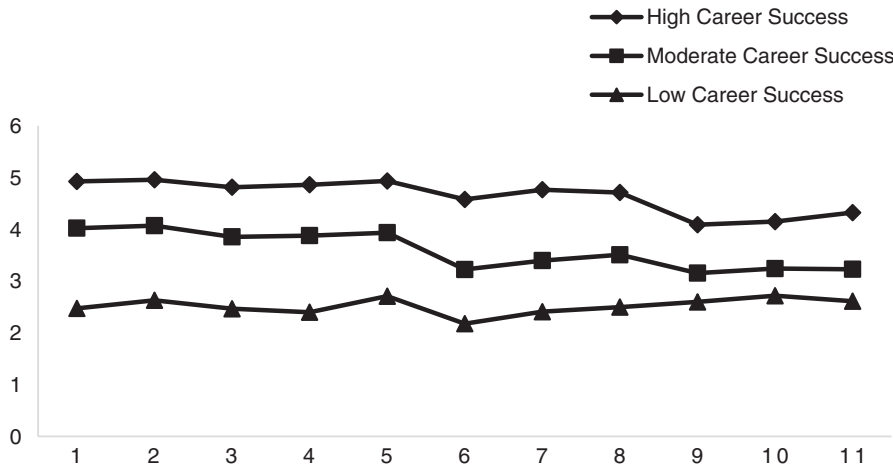


FIGURE 2 Estimated means of the 11 items of career success in each of the three profiles identified through latent profile analysis

TABLE 2 Indices of goodness of fit of latent profile models with increasing number of profiles

Number of profiles	AIC	BIC	Entropy	<i>p</i> BLRT
2	29,680.263	29,852.026	0.948	<.01
3	27,188.409	27,420.794	0.959	<.01
4	26,094.549	26,387.557	0.955	<.05
5	25,261.246	25,614.876	0.966	>.05

Abbreviations: AIC, Akaike's information criterion; BIC, Bayesian information criterion; *p* BLRT, *p*-value from bootstrapped parametric likelihood ratio test.

patients and their family members, even in the terminal stages of illness and death, which is emotionally taxing (Van der Heijden et al., 2019). When nurses experience emotional exhaustion (i.e. their emotional pay and return are not proportional), they become dissatisfied due to energy depletion and a decrease in their ability to perform their duties. This finding is in line with a previous study showing that emotional exhaustion is negatively associated with job satisfaction among nursing staff (Khamisa et al., 2016). Moreover, nurses who have experienced more personal accomplishments have greater career success. This result is consistent with previous studies in which personal accomplishment was positively correlated with nurses' job satisfaction (Akman et al., 2016). This may be because personal accomplishment indicates the attainment of work goals and affirmation of self-ability, thereby positively influencing job satisfaction and employability. This study extends job satisfaction to career success. Furthermore, emotional exhaustion and personal accomplishment were associated with a combination of satisfaction and perceived marketability. Therefore, hospital managers should implement interventions that focus on decreasing burnout to improve nurses' career success.

This study found that lower stress of conscience was more common among nurses with higher career success. Out of the nine items describing the stress of conscience, four scored relatively high. Item 1: 'How often do you lack the time to provide the care the patient needs?' received the highest score, similar to that in previous studies

(Juthberg et al., 2010). Items 3, 7 and 8: 'Do you ever have to deal with incompatible demands in your work?' 'Is your work in health care so demanding that you do not have the energy to devote as much time to your family as you would like?' and 'Do you ever feel that you cannot live up to others' expectations of your work?' had the highest scores. When nurses are unable to work according to their own conscience and beliefs, the stress caused by discomfort with their conscience is obvious (Johansson et al., 2022). The results indicated that nurses experience stress of conscience at work and in daily life, which is consistent with a previous study (Heikkilä et al., 2022). Internal stress among nurses can lead to poor career success. Moreover, most nurses in the current study experienced varying degrees of stress. Therefore, attention should be paid to constantly high levels of stress of conscience, which may cause a series of adverse consequences for nurses. Interventions focused on monitoring and managing stress of conscience may be beneficial to nurses' career success.

Our findings show that a good practice environment (nurse participation in hospital affairs) is conducive to the development of high career success for nurses. Moreover, the environment is positively correlated with career success among nurses with a master's or doctoral degree in China, which is in line with our study (Wang et al., 2019). Nurses can participate in the decision-making process and management of the hospital, which means that they receive attention and value from hospital administrators and are indispensable parts of hospital development, which enhances their sense of responsibility, belonging and accomplishment. This may explain why participation in hospital affairs is beneficial to nurses' career success. Hence, nurses' practice environments must be continuously improved in terms of not only hard power (i.e. equipment resources) in hospitals but also soft power (i.e. human management and culture).

## 5.1 | Limitations

Our study had the following limitations. First, as a cross-sectional study, it did not determine causality among the study variables.





Further longitudinal studies are needed to explore the causal relationships among burnout, stress of conscience, practice environment and career success. Second, researchers only used self-reported questionnaires to measure nurses' career success and lacked objective indicators, such as salary and promotion times. Self-reported data may lead to reporting bias. Therefore, future studies should combine subjective and objective indicators to explore factors that influence nurses' career success. Third, the researchers recruited nurses from two Chinese general hospitals using convenience sampling. Therefore, the generalizability of our findings is limited to a certain region. Fourth, many factors can influence nurses' career success. Therefore, future studies must investigate other factors that affect nurses' career success.

## 6 | CONCLUSIONS

This study used a person-centred approach to classify nurses' career success into three subgroups: high, moderate and low. This indicates that nurses in subgroups with low career success should attach importance to and offer further assistance. This study also provides new evidence for the relationships among burnout, stress of conscience, practice environment and career success in nurses. Managers are reminded to develop measures aimed at reducing burnout and conscience stress, as well as improving nursing practice environments to improve nurses' career success. Future research is warranted to assess nurses' career success using subjective and objective criteria (salary, title and so on) and to explore other determinants for formulating comprehensive intervention programmes to enhance nurses' career success.

### AUTHOR CONTRIBUTIONS

Yilin Zhang analysed data and drafted the manuscript. Yan An and Lyu Wang designed the study and performed the data collection. Qiuge Zhao participated in the analysis and interpretation of the data. Xiuzhen Fan and Haiying Li made substantive intellectual contributions to the conception of the work and the interpretation of the data and revised the manuscript. All authors have read and approved the final manuscript.

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### CONFLICT OF INTEREST

The authors declare that they no conflict of interest.

### PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15524>.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request and ethical approval. The data are not publicly available due to ethical restrictions.

### ETHICS STATEMENT

Approval for this study was obtained from the ethics committee of nursing and rehabilitation college of Shandong University (No. 2018-R-026).

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# Abusive supervision and employee well-being of nursing staff: Mediating role of occupational stress

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## Abstract

**Aim:** The study examined whether occupational stress mediated the relationship between abusive supervision and well-being of nursing staff.

**Design:** A cross-sectional questionnaire survey was administered.

**Methods:** Data were collected at three-time points between July 2020 and January 2021. A total of 313 valid responses were obtained from nurses working in a general hospital in Taiwan. The data were analysed using descriptive statistics, Pearson's correlation analysis and the bootstrap method.

**Results:** Abusive supervision was positively associated with occupational stress ( $\beta = 0.288$ , SE = 0.069, 95% CI [0.152, 0.423]) and negatively associated with employee well-being, including psychological ( $\beta = -0.350$ , SE = 0.084, 95% CI [-0.515, -0.186]), physical ( $\beta = -0.301$ , SE = 0.080, 95% CI [-0.459, -0.143]) and social well-being ( $\beta = -0.422$ , SE = 0.121, 95% CI [-0.661, -0.183]). Occupational stress was negatively related to employee well-being. A mediation analysis with bootstrapping revealed that occupational stress mediated the relationship between abusive supervision and employee well-being, which included psychological (95% bootstrap CI [-0.183, -0.046]), physical (95% bootstrap CI [-0.212, -0.062]) and social well-being (95% bootstrap CI [-0.178, -0.040]).

**Conclusion:** Abusive supervision influences employee well-being. Occupational stress mediates the relationship between abusive supervision and employee well-being. To improve employee well-being, hospital administrators should develop policies for effectively managing nursing supervisors' abusive behaviour and subordinates' stress management.

**Impact:** Abusive supervision increased the occupational stress of employees and influenced their well-being. Thus, educational courses should be implemented to train supervisors to practice positive leadership and treat employees fairly. Promoting stress management among nursing staff may lead to the prompt reporting of abusive events and improved employee well-being.

**No Patient or Public Contribution:** This study investigated the relationship between the abusive supervision and employee well-being of nursing employees. No patient or public contribution is involved in this study.

## KEYWORDS

abusive supervision, employee well-being, nurse occupational stress



## 1 | INTRODUCTION

Compared with people in other occupations, workers in the health care industry are more likely to experience high levels of stress (Puteri & Syaebani, 2018). Because they are required to cope with ill people, overtime work and leader/coworker relationships, health care workers often feel exhausted and overloaded with work, which may prompt them to consider quitting their jobs. Employee well-being can generally be divided into psychological, physical and social well-being (Grant et al., 2007). Research has indicated that poor employee well-being increases employees' intentions to leave their jobs (Holland et al., 2019; Singh et al., 2016).

Leaders can play a key role in shaping the work environment, and their behaviour is often associated with their subordinates' well-being (Arnold, 2017). Studies have suggested that effective nursing leadership can have a positive effect on work environments and patient safety, which can further influence the recruitment and retention of nursing staff (Aiken et al., 2002; Cummings et al., 2010; Hendricks et al., 2015; Marufu et al., 2021; Wong et al., 2013). Positive leadership such as transformational, authentic and ethical leadership have drawn substantial attention. Scholars are increasingly recognizing the influential role of negative leadership behaviours on employees (Harris & Jones, 2018; Hu et al., 2011; Kilic & Günsel, 2019), such as abusive supervision; however, few studies have explored the process by which leaders' actions influence their well-being (Inceoglu et al., 2018). Social cognition (e.g. follower self-efficacy and empowerment) and trust are the most common mediators, and affective pathways have not been adequately studied (Inceoglu et al., 2018). More theoretical development and empirical research are required to understand the causal mechanism of these processes (Inceoglu et al., 2018; Kaluza et al., 2019).

Abusive supervision is a type of harmful leadership that is characterized by the presence of egotistic, incompetent and ignorant leaders (Burns Jr, 2017). Abusive supervision refers to "subordinates' perceptions of the extent to which supervisors engage in the sustained display of hostile verbal and nonverbal behaviors, excluding physical contact" (Tepper, 2000, p. 178). Abusive leaders also create working environments that may not be conducive for new nurses to work in (Lavoie-Tremblay et al., 2016). Mackey et al. (2017) surveyed different occupations and industries and reported that supervisory abuse and general mistreatment are more likely to be reported in the health care industry than in other industries. Because nurses account for approximately half of the health care workforce worldwide (World Health Organization, 2020), our study focused on the well-being of nurses.

## 2 | BACKGROUND

### 2.1 | Abusive supervision and employee well-being

Abusive supervision refers to "subordinates' perceptions of the extent to which supervisors engage in the sustained display of hostile verbal and nonverbal behaviors, excluding physical

contact" (Tepper, 2000, p. 178); Rice et al. (2020) also asserted that abusive supervision is "a salient form of severe mistreatment and is status-degrading" and is characterized by reckless, cruel or malicious behaviours (Tepper, 2000). Nursing studies on abusive supervision have focused on verbal abuse (Michelle Rowe & Sherlock, 2005; Sofield & Salmond, 2003), which may include coworker abuse.

Supervisory abuse is viewed as a problem in health care organizations that are particularly vulnerable to the existence of abusive behaviour (Tepper, 2007). In nursing, abusive supervision reduces job performance (Estes, 2013), organizational citizenship behaviour (Chu, 2014), and moral courage (Afsar et al., 2019) and increases intention to leave (Lyu et al., 2019; Özkan, 2021; Rodwell et al., 2014), counterproductive work behaviour (Chu, 2014; Low et al., 2021), and workplace violence (Zhang et al., 2021). Given that studies have highlighted the negative effects of abusive supervision on job performance, work attitudes and behaviours in the nursing workplace, the present study focuses on how abusive supervision affects the employee well-being of nursing staff.

Justice theory provides insight into why abusive supervision negatively influences workers' attitudes and well-being. For example, abusive leaders cause employees to perceive organizational injustice, which has a negative effect on such employees' psychological well-being (Tepper, 2000). In summary, when employees are subjected to abusive supervision, they perceive unfairness and injustice, which further affect their well-being.

Relative to the definition of abusive supervision, the definition of well-being is broader and more multifaceted in scope, and studies have proposed various definitions for well-being (Grant et al., 2007; Page & Vella-Brodrick, 2009; Warr, 2012). Studies investigating employee well-being have used multidimensional measures, especially psychological and physical parameters (Inceoglu et al., 2018).

We applied the definition proposed by Grant et al. (2007) and used multidimensional measures to investigate employee well-being, which comprises psychological, physical and social well-being. Psychological well-being refers to positive mental states such as happiness or satisfaction (Robertson & Cooper, 2011), and it comprises hedonic and eudaimonic components (Ryan & Deci, 2001). Physical well-being comprises objective physiological measures and subjective experiences of physical health, and it has been extensively studied in the social and natural sciences (Testa & Simonson, 1996). Social well-being refers to the quality of a person's relationships with other people and communities (Keyes, 1998).

### 2.2 | Occupational stress

Occupational stress is defined as "the harmful physical and emotional responses that occur when the demands of the job exceed the capabilities, needs or resources of the worker" (Mohajan, 2012, p. 17). The health care industry is a typical interdisciplinary sector. In the workplace, nurses often interact in multidisciplinary teams



and frequently encounter work conflicts and dilemmas pertaining to interdisciplinary collaboration. A nursing work environment is a high-pressure environment, and nursing is a highly stressful occupation (Gu et al., 2019).

According to conservation of resources (COR) theory, stress can be defined "as a reaction to the environment in which there is: (a) the threat of a net loss of resources; (b) the net loss of resources; and (c) a lack of resource gain following the investment of resources" (Hobfoll, 1989, p. 516). When people perceive that their resources are insufficient or depleted, they experience increased stress and mental strain (Halbesleben & Buckley, 2004; Hobfoll, 2001). Resources can be defined as the elements that people value or the elements that enable people to obtain what they value (Hobfoll, 1988); in this context, the emphasis is on objects, states, conditions, personal characteristics and various forms of energy (Hobfoll, 1989). An individual's social support is a condition-related resource (Halbesleben et al., 2014) that may be provided by their family members, friends, colleagues or supervisors. From the perspective of COR, supervisor leadership is a condition-related resource. Supervisors may exhibit hostile verbal and nonverbal behaviours toward their subordinates during supervisor-subordinate interactions. The internal resources of subordinates who are affected by abusive supervision may be insufficient or depleted, which causes occupational stress.

Occupational stress negatively influences not only the health of nurses but also their ability to cope with job demands (Sharma et al., 2014). Empirical research has confirmed that stress leads to the development of negative employee attitudes, including those related to job satisfaction (Chou et al., 2014), job involvement (Thakre & Jadhav, 2022), turnover intentions (Mosadeghrad, 2013; Yousof et al., 2019), and employee well-being (Bostock et al., 2019; Griffin & Clarke, 2011). Although numerous studies have explored the relationship between occupational stress and employee well-being in various occupations, few studies have examined this problem in the nursing context (Gu et al., 2019).

### 2.3 | Mediating effect of occupational stress

Whether abusive supervision influences employee well-being through occupational stress is a question that should be addressed. COR theory covers two basic principles pertaining to the prevention of resource loss: First, for an individual, the risk of losing resources outweighs the benefits of gaining resources. Second, people tend to invest in resources to prevent resource loss, recover from loss and acquire resources (Hobfoll, 2001). On the basis of these principles, people with more resources are less likely to incur resource loss and more capable of coordinating resources to acquire more resources. By contrast, people with fewer resources are more vulnerable to the loss of resources, and they are less capable of coordinating resources to acquire more resources (Hobfoll & Lilly, 1993). The lack of adequate resources

and the presence of stress or strain can have a negative impact on the daily lives and well-being of people.

In the present study, abusive supervision was treated as a key precursor. When employees experience abusive supervision, their internal resources are depleted, their level of stress is increased, and they have poor well-being. Thus, applying COR theory, we inferred that employees' stress can mediate the relationship between abusive supervision and employee well-being.

## 2.4 | Hypotheses and hypothesized model

On the basis of the literature review, this study tested four hypotheses in the context of nursing staff, which are as follows: (a) abusive supervision would be negatively related to employee well-being, (b) abusive supervision would be positively associated with occupational stress, (c) occupational stress would be negatively related to employee well-being, and (d) stress would mediate the relationship between abusive supervision and employee well-being. The results of this study can (a) help organizations develop interventions that prevent the abusive behaviour of leaders and (b) augment the literature on abusive supervision and employee well-being within the context of nursing. Figure 1 presents the mediation model.

## 3 | THE STUDY

### 3.1 | Aims

On the basis of the preceding discussion, the present study examined the relationship between abusive supervision and employee well-being and the mediation effect of occupational stress on this relationship. A better theoretical understanding of these processes is expected to have practical implications related to leadership development and the promotion of employee well-being within the nursing context.

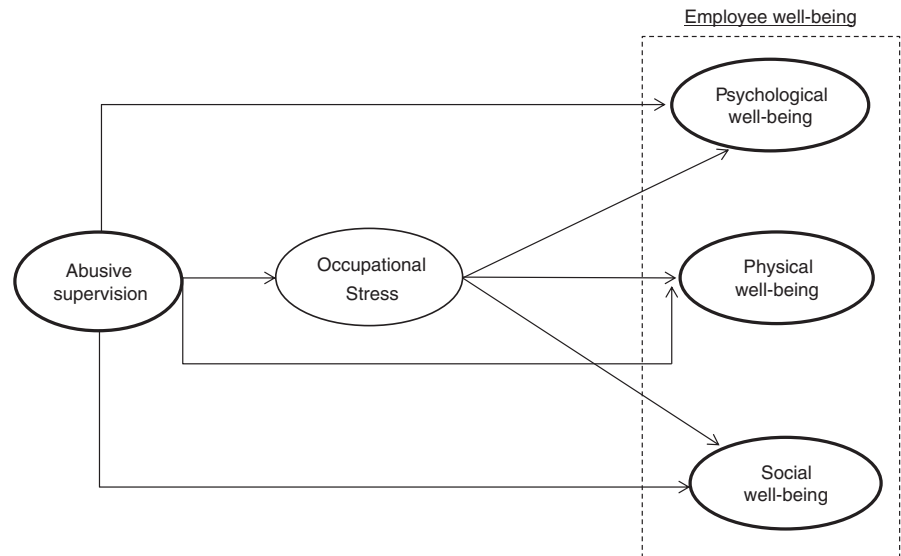
### 3.2 | Design

In this cross-sectional time-lag study, a survey questionnaire was administered to employees from a general hospital in Taiwan between July 2020 and January 2021. The questionnaire was translated using a forward-backward translation protocol involving the English and Chinese languages. The 'Enhancing the QUALity and Transparency of Health Research' (EQUATOR) guidelines were used to guide the study.

### 3.3 | Data collection

To minimize common method variance, the survey data were collected at three time points (time points 1, 2 and 3) that were separated

**FIGURE 1** Mediation model with components of stress as a mediator of the relationship between abusive supervision and employee well-being.



from each other by a 6-week interval (Podsakoff et al., 2003). The participants responded to the survey items that assessed their perceived abusive supervision (with respect to their supervisors), occupational stress and employee well-being at time points 1, 2 and 3, respectively. This process ensured that the independent (abusive supervision) and mediating (occupational stress) variables were temporally separated from the dependent variable (employee well-being).

### 3.4 | Participants

The study participants were registered nurses working in a general hospital in Taiwan. At the time of the study, the hospital employed a total of 1556 registered nurses who were deployed across 70 nursing units. The survey questionnaire was administered to nurses who were selected from the 70 nursing units of the aforementioned general hospital through quota sampling. The leadership styles of the heads of the 70 nursing units were assumed to be different, then a quota sampling method was adopted, and a target number of 354 questionnaires was set to ensure that the collected samples can be generalized to the overall population. We aimed to collect approximately four to six questionnaires from each nursing care unit.

A total of 354 questionnaires were sent to the nurses of the aforementioned units. Completed surveys were returned by 351 nurses at time point 1 (99.2% response rate), 350 time point 1 responders completed and returned the survey at time point 2 (99.2% response rate), and 343 time point 2 responders completed and returned the survey at time point 3 (98.0% response rate).

A returned questionnaire with one or more missing items was classified as a questionnaire with missing data and excluded from the final analysis. Among the 343 responses, 30 contained missing data. Therefore, the final sample comprised 313 valid responses. Full-time nurses with more than 3 months of experience working at one of the aforementioned nursing units were included in this study, whereas nursing student interns and newcomers (i.e. nurses with less than 3 months of experience working at these units) were excluded.

## 3.5 | Measures

### 3.5.1 | Abusive supervision

Abusive supervision was assessed using a 15-item scale developed by Tepper (2000). This scale was demonstrated to have favourable construct validity and reliability (Hu et al., 2011). An example of an item is "He or she blames me to save himself or herself from embarrassment." Each item was assessed using a 5-point scale from 1 (*I cannot remember him or her ever behaving in this manner toward me*) to 5 (*He or she behaves in this manner toward me very often*). In the present study, the Cronbach's  $\alpha$  for this scale was 0.862.

### 3.5.2 | Occupational stress

We used the 11-item scale developed by Revicki and Gershon (1996) to measure occupational stress. This scale was demonstrated to exhibit acceptable internal consistency reliability and construct validity (Revicki & Gershon, 1996). The participants' perceived job stress was assessed using a 4-point scale ranging from 1 (*never*) to 4 (*always*). An example of an item is "My interest in doing fun activities has decreased because of my work." In the present study, the Cronbach's  $\alpha$  for this scale was 0.894.

### 3.5.3 | Psychological well-being

We used the Warwick-Edinburgh Mental Well-being Scale to measure psychological well-being, and evidence indicated that the test-retest reliability and content validity of this scale were acceptable (Tennant et al., 2007). This scale comprised 14 questions that assessed how often participants have experienced the situation described by each item over the last 2 weeks using a 5-point scale ranging from 1 (*never*) to 5 (*all of the time*). An example of an item is

"I am feeling optimistic about the future." In the present study, the Cronbach's  $\alpha$  for this scale was 0.943.

### 3.5.4 | Physical well-being

Physical well-being was assessed using a 7-item subscale of the World Health Organization Quality of Life Scale Brief Version; this subscale exhibited acceptable test-retest reliability and discriminant validity (WHOQOL-BREF; Whoqol Group, 1998). The participants indicated how much the situation described by an item corresponded to their situation in the last 2 weeks using a 5-point scale ranging from 1 (*not at all*) to 5 (*very much so*). An example of an item is "How satisfied are you with your ability to perform your daily living activities?" In the present study, the Cronbach's  $\alpha$  for this subscale was 0.792.

### 3.5.5 | Social well-being

We used a subscale of the Ryff scale to measure the satisfaction of the participants and other relationships (Ryff & Keyes, 1995). This subscale was demonstrated to have favourable validity and test-retest reliability (Akin, 2008). The subscale comprises seven items that are rated on a 7-point scale with endpoints ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). An example of an item is "People describe me as a giving person who is willing to share my time with others." In the present study, the Cronbach's  $\alpha$  for this subscale was 0.813.

### 3.5.6 | Covariates

We controlled for several variables on the basis of their potential theoretical and empirical relations with our focal variables. Age was controlled because a study reported a U-shaped pattern for job satisfaction and an inverted U-shaped pattern for well-being (Birdi et al., 1995). Marital status was controlled because married people were previously reported to exhibit consistently higher levels of well-being than unmarried people (Soulsby & Bennett, 2015). Religion was controlled because a study discovered that individuals of various religious groups subscribe to a socially oriented cultural conception of subjective well-being and achieved it through various methods (Shiah et al., 2014). A study revealed a link between work schedule uncertainty and workers' well-being (including psychological distress, poor sleep quality and unhappiness). Thus, work schedule was set as a control variable in the present study (Schneider & Harknett, 2019).

## 3.6 | Ethical considerations

The present study was approved by the Institutional Review Board of E-Da Hospital, Taiwan (EMRP-109-057). Written informed consent, which comprised an information sheet and a consent certificate, was obtained from the participants prior to the commencement of the study.

## 3.7 | Data analysis

Descriptive statistics were used to analyse sample characteristics. Because our study data were normally distributed, Pearson's correlation coefficients were used to examine the correlations between variables. To test the research hypotheses, the bootstrap method (Shrout & Bolger, 2002) and Model 4 of Hayes (2017) PROCESS macro were used to examine the mediating role of occupational stress in the relationship between abusive supervision and employee well-being. SPSS WIN 24.0 (SPSS, Inc.) and the SPSS PROCESS macro—2.15 version ([www.afhayes.com](http://www.afhayes.com)) were used for our data analyses.

## 3.8 | Validity and reliability

After missing values were removed, the overall mean scores were used. The results of the correlational analysis are summarized in Table 2. All scales had good reliability (Cronbach's  $\alpha > 0.70$ ), and the correlations between scales were moderate. No strong collinearity was detected among the variables, and their discriminant validity was well established.

# 4 | RESULTS

## 4.1 | Descriptive analysis of samples

Table 1 presents the participants' demographic characteristics. Of the 313 participants, 97.44% were women, and their average age was 35.42 years. A slight majority of the participants were single (51.45%). Most participants were Taoist and had a junior college or university (94.25%) education. The participants' average total clinical experience was 13.11 years, and their average job tenure for their current job was 8.57 years. About 209 (66.99%) were shift workers.

The Pearson's correlation of the scales for the main variables of interest was determined. The mean scores for abusive supervision, occupational stress, psychological well-being, physical well-being and social well-being were  $1.35 \pm 0.39$ ,  $1.84 \pm 0.48$ ,  $3.63 \pm 0.56$ ,  $3.65 \pm 0.53$ , and  $5.11 \pm 0.68$ , respectively. Abusive supervision has shown a significant positive correlation with stress ( $r = 0.226$ ,  $p < .01$ ). Abusive supervision was negatively correlated with psychological ( $r = -0.232$ ,  $p < .01$ ), physical ( $r = -0.195$ ,  $p < .01$ ), and social well-being ( $r = -0.146$ ,  $p < .01$ ). Other correlation results are shown in Table 2.

## 4.2 | Hypothesis testing

Regression analyses were performed to investigate whether occupational stress mediated the effect of abusive supervision on employee well-being. This study revealed a significant relationship between abusive supervision with psychological ( $\beta = -0.350$ , standard error [SE] = 0.084, 95% CI [-0.515, -0.186]), physical ( $\beta = -0.301$ ,

SE = 0.080, 95% CI [-0.459, -0.143]) and social well-being ( $\beta = -0.422$ , SE = 0.121, 95% CI [-0.661, -0.183]). The results supported H1a, H1b and H1c. The results also indicated that abusive supervision was a significant predictor of occupational stress ( $\beta = 0.288$ , SE = 0.069, 95% CI [0.152, 0.423]). Thus, H2 was supported. Stress was revealed to be a significant predictor of psychological ( $\beta = -0.349$ , SE = 0.066, 95%

CI [-0.478, -0.219]), physical ( $\beta = -0.429$ , SE = 0.061, 95% CI [-0.549, -0.308]) and social well-being ( $\beta = -0.327$ , SE = 0.098, 95% CI [-0.519, -0.134]). These results supported H3a, H3b and H3c.

Multiple mediation analyses revealed that the relationship between abusive supervision and employee well-being (i.e. psychological, physical and social well-being) was partially mediated by occupational stress. Significant standardized indirect effects were observed for psychological well-being (95% bootstrap CI = -0.183 to -0.046); moreover, a significant indirect effect was observed for physical well-being (95% bootstrap CI = -0.212 to -0.062). A significant indirect effect was also observed for social well-being (95% bootstrap CI = -0.178 to -0.040). In addition, the direct effect of abusive supervision on employee well-being was significant. Thus, H4a, H4b and H4c were supported (Table 3).

TABLE 1 Demographic characteristics of participants (n = 313)

Variable	M (SD)	Range	n	%
Gender				
Female			305	97.44
Male			8	2.56
Age (years)	35.42 (7.74)	22–57		
Marital status				
Single			160	51.45
Married			151	48.55
Religion				
Taoism			154	50.16
Buddhism			39	12.70
Christianity			12	3.91
Others			8	2.61
No			94	30.62
Educational level				
Senior vocational school			2	0.64
Junior college or University			295	94.25
Graduate school or higher			16	5.11
Total clinical experience (years)	13.11 (7.75)	0.25–35.17		
Career in present job (years)	8.57 (5.47)	0.25–19.59		
Work shifts				
Yes			209	66.99
No			103	33.01

Note: M, mean; SD, standard deviation.

TABLE 2 Descriptive statistics and correlations among variables (n = 313)

Variables	M	SD	Range	1	2	3	4	5
1. Abusive supervision	1.35	0.39	1–5	(0.862)				
2. Occupational stress	1.84	0.48	1–4	0.226**	(0.894)			
3. Psychological well-being	3.63	0.56	1–5	-0.232**	-0.336**	(0.943)		
4. Physical well-being	3.65	0.53	1–5	-0.195**	-0.415**	0.663**	(0.792)	
5. Social well-being	5.11	0.68	1–7	-0.146**	-0.247**	0.532**	0.461**	(0.813)

Note: The higher the scores of variables (abusive supervision, occupational stress, psychological well-being, physical well-being and social well-being), the stronger the staff's perception, for example the score of abusive supervision is higher, staff's perception is stronger. Cronbach's alpha reliability coefficients are presented in parentheses.

Abbreviations: M, mean; SD, standard deviation.

\*\* $p < .01$ .

## 5 | DISCUSSION

### 5.1 | Theoretical implications

#### 5.1.1 | Abusive supervision is negatively associated with employee well-being

First, the present study explored the effect of abusive supervision on employee well-being after age, marital status, religion and work shift were controlled for. Our results are consistent with those of a study that examined a manufacturing company (Lin et al., 2013); that is, the present study revealed the presence of the same negative relationship in the nursing context. Second, justice theory posits that abusive supervision influences how subordinates perceive justice, which in turn negatively affects their psychological well-being (Tepper, 2000). The present study verified the applicability of justice theory in a leadership context and demonstrated that when supervisors treated their subordinates unfairly, these subordinates perceived the presence of abusive supervision and adopted supervisor-oriented deviation behaviour; that is, when subordinates perceived their supervisors to have acted unjustly, these subordinates then developed a negative sense of employee well-being (Aryee et al., 2007).

TABLE 3 Regression results of multiple mediation analyses

Model	R <sup>2</sup>	Path coefficient	SE	Bias corrected bootstrap, 95% confidence interval	
				Lower	Upper
IV on mediator					
AS→Stress	0.054	0.288**	0.069	0.152	0.423
Mediator on DV					
Stress→Psychological Well-being	0.162	-0.349**	0.066	-0.478	-0.219
Stress→Physical Well-being	0.203	-0.429**	0.061	-0.549	-0.308
Stress→Social Well-being	0.132	-0.327**	0.098	-0.519	-0.134
Total effect of IV on DV					
AS→Psychological Well-being	0.083	-0.350**	0.084	-0.515	-0.186
AS→Physical Well-being	0.071	-0.301**	0.080	-0.459	-0.143
AS→Social Well-being	0.099	-0.422**	0.121	-0.661	-0.183
Direct effect of IV on DV					
AS→Psychological Well-being		-0.240*	0.083	-0.403	-0.077
AS→Physical Well-being		-0.166*	0.077	-0.318	-0.014
AS→Social Well-being		-0.319*	0.123	-0.562	-0.076
Indirect effects of IV on DV					
AS→Stress→Psychological Well-being		-0.100*	0.034	-0.183	-0.046
AS→Stress→Physical Well-being		-0.123*	0.037	-0.212	-0.062
AS→Stress→Social Well-being		-0.094*	0.034	-0.178	-0.040
Control variables on DV					
Age→Psychological Well-being		-0.001	0.005	-0.010	0.010
Age→Physical Well-being		0.002	0.005	-0.008	0.012
Age→Social Well-being		0.013	0.007	-0.002	0.027
Marital status→Psychological Well-being		-0.136	0.071	-0.174	0.093
Marital status→Physical Well-being		-0.082	0.068	-0.217	0.052
Marital status→Social Well-being		-0.033	0.103	-0.236	0.170
Religion→Psychological Well-being		-0.041	0.068	-0.174	0.093
Religion→Physical Well-being		-0.055	0.065	-0.182	0.073
Religion→Social Well-being		-0.151	0.098	-0.344	0.042
Work shifts→Psychological Well-being		-0.117	0.073	-0.262	0.027
Work shifts→Physical Well-being		-0.137	0.070	-0.275	0.002
Work shifts→Social Well-being		-0.332*	0.106	-0.541	-0.123

Note: A total of 5000 bootstrap samples were used.

Abbreviation: AS, abusive supervision.

\* $p < .05$ ; \*\* $p < .001$ .

Studies have indicated that abusive supervision harms organization productivity. However, employees are key assets of an organization (Fulmer & Ployhart, 2014). Therefore, the well-being of employees should be emphasized to reduce their intent to leave (Murphy et al., 2021) and increase their job performance (Haddon, 2018). The present study revealed that abusive supervision is negatively related to employee well-being. Thus, organizations should pay attention to the abusive behaviours of its leaders and develop intervention strategies for preventing such behaviours. The topic of intervention strategies is discussed in the "Implications for nursing management" subsection.

### 5.1.2 | Occupational stress mediates the relationship between abusive supervision and employee well-being

First, the present study explored the mediation process that influences the relationship between abusive supervision and employee well-being; notably, empirical evidence pertaining to this topic is scarce (e.g. Hussain et al., 2020). Our results help to address this knowledge gap by verifying the crucial role of occupational stress in mediating the relationship between abusive supervision and well-being. Second, COR theory provides a framework for understanding

responses to stress; it asserts that stress is caused by situations involving the risk or actual loss of valuable resources and indicates that interpersonal strain and interpersonal conflict deplete an individual's internal resources, thereby leading to stress. When nurses are exposed to their leaders' abusive behaviours, they are at a risk of resource loss or experience resource loss followed by the failure to recover their invested resources; subsequently, they experience occupational stress and focus on protecting, conserving and acquiring the resources that they value (Hobfoll, 1989). The resulting occupational stress also further reduces their well-being.

Nurses already experience considerable stress in their work environment. For example, during the coronavirus disease 2019 (COVID-19) pandemic, the nurses who participated in the fight against the virus experienced high levels of stress (Mo et al., 2020). In addition to the stress originating from the external environment, the abusive behaviours of leaders were also revealed (in the present study) as a source of stress in the internal environment of nurses. This finding is meaningful because it further clarifies how abusive leaders can increase occupational stress in the workplace during an unanticipated event (e.g. COVID-19 pandemic).

## 5.2 | Implications for nursing management

Abusive supervision has severe consequences in the workplace. Studies on abusive supervision have reported that it increases the emotional exhaustion and intent to leave of subordinates and reduces their job satisfaction and organizational commitment (Mackey et al., 2017; Zhang & Liao, 2015). The present study revealed that abusive supervision increases occupational stress, which, in turn, reduces employee well-being in the nursing context. Therefore, organizations must address problems related to abusive supervision. Supervisors are sometimes oblivious to their abusive behaviours or may even feel that they are not responsible for the harm caused by their abusive behaviours (Tepper, 2000); consequently, such supervisors make only minor adjustments to their leadership behaviour, if any. Given that stress is a crucial mediator, the management and reduction of occupational stress constitute a key factor in promoting employee well-being (Clegg, 2001), and they can help reduce turnover intention among employees (Mosadeghrad, 2013). For the prevention of abusive supervision, researchers have suggested that organizations should develop solutions for addressing or preventing abusive supervision (Tepper et al., 2006). Interventions for preventing abusive supervision should be applied to both leaders and team members.

With respect to nurse leaders, management must apply prudence when appointing supervisors and avoid promoting individuals with a propensity for abusive behaviour. Creating a safe and supportive work environment for nurses to ensure excellent patient outcomes and professional well-being is the responsibility of multiple stakeholders, such as health care executives, administrators, managers and staff nurses. Organizations can also provide educational courses for nurse leaders. They can train supervisors to practice positive leadership and fair treatment during interactions with

employees. This also helps to improve these supervisors' awareness of leadership styles and reduce abusive supervision.

With respect to team members, organizations should enhance the stress management training for nurses and increase their ability to cope with occupational stress. Organizations can also establish systematic employee stress management procedures. When management is informed of occupational stress-related problems, it can quickly implement preventive interventions and effectively solve such problems. Organizations should also create an organizational culture that applies a zero-tolerance policy toward abusive supervision and train new employees to identify abusive behaviour through various organizational practices and processes (e.g. orientation programmes and explicit descriptions of abusive behaviour in employee manuals; Pradhan & Jena, 2018). A grievance procedure can be established to enable subordinates to report abusive events.

## 5.3 | Limitations

The present study had several limitations. First, although we adopted several strategies to minimize common method variance (e.g. separation of data collection) and did not use variable names (i.e. professional terminology) to avoid arousing the suspicion of respondents during questionnaire administration, the collected respondent data could still have been affected by single source bias due to common method variance (Podsakoff et al., 2003).

Furthermore, researchers have demonstrated that the temporal separation of measures can effectively reduce potential common method variance (Podsakoff et al., 2003). However, a longer time lag increases the possibility of intervening events (e.g. the COVID-19 pandemic) introducing new sources of biases and influencing test results (Chang et al., 2010; Podsakoff & Organ, 1986).

The nursing units of the investigated hospital all implement a 3-month orientation period for new employees. Therefore, we set the inclusion criterion that a participant must be a full-time nurse with more than 3 months of experience working at one of the aforementioned nursing units. However, the evidence for clarifying the time required for a new employee to experience inappropriate abusive behaviour from a supervisor is insufficient; thus, sample selection bias may be present.

## 5.4 | Future research

The current study explored the effect of abusive supervision on employee well-being by using individual-level data. However, different subordinates may perceive varying degrees of abusive behaviour from a single supervisor (Tepper, 2007). Future studies can collect group-level data for multi-level analysis to explore how abusive supervision (group level) influences employee well-being (individual level).

Future studies can use moderator variables such as emotional quotient or resilience to expand on the research framework of the present study. The theoretical framework of COR theory can be



thoroughly examined, and the relationship between the variables can be further clarified. Participants subjectively assessed their physical well-being in the present study. Future studies can incorporate objective measurements such as somatic complaints, cortisol levels, physician visits and self-medicating behaviour (Tepper et al., 2017). These objective measures can provide information on employees' health outcomes.

## 6 | CONCLUSION

This study revealed that abusive supervision significantly increases occupational stress and significantly reduces employee well-being. The aforementioned findings clarify why some nurses experience poor employee well-being. The insights provided by this study indicate that organizations should develop suitable interventions for nurse leaders and team members to help protect nurses from abusive supervision; organizations should also create a safe and supportive work environment for nursing staff by appointing nurse leaders who are supportive and positive and providing leadership training for nurse leaders. They should also enhance stress management training for nurses to increase their ability to cope with occupational stress and emphasize a zero-tolerance policy toward abusive supervision.

### AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet the following criteria: (1) substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content. The detailed contribution as follows. FC Shih, SCJ Yeh, WL Hsu: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data. SCJ Yeh and FC Shih: Involved in drafting the manuscript or revising it critically for important intellectual content. SCJ Yeh, FC Shih, WL Hsu: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. FC Shih and SCJ Yeh: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

### CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

### PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15538>.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - QUANTITATIVE**

# Abusive supervision and employee well-being of nursing staff: Mediating role of occupational stress

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**Abstract**

**Aim:** The study examined whether occupational stress mediated the relationship between abusive supervision and well-being of nursing staff.

**Design:** A cross-sectional questionnaire survey was administered.

**Methods:** Data were collected at three-time points between July 2020 and January 2021. A total of 313 valid responses were obtained from nurses working in a general hospital in Taiwan. The data were analysed using descriptive statistics, Pearson's correlation analysis and the bootstrap method.

**Results:** Abusive supervision was positively associated with occupational stress ( $\beta = 0.288$ , SE = 0.069, 95% CI [0.152, 0.423]) and negatively associated with employee well-being, including psychological ( $\beta = -0.350$ , SE = 0.084, 95% CI [-0.515, -0.186]), physical ( $\beta = -0.301$ , SE = 0.080, 95% CI [-0.459, -0.143]) and social well-being ( $\beta = -0.422$ , SE = 0.121, 95% CI [-0.661, -0.183]). Occupational stress was negatively related to employee well-being. A mediation analysis with bootstrapping revealed that occupational stress mediated the relationship between abusive supervision and employee well-being, which included psychological (95% bootstrap CI [-0.183, -0.046]), physical (95% bootstrap CI [-0.212, -0.062]) and social well-being (95% bootstrap CI [-0.178, -0.040]).

**Conclusion:** Abusive supervision influences employee well-being. Occupational stress mediates the relationship between abusive supervision and employee well-being. To improve employee well-being, hospital administrators should develop policies for effectively managing nursing supervisors' abusive behaviour and subordinates' stress management.

**Impact:** Abusive supervision increased the occupational stress of employees and influenced their well-being. Thus, educational courses should be implemented to train supervisors to practice positive leadership and treat employees fairly. Promoting stress management among nursing staff may lead to the prompt reporting of abusive events and improved employee well-being.

**No Patient or Public Contribution:** This study investigated the relationship between the abusive supervision and employee well-being of nursing employees. No patient or public contribution is involved in this study.

**KEYWORDS**

abusive supervision, employee well-being, nurse occupational stress



## 1 | INTRODUCTION

Compared with people in other occupations, workers in the health care industry are more likely to experience high levels of stress (Puteri & Syaebani, 2018). Because they are required to cope with ill people, overtime work and leader/coworker relationships, health care workers often feel exhausted and overloaded with work, which may prompt them to consider quitting their jobs. Employee well-being can generally be divided into psychological, physical and social well-being (Grant et al., 2007). Research has indicated that poor employee well-being increases employees' intentions to leave their jobs (Holland et al., 2019; Singh et al., 2016).

Leaders can play a key role in shaping the work environment, and their behaviour is often associated with their subordinates' well-being (Arnold, 2017). Studies have suggested that effective nursing leadership can have a positive effect on work environments and patient safety, which can further influence the recruitment and retention of nursing staff (Aiken et al., 2002; Cummings et al., 2010; Hendricks et al., 2015; Marufu et al., 2021; Wong et al., 2013). Positive leadership such as transformational, authentic and ethical leadership have drawn substantial attention. Scholars are increasingly recognizing the influential role of negative leadership behaviours on employees (Harris & Jones, 2018; Hu et al., 2011; Kilic & Günsel, 2019), such as abusive supervision; however, few studies have explored the process by which leaders' actions influence their well-being (Inceoglu et al., 2018). Social cognition (e.g. follower self-efficacy and empowerment) and trust are the most common mediators, and affective pathways have not been adequately studied (Inceoglu et al., 2018). More theoretical development and empirical research are required to understand the causal mechanism of these processes (Inceoglu et al., 2018; Kaluza et al., 2019).

Abusive supervision is a type of harmful leadership that is characterized by the presence of egotistic, incompetent and ignorant leaders (Burns Jr, 2017). Abusive supervision refers to "subordinates' perceptions of the extent to which supervisors engage in the sustained display of hostile verbal and nonverbal behaviors, excluding physical contact" (Tepper, 2000, p. 178). Abusive leaders also create working environments that may not be conducive for new nurses to work in (Lavoie-Tremblay et al., 2016). Mackey et al. (2017) surveyed different occupations and industries and reported that supervisory abuse and general mistreatment are more likely to be reported in the health care industry than in other industries. Because nurses account for approximately half of the health care workforce worldwide (World Health Organization, 2020), our study focused on the well-being of nurses.

## 2 | BACKGROUND

### 2.1 | Abusive supervision and employee well-being

Abusive supervision refers to "subordinates' perceptions of the extent to which supervisors engage in the sustained display of hostile verbal and nonverbal behaviors, excluding physical

contact" (Tepper, 2000, p. 178); Rice et al. (2020) also asserted that abusive supervision is "a salient form of severe mistreatment and is status-degrading" and is characterized by reckless, cruel or malicious behaviours (Tepper, 2000). Nursing studies on abusive supervision have focused on verbal abuse (Michelle Rowe & Sherlock, 2005; Sofield & Salmond, 2003), which may include coworker abuse.

Supervisory abuse is viewed as a problem in health care organizations that are particularly vulnerable to the existence of abusive behaviour (Tepper, 2007). In nursing, abusive supervision reduces job performance (Estes, 2013), organizational citizenship behaviour (Chu, 2014), and moral courage (Afsar et al., 2019) and increases intention to leave (Lyu et al., 2019; Özkan, 2021; Rodwell et al., 2014), counterproductive work behaviour (Chu, 2014; Low et al., 2021), and workplace violence (Zhang et al., 2021). Given that studies have highlighted the negative effects of abusive supervision on job performance, work attitudes and behaviours in the nursing workplace, the present study focuses on how abusive supervision affects the employee well-being of nursing staff.

Justice theory provides insight into why abusive supervision negatively influences workers' attitudes and well-being. For example, abusive leaders cause employees to perceive organizational injustice, which has a negative effect on such employees' psychological well-being (Tepper, 2000). In summary, when employees are subjected to abusive supervision, they perceive unfairness and injustice, which further affect their well-being.

Relative to the definition of abusive supervision, the definition of well-being is broader and more multifaceted in scope, and studies have proposed various definitions for well-being (Grant et al., 2007; Page & Vella-Brodrick, 2009; Warr, 2012). Studies investigating employee well-being have used multidimensional measures, especially psychological and physical parameters (Inceoglu et al., 2018).

We applied the definition proposed by Grant et al. (2007) and used multidimensional measures to investigate employee well-being, which comprises psychological, physical and social well-being. Psychological well-being refers to positive mental states such as happiness or satisfaction (Robertson & Cooper, 2011), and it comprises hedonic and eudaimonic components (Ryan & Deci, 2001). Physical well-being comprises objective physiological measures and subjective experiences of physical health, and it has been extensively studied in the social and natural sciences (Testa & Simonson, 1996). Social well-being refers to the quality of a person's relationships with other people and communities (Keyes, 1998).

### 2.2 | Occupational stress

Occupational stress is defined as "the harmful physical and emotional responses that occur when the demands of the job exceed the capabilities, needs or resources of the worker" (Mohajan, 2012, p. 17). The health care industry is a typical interdisciplinary sector. In the workplace, nurses often interact in multidisciplinary teams



and frequently encounter work conflicts and dilemmas pertaining to interdisciplinary collaboration. A nursing work environment is a high-pressure environment, and nursing is a highly stressful occupation (Gu et al., 2019).

According to conservation of resources (COR) theory, stress can be defined "as a reaction to the environment in which there is: (a) the threat of a net loss of resources; (b) the net loss of resources; and (c) a lack of resource gain following the investment of resources" (Hobfoll, 1989, p. 516). When people perceive that their resources are insufficient or depleted, they experience increased stress and mental strain (Halbesleben & Buckley, 2004; Hobfoll, 2001). Resources can be defined as the elements that people value or the elements that enable people to obtain what they value (Hobfoll, 1988); in this context, the emphasis is on objects, states, conditions, personal characteristics and various forms of energy (Hobfoll, 1989). An individual's social support is a condition-related resource (Halbesleben et al., 2014) that may be provided by their family members, friends, colleagues or supervisors. From the perspective of COR, supervisor leadership is a condition-related resource. Supervisors may exhibit hostile verbal and nonverbal behaviours toward their subordinates during supervisor-subordinate interactions. The internal resources of subordinates who are affected by abusive supervision may be insufficient or depleted, which causes occupational stress.

Occupational stress negatively influences not only the health of nurses but also their ability to cope with job demands (Sharma et al., 2014). Empirical research has confirmed that stress leads to the development of negative employee attitudes, including those related to job satisfaction (Chou et al., 2014), job involvement (Thakre & Jadhav, 2022), turnover intentions (Mosaddeghrad, 2013; Yousaf et al., 2019), and employee well-being (Bostock et al., 2019; Griffin & Clarke, 2011). Although numerous studies have explored the relationship between occupational stress and employee well-being in various occupations, few studies have examined this problem in the nursing context (Gu et al., 2019).

### 2.3 | Mediating effect of occupational stress

Whether abusive supervision influences employee well-being through occupational stress is a question that should be addressed. COR theory covers two basic principles pertaining to the prevention of resource loss: First, for an individual, the risk of losing resources outweighs the benefits of gaining resources. Second, people tend to invest in resources to prevent resource loss, recover from loss and acquire resources (Hobfoll, 2001). On the basis of these principles, people with more resources are less likely to incur resource loss and more capable of coordinating resources to acquire more resources. By contrast, people with fewer resources are more vulnerable to the loss of resources, and they are less capable of coordinating resources to acquire more resources (Hobfoll & Lilly, 1993). The lack of adequate resources

and the presence of stress or strain can have a negative impact on the daily lives and well-being of people.

In the present study, abusive supervision was treated as a key precursor. When employees experience abusive supervision, their internal resources are depleted, their level of stress is increased, and they have poor well-being. Thus, applying COR theory, we inferred that employees' stress can mediate the relationship between abusive supervision and employee well-being.

## 2.4 | Hypotheses and hypothesized model

On the basis of the literature review, this study tested four hypotheses in the context of nursing staff, which are as follows: (a) abusive supervision would be negatively related to employee well-being, (b) abusive supervision would be positively associated with occupational stress, (c) occupational stress would be negatively related to employee well-being, and (d) stress would mediate the relationship between abusive supervision and employee well-being. The results of this study can (a) help organizations develop interventions that prevent the abusive behaviour of leaders and (b) augment the literature on abusive supervision and employee well-being within the context of nursing. Figure 1 presents the mediation model.

## 3 | THE STUDY

### 3.1 | Aims

On the basis of the preceding discussion, the present study examined the relationship between abusive supervision and employee well-being and the mediation effect of occupational stress on this relationship. A better theoretical understanding of these processes is expected to have practical implications related to leadership development and the promotion of employee well-being within the nursing context.

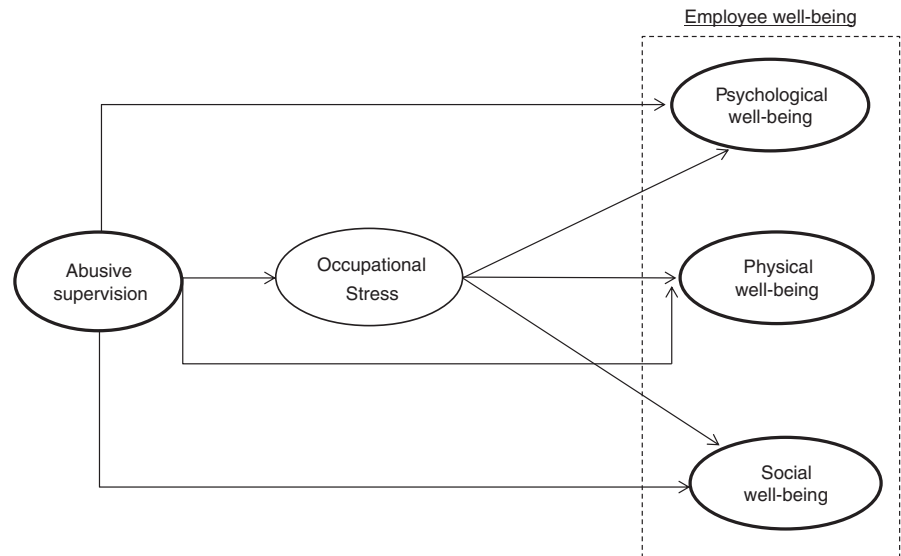
### 3.2 | Design

In this cross-sectional time-lag study, a survey questionnaire was administered to employees from a general hospital in Taiwan between July 2020 and January 2021. The questionnaire was translated using a forward-backward translation protocol involving the English and Chinese languages. The 'Enhancing the QUALity and Transparency of Health Research' (EQUATOR) guidelines were used to guide the study.

### 3.3 | Data collection

To minimize common method variance, the survey data were collected at three time points (time points 1, 2 and 3) that were separated

**FIGURE 1** Mediation model with components of stress as a mediator of the relationship between abusive supervision and employee well-being.



from each other by a 6-week interval (Podsakoff et al., 2003). The participants responded to the survey items that assessed their perceived abusive supervision (with respect to their supervisors), occupational stress and employee well-being at time points 1, 2 and 3, respectively. This process ensured that the independent (abusive supervision) and mediating (occupational stress) variables were temporally separated from the dependent variable (employee well-being).

### 3.4 | Participants

The study participants were registered nurses working in a general hospital in Taiwan. At the time of the study, the hospital employed a total of 1556 registered nurses who were deployed across 70 nursing units. The survey questionnaire was administered to nurses who were selected from the 70 nursing units of the aforementioned general hospital through quota sampling. The leadership styles of the heads of the 70 nursing units were assumed to be different, then a quota sampling method was adopted, and a target number of 354 questionnaires was set to ensure that the collected samples can be generalized to the overall population. We aimed to collect approximately four to six questionnaires from each nursing care unit.

A total of 354 questionnaires were sent to the nurses of the aforementioned units. Completed surveys were returned by 351 nurses at time point 1 (99.2% response rate), 350 time point 1 responders completed and returned the survey at time point 2 (99.2% response rate), and 343 time point 2 responders completed and returned the survey at time point 3 (98.0% response rate).

A returned questionnaire with one or more missing items was classified as a questionnaire with missing data and excluded from the final analysis. Among the 343 responses, 30 contained missing data. Therefore, the final sample comprised 313 valid responses. Full-time nurses with more than 3 months of experience working at one of the aforementioned nursing units were included in this study, whereas nursing student interns and newcomers (i.e. nurses with less than 3 months of experience working at these units) were excluded.

## 3.5 | Measures

### 3.5.1 | Abusive supervision

Abusive supervision was assessed using a 15-item scale developed by Tepper (2000). This scale was demonstrated to have favourable construct validity and reliability (Hu et al., 2011). An example of an item is "He or she blames me to save himself or herself from embarrassment." Each item was assessed using a 5-point scale from 1 (*I cannot remember him or her ever behaving in this manner toward me*) to 5 (*He or she behaves in this manner toward me very often*). In the present study, the Cronbach's  $\alpha$  for this scale was 0.862.

### 3.5.2 | Occupational stress

We used the 11-item scale developed by Revicki and Gershon (1996) to measure occupational stress. This scale was demonstrated to exhibit acceptable internal consistency reliability and construct validity (Revicki & Gershon, 1996). The participants' perceived job stress was assessed using a 4-point scale ranging from 1 (*never*) to 4 (*always*). An example of an item is "My interest in doing fun activities has decreased because of my work." In the present study, the Cronbach's  $\alpha$  for this scale was 0.894.

### 3.5.3 | Psychological well-being

We used the Warwick-Edinburgh Mental Well-being Scale to measure psychological well-being, and evidence indicated that the test-retest reliability and content validity of this scale were acceptable (Tennant et al., 2007). This scale comprised 14 questions that assessed how often participants have experienced the situation described by each item over the last 2 weeks using a 5-point scale ranging from 1 (*never*) to 5 (*all of the time*). An example of an item is

"I am feeling optimistic about the future." In the present study, the Cronbach's  $\alpha$  for this scale was 0.943.

### 3.5.4 | Physical well-being

Physical well-being was assessed using a 7-item subscale of the World Health Organization Quality of Life Scale Brief Version; this subscale exhibited acceptable test-retest reliability and discriminant validity (WHOQOL-BREF; Whoqol Group, 1998). The participants indicated how much the situation described by an item corresponded to their situation in the last 2 weeks using a 5-point scale ranging from 1 (*not at all*) to 5 (*very much so*). An example of an item is "How satisfied are you with your ability to perform your daily living activities?" In the present study, the Cronbach's  $\alpha$  for this subscale was 0.792.

### 3.5.5 | Social well-being

We used a subscale of the Ryff scale to measure the satisfaction of the participants and other relationships (Ryff & Keyes, 1995). This subscale was demonstrated to have favourable validity and test-retest reliability (Akin, 2008). The subscale comprises seven items that are rated on a 7-point scale with endpoints ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). An example of an item is "People describe me as a giving person who is willing to share my time with others." In the present study, the Cronbach's  $\alpha$  for this subscale was 0.813.

### 3.5.6 | Covariates

We controlled for several variables on the basis of their potential theoretical and empirical relations with our focal variables. Age was controlled because a study reported a U-shaped pattern for job satisfaction and an inverted U-shaped pattern for well-being (Birdi et al., 1995). Marital status was controlled because married people were previously reported to exhibit consistently higher levels of well-being than unmarried people (Soulsby & Bennett, 2015). Religion was controlled because a study discovered that individuals of various religious groups subscribe to a socially oriented cultural conception of subjective well-being and achieved it through various methods (Shiah et al., 2014). A study revealed a link between work schedule uncertainty and workers' well-being (including psychological distress, poor sleep quality and unhappiness). Thus, work schedule was set as a control variable in the present study (Schneider & Harknett, 2019).

## 3.6 | Ethical considerations

The present study was approved by the Institutional Review Board of E-Da Hospital, Taiwan (EMRP-109-057). Written informed consent, which comprised an information sheet and a consent certificate, was obtained from the participants prior to the commencement of the study.

## 3.7 | Data analysis

Descriptive statistics were used to analyse sample characteristics. Because our study data were normally distributed, Pearson's correlation coefficients were used to examine the correlations between variables. To test the research hypotheses, the bootstrap method (Shrout & Bolger, 2002) and Model 4 of Hayes (2017) PROCESS macro were used to examine the mediating role of occupational stress in the relationship between abusive supervision and employee well-being. SPSS WIN 24.0 (SPSS, Inc.) and the SPSS PROCESS macro—2.15 version ([www.afhayes.com](http://www.afhayes.com)) were used for our data analyses.

## 3.8 | Validity and reliability

After missing values were removed, the overall mean scores were used. The results of the correlational analysis are summarized in Table 2. All scales had good reliability (Cronbach's  $\alpha > 0.70$ ), and the correlations between scales were moderate. No strong collinearity was detected among the variables, and their discriminant validity was well established.

# 4 | RESULTS

## 4.1 | Descriptive analysis of samples

Table 1 presents the participants' demographic characteristics. Of the 313 participants, 97.44% were women, and their average age was 35.42 years. A slight majority of the participants were single (51.45%). Most participants were Taoist and had a junior college or university (94.25%) education. The participants' average total clinical experience was 13.11 years, and their average job tenure for their current job was 8.57 years. About 209 (66.99%) were shift workers.

The Pearson's correlation of the scales for the main variables of interest was determined. The mean scores for abusive supervision, occupational stress, psychological well-being, physical well-being and social well-being were  $1.35 \pm 0.39$ ,  $1.84 \pm 0.48$ ,  $3.63 \pm 0.56$ ,  $3.65 \pm 0.53$ , and  $5.11 \pm 0.68$ , respectively. Abusive supervision has shown a significant positive correlation with stress ( $r = 0.226$ ,  $p < .01$ ). Abusive supervision was negatively correlated with psychological ( $r = -0.232$ ,  $p < .01$ ), physical ( $r = -0.195$ ,  $p < .01$ ), and social well-being ( $r = -0.146$ ,  $p < .01$ ). Other correlation results are shown in Table 2.

## 4.2 | Hypothesis testing

Regression analyses were performed to investigate whether occupational stress mediated the effect of abusive supervision on employee well-being. This study revealed a significant relationship between abusive supervision with psychological ( $\beta = -0.350$ , standard error [SE] = 0.084, 95% CI [-0.515, -0.186]), physical ( $\beta = -0.301$ ,

SE = 0.080, 95% CI [-0.459, -0.143]) and social well-being ( $\beta = -0.422$ , SE = 0.121, 95% CI [-0.661, -0.183]). The results supported H1a, H1b and H1c. The results also indicated that abusive supervision was a significant predictor of occupational stress ( $\beta = 0.288$ , SE = 0.069, 95% CI [0.152, 0.423]). Thus, H2 was supported. Stress was revealed to be a significant predictor of psychological ( $\beta = -0.349$ , SE = 0.066, 95%

CI [-0.478, -0.219]), physical ( $\beta = -0.429$ , SE = 0.061, 95% CI [-0.549, -0.308]) and social well-being ( $\beta = -0.327$ , SE = 0.098, 95% CI [-0.519, -0.134]). These results supported H3a, H3b and H3c.

Multiple mediation analyses revealed that the relationship between abusive supervision and employee well-being (i.e. psychological, physical and social well-being) was partially mediated by occupational stress. Significant standardized indirect effects were observed for psychological well-being (95% bootstrap CI = -0.183 to -0.046); moreover, a significant indirect effect was observed for physical well-being (95% bootstrap CI = -0.212 to -0.062). A significant indirect effect was also observed for social well-being (95% bootstrap CI = -0.178 to -0.040). In addition, the direct effect of abusive supervision on employee well-being was significant. Thus, H4a, H4b and H4c were supported (Table 3).

TABLE 1 Demographic characteristics of participants (n = 313)

Variable	M (SD)	Range	n	%
Gender				
Female			305	97.44
Male			8	2.56
Age (years)	35.42 (7.74)	22–57		
Marital status				
Single			160	51.45
Married			151	48.55
Religion				
Taoism			154	50.16
Buddhism			39	12.70
Christianity			12	3.91
Others			8	2.61
No			94	30.62
Educational level				
Senior vocational school			2	0.64
Junior college or University			295	94.25
Graduate school or higher			16	5.11
Total clinical experience (years)	13.11 (7.75)	0.25–35.17		
Career in present job (years)	8.57 (5.47)	0.25–19.59		
Work shifts				
Yes			209	66.99
No			103	33.01

Note: M, mean; SD, standard deviation.

TABLE 2 Descriptive statistics and correlations among variables (n = 313)

Variables	M	SD	Range	1	2	3	4	5
1. Abusive supervision	1.35	0.39	1–5	(0.862)				
2. Occupational stress	1.84	0.48	1–4	0.226**	(0.894)			
3. Psychological well-being	3.63	0.56	1–5	-0.232**	-0.336**	(0.943)		
4. Physical well-being	3.65	0.53	1–5	-0.195**	-0.415**	0.663**	(0.792)	
5. Social well-being	5.11	0.68	1–7	-0.146**	-0.247**	0.532**	0.461**	(0.813)

Note: The higher the scores of variables (abusive supervision, occupational stress, psychological well-being, physical well-being and social well-being), the stronger the staff's perception, for example the score of abusive supervision is higher, staff's perception is stronger. Cronbach's alpha reliability coefficients are presented in parentheses.

Abbreviations: M, mean; SD, standard deviation.

\*\* $p < .01$ .

## 5 | DISCUSSION

### 5.1 | Theoretical implications

#### 5.1.1 | Abusive supervision is negatively associated with employee well-being

First, the present study explored the effect of abusive supervision on employee well-being after age, marital status, religion and work shift were controlled for. Our results are consistent with those of a study that examined a manufacturing company (Lin et al., 2013); that is, the present study revealed the presence of the same negative relationship in the nursing context. Second, justice theory posits that abusive supervision influences how subordinates perceive justice, which in turn negatively affects their psychological well-being (Tepper, 2000). The present study verified the applicability of justice theory in a leadership context and demonstrated that when supervisors treated their subordinates unfairly, these subordinates perceived the presence of abusive supervision and adopted supervisor-oriented deviation behaviour; that is, when subordinates perceived their supervisors to have acted unjustly, these subordinates then developed a negative sense of employee well-being (Aryee et al., 2007).

TABLE 3 Regression results of multiple mediation analyses

Model	R <sup>2</sup>	Path coefficient	SE	Bias corrected bootstrap, 95% confidence interval	
				Lower	Upper
IV on mediator					
AS→Stress	0.054	0.288**	0.069	0.152	0.423
Mediator on DV					
Stress→Psychological Well-being	0.162	-0.349**	0.066	-0.478	-0.219
Stress→Physical Well-being	0.203	-0.429**	0.061	-0.549	-0.308
Stress→Social Well-being	0.132	-0.327**	0.098	-0.519	-0.134
Total effect of IV on DV					
AS→Psychological Well-being	0.083	-0.350**	0.084	-0.515	-0.186
AS→Physical Well-being	0.071	-0.301**	0.080	-0.459	-0.143
AS→Social Well-being	0.099	-0.422**	0.121	-0.661	-0.183
Direct effect of IV on DV					
AS→Psychological Well-being		-0.240*	0.083	-0.403	-0.077
AS→Physical Well-being		-0.166*	0.077	-0.318	-0.014
AS→Social Well-being		-0.319*	0.123	-0.562	-0.076
Indirect effects of IV on DV					
AS→Stress→Psychological Well-being		-0.100*	0.034	-0.183	-0.046
AS→Stress→Physical Well-being		-0.123*	0.037	-0.212	-0.062
AS→Stress→Social Well-being		-0.094*	0.034	-0.178	-0.040
Control variables on DV					
Age→Psychological Well-being		-0.001	0.005	-0.010	0.010
Age→Physical Well-being		0.002	0.005	-0.008	0.012
Age→Social Well-being		0.013	0.007	-0.002	0.027
Marital status→Psychological Well-being		-0.136	0.071	-0.174	0.093
Marital status→Physical Well-being		-0.082	0.068	-0.217	0.052
Marital status→Social Well-being		-0.033	0.103	-0.236	0.170
Religion→Psychological Well-being		-0.041	0.068	-0.174	0.093
Religion→Physical Well-being		-0.055	0.065	-0.182	0.073
Religion→Social Well-being		-0.151	0.098	-0.344	0.042
Work shifts→Psychological Well-being		-0.117	0.073	-0.262	0.027
Work shifts→Physical Well-being		-0.137	0.070	-0.275	0.002
Work shifts→Social Well-being		-0.332*	0.106	-0.541	-0.123

Note: A total of 5000 bootstrap samples were used.

Abbreviation: AS, abusive supervision.

\* $p < .05$ ; \*\* $p < .001$ .

Studies have indicated that abusive supervision harms organization productivity. However, employees are key assets of an organization (Fulmer & Ployhart, 2014). Therefore, the well-being of employees should be emphasized to reduce their intent to leave (Murphy et al., 2021) and increase their job performance (Haddon, 2018). The present study revealed that abusive supervision is negatively related to employee well-being. Thus, organizations should pay attention to the abusive behaviours of its leaders and develop intervention strategies for preventing such behaviours. The topic of intervention strategies is discussed in the "Implications for nursing management" subsection.

### 5.1.2 | Occupational stress mediates the relationship between abusive supervision and employee well-being

First, the present study explored the mediation process that influences the relationship between abusive supervision and employee well-being; notably, empirical evidence pertaining to this topic is scarce (e.g. Hussain et al., 2020). Our results help to address this knowledge gap by verifying the crucial role of occupational stress in mediating the relationship between abusive supervision and well-being. Second, COR theory provides a framework for understanding

responses to stress; it asserts that stress is caused by situations involving the risk or actual loss of valuable resources and indicates that interpersonal strain and interpersonal conflict deplete an individual's internal resources, thereby leading to stress. When nurses are exposed to their leaders' abusive behaviours, they are at a risk of resource loss or experience resource loss followed by the failure to recover their invested resources; subsequently, they experience occupational stress and focus on protecting, conserving and acquiring the resources that they value (Hobfoll, 1989). The resulting occupational stress also further reduces their well-being.

Nurses already experience considerable stress in their work environment. For example, during the coronavirus disease 2019 (COVID-19) pandemic, the nurses who participated in the fight against the virus experienced high levels of stress (Mo et al., 2020). In addition to the stress originating from the external environment, the abusive behaviours of leaders were also revealed (in the present study) as a source of stress in the internal environment of nurses. This finding is meaningful because it further clarifies how abusive leaders can increase occupational stress in the workplace during an unanticipated event (e.g. COVID-19 pandemic).

## 5.2 | Implications for nursing management

Abusive supervision has severe consequences in the workplace. Studies on abusive supervision have reported that it increases the emotional exhaustion and intent to leave of subordinates and reduces their job satisfaction and organizational commitment (Mackey et al., 2017; Zhang & Liao, 2015). The present study revealed that abusive supervision increases occupational stress, which, in turn, reduces employee well-being in the nursing context. Therefore, organizations must address problems related to abusive supervision. Supervisors are sometimes oblivious to their abusive behaviours or may even feel that they are not responsible for the harm caused by their abusive behaviours (Tepper, 2000); consequently, such supervisors make only minor adjustments to their leadership behaviour, if any. Given that stress is a crucial mediator, the management and reduction of occupational stress constitute a key factor in promoting employee well-being (Clegg, 2001), and they can help reduce turnover intention among employees (Mosadeghrad, 2013). For the prevention of abusive supervision, researchers have suggested that organizations should develop solutions for addressing or preventing abusive supervision (Tepper et al., 2006). Interventions for preventing abusive supervision should be applied to both leaders and team members.

With respect to nurse leaders, management must apply prudence when appointing supervisors and avoid promoting individuals with a propensity for abusive behaviour. Creating a safe and supportive work environment for nurses to ensure excellent patient outcomes and professional well-being is the responsibility of multiple stakeholders, such as health care executives, administrators, managers and staff nurses. Organizations can also provide educational courses for nurse leaders. They can train supervisors to practice positive leadership and fair treatment during interactions with

employees. This also helps to improve these supervisors' awareness of leadership styles and reduce abusive supervision.

With respect to team members, organizations should enhance the stress management training for nurses and increase their ability to cope with occupational stress. Organizations can also establish systematic employee stress management procedures. When management is informed of occupational stress-related problems, it can quickly implement preventive interventions and effectively solve such problems. Organizations should also create an organizational culture that applies a zero-tolerance policy toward abusive supervision and train new employees to identify abusive behaviour through various organizational practices and processes (e.g. orientation programmes and explicit descriptions of abusive behaviour in employee manuals; Pradhan & Jena, 2018). A grievance procedure can be established to enable subordinates to report abusive events.

## 5.3 | Limitations

The present study had several limitations. First, although we adopted several strategies to minimize common method variance (e.g. separation of data collection) and did not use variable names (i.e. professional terminology) to avoid arousing the suspicion of respondents during questionnaire administration, the collected respondent data could still have been affected by single source bias due to common method variance (Podsakoff et al., 2003).

Furthermore, researchers have demonstrated that the temporal separation of measures can effectively reduce potential common method variance (Podsakoff et al., 2003). However, a longer time lag increases the possibility of intervening events (e.g. the COVID-19 pandemic) introducing new sources of biases and influencing test results (Chang et al., 2010; Podsakoff & Organ, 1986).

The nursing units of the investigated hospital all implement a 3-month orientation period for new employees. Therefore, we set the inclusion criterion that a participant must be a full-time nurse with more than 3 months of experience working at one of the aforementioned nursing units. However, the evidence for clarifying the time required for a new employee to experience inappropriate abusive behaviour from a supervisor is insufficient; thus, sample selection bias may be present.

## 5.4 | Future research

The current study explored the effect of abusive supervision on employee well-being by using individual-level data. However, different subordinates may perceive varying degrees of abusive behaviour from a single supervisor (Tepper, 2007). Future studies can collect group-level data for multi-level analysis to explore how abusive supervision (group level) influences employee well-being (individual level).

Future studies can use moderator variables such as emotional quotient or resilience to expand on the research framework of the present study. The theoretical framework of COR theory can be



thoroughly examined, and the relationship between the variables can be further clarified. Participants subjectively assessed their physical well-being in the present study. Future studies can incorporate objective measurements such as somatic complaints, cortisol levels, physician visits and self-medicating behaviour (Tepper et al., 2017). These objective measures can provide information on employees' health outcomes.

## 6 | CONCLUSION

This study revealed that abusive supervision significantly increases occupational stress and significantly reduces employee well-being. The aforementioned findings clarify why some nurses experience poor employee well-being. The insights provided by this study indicate that organizations should develop suitable interventions for nurse leaders and team members to help protect nurses from abusive supervision; organizations should also create a safe and supportive work environment for nursing staff by appointing nurse leaders who are supportive and positive and providing leadership training for nurse leaders. They should also enhance stress management training for nurses to increase their ability to cope with occupational stress and emphasize a zero-tolerance policy toward abusive supervision.

## AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet the following criteria: (1) substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content. The detailed contribution as follows. FC Shih, SCJ Yeh, WL Hsu: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data. SCJ Yeh and FC Shih: Involved in drafting the manuscript or revising it critically for important intellectual content. SCJ Yeh, FC Shih, WL Hsu: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. FC Shih and SCJ Yeh: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

## CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

## PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15538>.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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# Nursing students' attitudes regarding euthanasia due to unbearable mental suffering: Cross-sectional study using the adapted and validated Euthanasia Attitude Scale

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## Abstract

**Aim:** To explore final year nursing students' attitudes towards euthanasia due to unbearable mental suffering by using the adapted and validated Euthanasia Attitude Scale.

**Design:** Cross-sectional survey.

**Methods:** Explorative, descriptive cross-sectional study conducted using an e-mail survey between October 2020 and March 2021 by a sample of final-year baccalaureate nursing students ( $n = 273$ ) from eight of the eleven Flemish university colleges. The actual questionnaire contains 21 questions and was developed based on a consensus reached following independent translations. The psychometric properties of the Euthanasia Attitude Scale were assessed, including reliability and validity. Independent-sample Mann-Whitney U-test was used to investigate relation between demographic and education-related data, and domain and total score of the UMS-EAS-NL. This study received ethical approval from the Ethical Committee of the University Hospital Brussels, Belgium.

**Results:** McDonald's omega was 0.838 for the total Euthanasia Attitude Scale scores, supporting the validity of the questionnaire. A statistically significant difference in 'Naturalistic beliefs' score was found relating to the year of birth. There are clinically important results between those students who have been involved in euthanasia and those who have not.

**Conclusions:** Most of the final-year nursing students supported the probability of patients' access to euthanasia due to unbearable mental suffering. To monitor adequate care, it is necessary to prepare nursing students adequately for this complex matter.

**Impact:** To date, no large-scale study has examined nursing students' attitudes towards euthanasia because of unbearable mental suffering. It is expected that nursing students may be confronted with such a euthanasia request during an internship, or later in their professional career, in countries where euthanasia is legal. Students showed a high acceptability towards UMS-euthanasia. Clinically significant differences were found for students who had ever been involved in euthanasia.



## KEYWORDS

attitudes, end of life, mental health, nursing students

## 1 | INTRODUCTION

In euthanasia, drugs are administered to the patient who suffers unbearably due to an incurable disease, with the explicit intention of ending the patient's life at their explicit request (Bellon et al., 2022). To date, euthanasia is legal in Colombia, Canada, the Australian states of Victoria and Western Australia, New Zealand, Austria, Belgium, the Netherlands, Luxembourg, and Spain (Mroz et al., 2021; Rada, 2021). Switzerland and 10 states in the United States of America (California, Colorado, District of Columbia, Hawaii, Maine, Montana, New Jersey, Oregon, Vermont, Washington) rely on legalized physician-assisted suicide, which means that a patient is assisted to end their life by supplied life-ending drugs, but the patient has to take these drugs themselves (Mroz et al., 2021). Both euthanasia and assisted suicide are medical-assisted dying practices. In all countries, the unbearable suffering of the involved patients must be of a kind that cannot be alleviated anymore by drugs or alternative therapies (Calati et al., 2021). Most countries in which medical-assisted dying is legal further impose that the unbearable suffering must be caused by a terminal disease. This is not the case in Switzerland, Spain, Belgium, the Netherlands or Luxembourg. The constitution of these countries clearly states that medical-assisted death can also be requested by patients unbearably suffering due to a non-terminal disease. Such disease may be of a physical and/or mental nature (Calati et al., 2021). This paper specifically focuses on euthanasia because of unbearable mental suffering due to a mental disease (UMS-euthanasia).

## 2 | BACKGROUND

Over the years, an increasing body of scientific literature on the topic of euthanasia has been developed. It is notable that, even though studies about nurses' attitudes towards and involvement in euthanasia have increased, they still remain relatively scarce. These nursing studies reveal that, in general, nurses' opinions about the acceptability of euthanasia substantially differ between countries. In countries where euthanasia is legal, a higher degree of acceptance towards euthanasia can be observed than in countries where euthanasia is illegal (Cayetano-Penman et al., 2021; Naseh et al., 2015). When we examine nursing students and their attitudes towards euthanasia for terminal patients, similar results emerge as for working nurses (Malary et al., 2019; Yildirim, 2020). When focusing exclusively on UMS-euthanasia, only two nursing studies could be identified (De Hert et al., 2015; Demedts et al., 2018). Both studies reveal a high degree of acceptability of psychiatric nurses towards UMS-euthanasia, be it under strict conditions, and only for certain types of patients. For example, there is a greater degree of acceptability

towards UMS-euthanasia in patients with psychotic disorder, personality disorder, or mood disorder, than those with addiction or dissociative disorder (De Hert et al., 2015; Demedts et al., 2018). Since UMS-euthanasia is legal in Belgium, The Netherlands, and Luxemburg, it is expected that also nursing students may be confronted with an UMS-euthanasia request during an internship, and later in their professional career. During their internship, Belgian nursing students can carry out all the techniques taught to them, provided that they are supervised by the nurse, including an in-depth conversation. Therefore, it is important to explore their attitudes towards this form of euthanasia so that targeted actions can be taken to better support them during their training. A pilot study by Demedts et al. (2022) has provided an initial impetus to see what findings are found among nursing students. However, this was a monocentric pilot study with a limited response rate and number of respondents. This study is therefore the first large-scale study to examine nursing students' attitudes towards UMS-euthanasia by using an adaptation of the existing Euthanasia Attitude Scale (EAS), whose use for this type of euthanasia will also be validated.

## 3 | THE STUDY

### 3.1 | Aims

The aim of this study was to explore Flemish (Belgium) final year nursing students' attitudes towards euthanasia due to unbearable mental suffering by using an adaptation of the EAS. The EAS needed to be validated for this type of euthanasia as well as for its Dutch translation.

### 3.2 | Design

Cross-sectional survey.

### 3.3 | Sample/participants

A total of 11 Belgian Dutch-speaking university colleges providing nursing studies exist in Belgium. All final-year bachelor nursing students at these university colleges were invited by the researchers to participate in this study that took place between October 2020 and March 2021. Eight university colleges were willing to distribute the link to the questionnaire of this study to their 670 final-year students by e-mail. The other three university colleges refused to participate in the study. For two of these universities, no reason was stated; for the third one, their students were



already involved in other research studies, and the management declined participation. All participants gave their informed consent before participating in the study. This study ensured total anonymity of the participants by using an anonymous survey link to the online questionnaire in the mail (Qualtrics<sup>SM</sup>). Three reminders to participate in this questionnaire were sent to all students (after 1 week, after 2 weeks and after 4 weeks). The students who had already participated were thanked for their participation and could ignore the reminders.

### 3.4 | Data collection

Nursing faculties were physically closed at the time of data collection because of Covid-19 restrictions, we decided to transform our survey into an online questionnaire instead of a paper survey as previously envisaged. The questions in our study are based on the EAS questionnaire (Tordella & Neutens, 1979). From their original pool of 74 statements, they eventually selected 21 questions after a group of 19 judges, all experts in the area of thanatology, rated the statements. These 21 questions statistically represented the greatest consensus of the group of judges. Tordella and Neutens (1979) reported an internal consistency index of 0.84 (Cronbach alpha) after a one-week test-retest analysis. Rogers (1996) adjusted the questionnaire by editing the items for gender-biased language and reported an internal consistency of 0.85. Another important addition was made by Chong and Fok (2004). Using factor analysis, they grouped the questions into four domains: ethical considerations (11 questions), practical considerations (four questions), treasuring life (four questions) and naturalistic beliefs (two questions). Additionally, Chong and Fok (2004) modified the original dichotomous response to a 5-point Likert scale option for each statement, including such categories as follows: 'strongly agree', 'agree', 'neutral', 'disagree' and 'strongly disagree'. Thus, since there are 21 questions with item scores in between 1 and 5, the total sum of scores could range from 21 to 105, with higher scores indicating higher acceptability of euthanasia. The scores of negatively formulated questions are reversed, including questions 1b, 1d, 1g, 1i, 2c, 3a, 3b, 3c, 3d and 4b (see Table 2). Each domain contains at least one negatively formulated question. Besides the EAS questions, also *demographic and education-related data* were gathered: gender, year of birth, previous experience in a mental health placement and whether the student had ever been involved in a euthanasia procedure.

### 3.5 | Ethical considerations

This study was submitted to and approved by the ethics committee of the University Hospital Brussels (B.U.N. 1432020000138/I/U). All participants were informed in advance of the purpose of this study, what was expected of them, its voluntary nature, that anonymity was guaranteed, and no remuneration would be received. Completing and returning the questionnaire constituted informed

consent. To emphasize the voluntary nature, the questionnaire was distributed by the structural researcher of the program, not by the program director or any of their teachers.

### 3.6 | Data analysis

The reliability of the questionnaire was estimated, both using the Cronbach's alpha as well as the McDonald's omega. Cronbach's alpha ( $\alpha$ ) was chosen since it was used in the previous studies and thus allows for comparison. However, because the implied assumption of tau-equivalence is highly questionable, following Hayes and Coutts (2020), the McDonald's omega ( $\omega$ ) is also included as a measure of reliability. Missing values do not exist and therefore do not affect the analyses. Attitudes were described by calculating scores of respondents responding affirmative on a 5-point Likert scale (from 1. strongly disagree to 5. strongly agree) with regard to all 21 statements of the UMS-EAS-NL. Further also the total score, mean and standard deviation were calculated. Independent-sample Mann-Whitney U-test was used to investigate relation between demographic and education-related data on the one hand, and domain and total score of the UMS-EAS-NL on the other hand. Statistical analyses were performed using SPSS® 27.0. The dataset can be consulted at Mendeley Data (Demedts, 2022).

### 3.7 | Validity, reliability and rigour

The EAS was translated to Dutch, while considering that the main aim of this study was to investigate attitudes towards UMS-euthanasia instead of towards euthanasia in general, originally focused on by EAS. This was done, independently by three experts from different fields, each contributing their own expertise. The first one, a translation expert is a native English speaker who has completed his education in Dutch. He has a Master of Arts degree in translation and is currently employed as a sworn translator in Dutch to English. The second one, a healthcare education expert, obtained a Master of Sciences in nursing and midwifery, and has been employed as a senior lecturer at a university college, teaching the target group, for decades. The third expert is a PhD in Health Sciences with a dissertation in end-of-life care. After these experts submitted their Dutch translations, they were reviewed by three authors of this study who combined the questions into a first proposal questionnaire. Next, the questionnaire was resubmitted again to the three experts for feedback. Their feedback was then revised again by the authors. After four revisions, a final consensus was reached. A final fifth round was necessary after feedback of the ethics committee of the University Hospital Brussels whereby one question was adjusted (question 2a). The final version is named the UMS-EAS-NL questionnaire and consist of 21 questions in four domains: ethical considerations (11 questions), practical considerations (four questions), treasuring life (four questions) and naturalistic beliefs (two questions). The UMS-EAS-NL can be found in the appendices.

## 4 | RESULTS/FINDINGS

After three reminders, 237 of the 670 students completed the questionnaire (response rate of 41%). Ninety-five percent of the participants ( $n = 162$ ) were born between 1997 and 1999 ( $md = 1998$ ,  $mo = 1999$ ). The vast majority of respondents are women ( $n = 237$ , 87%). Eight out of ten students ( $n = 224$ , 82%) had already completed a mental health internship, and 154 students (56%) had already been involved in euthanasia (not specified to UMS-euthanasia). This could be either the request, the preparation, the act and/or the aftercare in the role of a nursing trainee or as a relative.

About the validation of the EAS-UMS-NL, the homogeneity index ranged between 0.090 and 0.721 (Table 1). There were two items with very low corrected item-total correlation scores: item 1 h "UMS-euthanasia should be applied when a mentally ill person is out of treatment." (Corrected Item-Total Correlation: 0.090, Cronbach's Alpha if Item Deleted: 0.822) and item 4a "A person should not be kept alive by machines." (Corrected Item-Total Correlation: 0.108, Cronbach's Alpha if Item Deleted: 0.818). The Cronbach's alpha was 0.812 and the McDonald's omega was 0.838 for the total EAS scores.

The Kaiser-Meyer-Olkin measure of sampling adequacy was .898 and the Bartlett's test of sphericity 2180.787 ( $p < 0.001$ ). Six factors were initially presented in the factor analysis. These six factors explained 63.733% of the total variance. Varimax rotation and eigenvalue greater than 1 were entered. Factor 5 (4b) and factor 6 (4a) contain only one item and both factors had an eigenvalue close to 1 (factor 5: 1.051; factor 6: 1.003). The scree plot suggests a 2-factor model with 18 items who load on factor 1 and three items who load on factor 2 (1 h, 1j, 2b), explaining 41.894% of the total variance. Thus, we end up with four factors explaining 53.953% of the total variance.

The answers for the individual items of the UMS-EAS-NL are described in detail (Table 2). Most nursing students were supportive towards the acceptability of UMS-euthanasia. Nursing students indicate that euthanasia should not only be limited to these patients with unbearable suffering due to a terminal illness (89%). A great majority of nursing students stated that a person with a mental illness has the right to decide to die (85%), as well as UMS-euthanasia should be accepted in today's society (84%). They believed that UMS-euthanasia can be helpful at the right time and place (80%). About the legal status of UMS-euthanasia, students indicated that UMS-euthanasia may be legal (88%), but that taking away a human life is wrong regardless of the circumstances (85%). However, UMS-euthanasia can be an opportunity to die with dignity (88%), and you do not have to be over 75 years old to do so (92%).

Independent-sample Mann-Whitney U-test found a statistically significant difference in scores for 'Naturalistic beliefs' according to year of birth,  $U(N_{\text{born} \leq 1999} = 181, N_{\text{born} > 1999} = 92) = 7104.500$ ,  $z = -2.055$ ,  $p = 0.040$ . No statistically significant difference in total questionnaire score or domains was found for gender differences, year of birth, ever involved in euthanasia or for those who had a previous experience in a mental health placement (Table 3). Clinically

important differences were found in between those ever involved in euthanasia and those not.

## 5 | DISCUSSION

The objective of this study was to explore final-year nursing students in Flanders (Belgium) attitudes towards UMS-euthanasia. Consequently, we had to adapt and validate the EAS towards euthanasia because of unbearable mental suffering due to a mental disease (UMS-euthanasia). Validation of this questionnaire is essential because, to our knowledge, no validated instruments exist that specifically measures attitudes towards UMS-euthanasia. Since UMS-euthanasia is legal and practised in Belgium, it is important to explore the attitudes of nursing students because they will be confronted with UMS-euthanasia during their internships and their professional career as a nurse. Most of the nursing students supported the probability of UMS-euthanasia. Clinically important differences were found between those students who had ever been involved in euthanasia and those who had not. So targeted actions must be taken to better support them during their training.

In addition to their usual online classes and internships, a total of 273 students were willing to participate in our survey, which accounts for a 41% response rate. This is considered reasonably good for an online survey (Saleh & Bista, 2017) and particularly amidst the Covid-19 pandemic. Our a priori defined sample was estimated on 245 responses, considering the total population of 670 students. A ratio of 13%–87% by gender (m/f) is equally in line with the general ratios in Belgian nursing programmes (14% - 86%). The age is also in line with what can be expected according to the year of birth of the final-year student since this study was conducted in 2020 and 2021. A majority of the students (82%) had already done an internship in mental healthcare, which is explained by the obligation for students to come into contact with psychiatric patients during their first 3 years of training. Most schools opt for an internship, but some university colleges choose a project week. Taking all these data together, we can conclude that our sample is representative of the nursing students in Flanders. There are university colleges represented from both networks (catholic or laic origin) and at least one university college is represented from each Flemish province. We have no reason to assume that the non-participation of three college universities would have a different outcome.

As previously indicated in the methods section, the questions of this tool were independently translated by three experts from different fields: A native English speaker, a healthcare education expert and an end-of-life care specialist. Both the healthcare education expert and end-of-life care specialist confirmed the face validity of the proposed items. The translation was obtained by consensus after five rounds. Looking at the internal consistency of the UMS-EAS-NL, we obtain a Cronbach's alpha of 0.812. This score is in line with the original study (Tordella & Neutens, 1979) ( $\alpha = 0.84$ ), as well as the one obtained previously by authors in the Chinese version (Tang et al., 2010) ( $\alpha = 0.84$ ), and in the Spanish

		M	Corrected item-Total correlation	Cronbach's alpha if item deleted
1a	A person with a mental illness has the right to decide to die.	4.15	0.721	0.788
1b	Inducing death for merciful reason is wrong.	3.04	0.340	0.806
1c	UMS euthanasia should be accepted in today's society.	4.14	0.682	0.789
1d	There are never cases when UMS euthanasia is appropriate.	4.11	0.599	0.793
1e	UMS euthanasia is helpful at the right time and place.	4.00	0.604	0.793
1f	UMS euthanasia is a human act.	3.82	0.559	0.795
1g	UMS euthanasia should be against the law.	4.37	0.637	0.793
1h	UMS euthanasia should be applied when a mentally ill person is out of treatment.	3.18	0.090	0.822
1i	The taking of human life is wrong no matter what the circumstances.	4.31	0.686	0.788
1j	UMS euthanasia is acceptable in cases when all hope of recovery is gone.	2.15	-0.486	0.849
1k	UMS euthanasia gives a person a chance to die with dignity.	4.32	0.661	0.790
2a	UMS euthanasia is acceptable if the person is 75 years or older.	1.56	-0.469	0.836
2b	If a mentally incurable person is increasingly concerned about the burden that his or her deterioration of health has placed on his or her family, I will support his or her request for euthanasia.	3.18	0.309	0.808
2c	UMS euthanasia will lead to abuses	3.55	0.502	0.798
2d	I have faith in the Belgian medical system to implement UMS euthanasia properly.	3.48	0.333	0.807
3a	There are very few cases when UMS euthanasia is acceptable.	3.47	0.373	0.805
3b	UMS euthanasia should be practiced only to eliminate physical pain and not mental suffering.	4.37	0.552	0.798
3c	One's job is to sustain and preserve life, not to end it.	3.52	0.583	0.792
3d	One of the key professional ethics of physicians is to prolong lives, not to end lives.	3.66	0.488	0.798
4a	A person should not be kept alive by machines.	3.42	0.108	0.818
4b	Natural death is a cure for suffering.	3.14	0.272	0.810

TABLE 1 Means (M), corrected item-Total correlation, and Cronbach's alpha if item is deleted, of the total EAS scores. (N = 273)

version (Onieva-Zafra et al., 2020) ( $\alpha = 0.87$ ). A Cronbach's alpha of 0.812 is generally acceptable, adequate, and robust, and indicates that the adopted scale is fit for purpose. McDonald's omega is another reliability coefficient which is similar to Cronbach's alpha and has the same interpretation and reporting (Hayes & Coutts, 2020).

However, McDonald's omega remains unbiased with congeneric items with uncorrelated errors because it considers the strength of the association between items and constructs, as well as item-specific measurement errors. This is because factor loadings are allowed to vary, in contrast to Cronbach's alpha, where item factor

TABLE 2 Attitude towards UMS-euthanasia of final-year nursing students in Flanders, 2021 (N = 273)

		Mdn	IQR	Strongly agree N (%)	Agree N (%)	Neutral N (%)	Disagree N (%)	Strongly disagree N (%)
<b>Ethical considerations</b>								
1a	A person with a mental illness has the right to decide to die.	4	4-5	101 (37)	132 (48)	22 (8)	15 (5)	3 (1)
1b	Inducing death for merciful reason is wrong.	3	2-4	25 (9)	53 (19)	101 (37)	73 (27)	21 (8)
1c	UMS-euthanasia should be accepted in today's society.	4	4-5	104 (38)	126 (46)	25 (9)	13 (5)	5 (2)
1d	There are never cases when UMS-euthanasia is appropriate.	4	4-5	5 (2)	15 (5)	31 (11)	117 (43)	105 (38)
1e	UMS-euthanasia is helpful at the right time and place.	4	4-5	85 (31)	133 (49)	28 (10)	25 (9)	2 (1)
1f	UMS-euthanasia is a human act.	4	3-4	67 (25)	122 (45)	55 (20)	25 (9)	4 (1)
1g	UMS-euthanasia should be against the law.	5	4-5	3 (1)	9 (3)	20 (7)	93 (34)	148 (54)
1h	UMS-euthanasia should be applied when a mentally ill person is out of treatment.	3	2-4	25 (9)	53 (19)	76 (28)	87 (32)	32 (12)
1i	The taking of human life is wrong no matter what the circumstances.	5	4-5	148 (54)	85 (31)	25 (9)	7 (3)	8 (3)
1j	UMS-euthanasia is acceptable in cases when all hope of recovery is gone.	2	1-3	7 (3)	13 (5)	40 (15)	112 (41)	83 (30)
1k	UMS-euthanasia gives a person a chance to die with dignity.	5	4-5	141 (52)	99 (36)	16 (6)	12 (4)	5 (2)
<b>Treasuring life</b>								
2a	UMS-euthanasia is only acceptable if the person is 75 years or older.	1	1-2	2 (1)	4 (1)	16 (6)	102 (37)	149 (55)
2b	If a mentally incurable person is increasingly concerned about the burden that his or her deterioration of health has placed on his or her family, I will support his or her request for euthanasia.	3	2-4	27 (10)	87 (32)	88 (32)	51 (19)	20 (7)
2c	UMS-euthanasia will lead to abuses.	4	3-4	7 (3)	36 (13)	72 (26)	115 (42)	43 (16)
2d	I have faith in the Belgian medical system to implement UMS-euthanasia properly.	4	3-4	31 (11)	126 (46)	70 (26)	36 (13)	10 (4)
<b>Practical considerations</b>								
3a	There are very few cases when UMS-euthanasia is acceptable.	4	3-4	8 (3)	45 (16)	74 (27)	102 (37)	44 (16)
3b	UMS-euthanasia should be practiced only to eliminate physical pain and not mental suffering.	5	4-5	1 (1)	8 (3)	20 (7)	105 (38)	139 (51)
3c	One's job is to sustain and preserve life, not to end it.	4	3-4	14 (5)	32 (12)	74 (27)	104 (38)	49 (18)
3d	One of the key professional ethics of physicians is to prolong lives, not to end lives.	4	3-4	7 (3)	34 (12)	65 (24)	107 (39)	60 (22)
<b>Naturalistic beliefs</b>								
4a	A person should not be kept alive by machines.	3	3-4	41 (15)	88 (32)	98 (36)	37 (14)	9 (3)
4b	Natural death is a cure for suffering.	3	2-4	10 (4)	63 (23)	108 (40)	63 (23)	29 (11)

Abbreviations: Mdn, median; IQR, interquartile range.

		U	Z	p
	Gender (n)			
Total UMS-EAS-NL	Male (36)	4036.500	-0.520	0.603
	Female (237)			
	Year of birth (n)			
Total UMS-EAS-NL	≤1999 (181)	7700.000	-1.016	0.310
	>1999 (92)			
	Mental health placement (n)			
Total UMS-EAS-NL	Yes (224)	5443.500	-1.001	0.929
	No (49)			
	Ever involved in euthanasia (n)			
Total UMS-EAS-NL	Yes (154)	8256.500	-1.403	0.161
	No (119)			
Ethical considerations	Yes	7983.500	-1.828	0.068
	No			
Practical considerations	Yes	9115.500	-0.074	0.941
	No			
Treasuring life	Yes	8090.500	-1.669	0.095
	No			
Naturalistic beliefs	Yes	8142.000	-1.637	0.102
	No			

TABLE 3 Independent-sample Mann-Whitney U test between total UMS-EAS-NL and demographic, education-related data. (N = 273)

loadings on a single target factor are equal (Watkins, 2017). As a result, McDonald's omega provides more realistic estimates of true reliability when items vary in their relation to the underlying dimension. In our case, McDonald's omega was 0.838 and therefore indicates a high internal consistency. There are two items with very low corrected item-total correlation scores: item 1 h (0.090) and item 4a (0.108). A low corrected item-total correlation score indicates that this question is not really related to the construct it is assumed to measure (Zijlmans et al., 2019). It should therefore be considered whether this question should be kept. Extensive analyses have already been carried out on the EAS and these have kept the existing 21 questions despite a lower corrected item-total correlation score on a question (Onieva-Zafra et al., 2020). While we propose to keep these items despite their poor psychometric properties, for the purpose of comparison with the translations in other languages, our analysis clearly indicates that they are not informative. In terms of factor analysis, six factors were initially presented. After analysis, we end up with the same number of factors as in the previous studies, namely four (Chong et al., 2004; Onieva-Zafra et al., 2020). These four factors explain 53.953% of the total variance, which is comparable with previous studies where percentages were found between 52.79% and 56.74%. However, the items that load on the different factors are different than those reported in those studies. This can possibly be explained by the fact that the translation into Dutch involves different wording, but also that euthanasia was defined as UMS euthanasia. This means that, in addition to the language differences, there are also differences in terms of content because some questions were given a different context. However, the validity of

the questionnaire was not compromised. When this study can be conducted with larger numbers, we may notice a shift in the factors. Furthermore, the previous studies were conducted in a country where euthanasia is not legal, whereas it is in Belgium. This may also change the content of the factors. Using this information, a new model might be constructed which's properties will be examined by means of a new confirmatory factor analysis, but this was not the ultimate aim of this study.

As indicated earlier, Belgium is one of the countries in which euthanasia has been legalized (Mroz et al., 2021). Besides euthanasia because of unbearable suffering due to a terminal disease, euthanasia for unbearable suffering due to a non-terminal disease is also permitted under strict conditions, and as such UMS-euthanasia falls under the regulation for unbearable suffering due to a non-terminal disease. The figures about the number of euthanasia carried out in Belgium in 2020 ( $n = 2444$ ) show that 0.9% ( $n = 21$ ) were considered UMS (Belgian Ministry of Justice. Euthanasia – Numbers of the year 2020, 2022 March 31). This indicates that despite the legal option, UMS-euthanasia is still rare. This may be explained by the strict regulation as well as the caution that must be exercised in the case of unbearable suffering due to a non-terminal disease. Although legally possible, specific problems arise in assessing the suitability of patients requesting euthanasia due to psychological suffering caused by a psychiatric disorder. The level of unbearable suffering is less comprehensible than in the case of a terminal illness. In addition, clarifying the competence of the patient is complex because the wish to die can be part of the psychiatric pathology. Finally, assessing mental pain has a

shorter tradition than measuring pain in physical illness (De Hert et al., 2015). A descriptive study of 100 Belgian patients who requested UMS-euthanasia indicates that 35 patients were granted euthanasia. It is, therefore, not the case that a request is automatically approved despite its legality (Thienpont et al., 2015).

Looking at the results of our study, it is notable that the majority of final-year nursing students are supportive of the probability of UMS-euthanasia. They indicated that euthanasia should be possible both for patients with unbearable suffering due to a terminal illness and for those with unbearable mental suffering (mostly not due to terminal illness). What is striking about these results is that a large majority (82%) states that UMS-euthanasia should be accepted by society. However, this is not yet the case in Belgian society. This could be illustrated by the Tine Nys case (a local lawsuit) whereby three doctors were accused of murder by poisoning in the case of a UMS-euthanasia procedure but were not subsequently condemned (Day, 2018). Nevertheless, this case has caused a stir in the national politics and media. UMS-euthanasia should be approached with caution due to the difficulties of unbearable mental suffering, such as remaining therapeutic options, capacity to act, awareness, and estimating the degree of pain. This is also reflected in two studies on attitudes of working psychiatric nurses towards UMS-euthanasia (De Hert et al., 2015; Demedts et al., 2018). Despite the complexities involved in unbearable mental suffering, final-year students show a high degree of acceptability towards UMS-euthanasia, showing clinically important, but no significant differences between those students who had ever been involved in euthanasia and those who had not. This finding is important because it suggests that a previous experience with euthanasia does not influence the attitudes towards UMS-euthanasia. This can be explained by the fact that generations change behaviours, attitudes, and reasoning through their own experiences (Onieva-Zafra et al., 2020.) Furthermore, the law in Belgium has existed for 20 years, which makes euthanasia more established (Mroz et al., 2021). We cannot compare with previous or current generations because there are no studies about UMS-euthanasia and nursing students.

Some students do show some caution. There are less pronounced results when UMS-euthanasia becomes compulsory or whether or not they will support a request. They do not believe that the legislation will lead to abuse (58%) but that it will be implemented correctly (57%). UMS-euthanasia should be limited to a few cases (53%). A slight majority indicates that their job does not necessarily involve sustaining and preserving life (56%), nor prolonging it (61%). Finally, there are less pronounced results about natural death as a cure for suffering, nor for mechanical life support.

To monitor adequate care, it is necessary to prepare nursing students adequately for this complex matter. Given that 154 students (56%) in this study had been involved in euthanasia procedures (not specified to UMS-euthanasia) as nursing trainees or as family members, the results suggest that there is a real chance that, as a nurse, one may be involved in euthanasia at some point. It does not matter whether an individual becomes involved in the process as a nurse or

as a family member, as one cannot disregard the role of a nurse. In countries where UMS-euthanasia is legal, it is therefore the task of education to prepare nursing students optimally for their future role as a healthcare expert. Especially since differences in attitudes are found between students who were involved in euthanasia and those who were not. The students who had already come into contact with euthanasia had higher averages and thus showed a higher degree of acceptance. De Hert et al. (2015) and Demedts et al. (2018) indicate that psychiatric nurses feel insufficiently prepared for their future task, theoretically and practically. Whereas we can state that some of these nurses had already graduated when the Belgian euthanasia law came into force, this is not the case for the current nursing students. However, Demedts et al. (2022) indicate that current nursing students also feel inadequately prepared. This instrument and results are only one strand of a larger awareness-raising package. In addition to becoming aware of their own attitudes, students should also be educated in psychopathology, ethics, law, and communication skills. Theoretical education is only part of the solution. The integration of theories, and philosophy behind such a procedure as well as the personal attitude seems essential. Discussion groups are also a way of achieving integration. Depending on the phase of their education, these can be mono or multidisciplinary. Selter et al. (2022) suggest that it may be useful for general practitioners and palliative care providers to talk to professionals from small animal practices. Even though there is a vast difference between euthanasia in humans and in animals, the experience may be somehow similar. After all, small pets are increasingly seen as family members, which makes the experience somehow related. Thus, there is considerable emotional and psychological distress in both cases. Discussion groups in which opinions and experiences are shared can be an added value for both student groups. In addition to discussion groups, simulation training gives students the opportunity to practice in a safe but authentic environment where they are encouraged to learn from mistakes but also to combine all their knowledge and skills. This increases the students' confidence, competence, and knowledge (Vermeulen et al., 2017).

## 5.1 | Limitations

This study indicates that more than half of the respondents have already been confronted with euthanasia. It is possible that those students who have already had contact with euthanasia were more inclined to participate than students for whom this topic is less familiar. Therefore, the indicated percentage may give a distorted picture of reality. To reach these students, we would have liked to visit the university colleges ourselves to explain the study and distribute the questionnaires. By doing so, we might have obtained a higher response rate with possibly more nuanced figures because the results showed that there were clinically significant differences between students who had already experienced euthanasia and those who had not. However, this was not possible due to the coronation measures in place at the time.



## 6 | CONCLUSION

The translation of the EAS into Dutch, as well as its adaptation to UMS-euthanasia, proved that UMS-EAS-NL is a valid and reliable tool with similar psychometric aspects to those found previously. Students showed a high acceptability towards UMS-euthanasia. Clinically important differences were found for students who had ever been involved in euthanasia. The UMS-EAS-NL questionnaire can be used to assess the attitude towards UMS-euthanasia and can be an added value to the overall education which should focus more on the integration of knowledge and skills about UMS-euthanasia.

### AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE): (1) substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content.

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### CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

### PEER REVIEW

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### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available in Mendeley at <https://data.mendeley.com/datasets/4y3txnhg8z/1>.

### CLINICAL TRIAL REGISTRATION NUMBER AND NAME OF TRIAL REGISTER

This study was not registered.

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# Nurse practitioners on 'the leading edge' of medication abortion care: A feminist qualitative approach

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## Abstract

**Aims:** To explore nurse practitioners' experiences of medication abortion implementation in Canada and to identify ways to further support the implementation of medication abortion by nurse practitioners in Canada.

**Design:** A qualitative approach informed by feminist theory and integrated knowledge translation.

**Methods:** Qualitative interviews with stakeholders and nurse practitioners between January 2020 and May 2021. Data were analysed using critical feminist theory.

**Results:** Participants included 20 stakeholders, 16 nurse practitioner abortion providers, and seven nurse practitioners who did not provide abortions. We found that nurse practitioners conduct educational, communication and networking activities in the implementation of medication abortion in their communities. Nurse practitioners navigated resistance to abortion care in the health system from employers, colleagues and funders. Participants valued making abortion care more accessible to their patients and indicated that normalizing medication abortion in primary care was important to them.

**Conclusion:** When trained in abortion care and supported by employers, nurse practitioners are leaders of abortion care in their communities and want to provide accessible, inclusive services to their patients. We recommend nursing curricula integrate abortion services in education, and that policymakers and health administrators partner with nurses, physicians, midwives, social workers and pharmacists, for comprehensive provincial/territorial sexual and reproductive health strategies for primary care.

**Impact:** The findings from this study may inform future policy, health administration and curriculum decisions related to reproductive health, and raise awareness about the crucial role of nurse practitioners in abortion care and contributions to reproductive health equity.

**Patient or Public Contribution:** This study focused on provider experiences. In-kind support was provided by Action Canada for Sexual Health & Rights, an organization that provides direct support and resources to the public and is committed to advocating on behalf of patients and the public seeking sexual and reproductive health services.

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## KEYWORDS

abortion, feminist theory, health services research, nurse practitioner, nursing, qualitative methods, reproductive health

## 1 | INTRODUCTION

More than 73 million abortions occur annually worldwide (Bearak et al., 2020). Access to safe and efficient abortion is a matter of gender and reproductive equity, ensuring an individual's ability to control one's life, enjoy sexuality and "participate fully in society" (Our Bodies Our Selves, 2022, p. n/a). Where available, medication abortion via the drug combination mifepristone (200mg) and misoprostol (2×400mcg) has expanded access to abortion. It is a safe and effective form of abortion (Aiken et al., 2022; Chen & Creinin, 2015; Schummers et al., 2022; Upadhyay et al., 2022) available in over 60 countries worldwide. Patient acceptability of medication abortion is high (Reynolds-Wright et al., 2021) and may provide pregnant people autonomy during their abortions as it can be taken at home (Erdman et al., 2018).

In Canada, medication abortion is authorized to be prescribed up to 63 days (9 weeks) gestation. Prior to mifepristone, only physicians were authorized to perform abortions in Canada. Due to the safety of medication abortion and ample international evidence of the competency and effectiveness of nurse-delivered abortion (Barnard et al., 2015; de Moel-Mandel et al., 2019; Mainey et al., 2020), nursing regulatory colleges across Canada began in 2017 to authorize nurse practitioners (NPs) to independently provide mifepristone medication abortion care. The decision was transformative; NPs became the first "non-physician" independent providers of abortion in the country. Nurses have played key roles in the provision of essential family planning services including sexual health education, contraceptive counselling, and abortion care. Nurse practitioners hold a Master of Nursing graduate degree, and their legal scope of practice includes assessment, diagnosis, prescription and treatment. In Canada, there are over 6600 NPs who work in a variety of settings, including primary care, community care, public health and long-term care (Canadian Institute for Health Information, 2021; Canadian Nurses Association, 2022). NPs provide a range of family planning services for communities and can increase the availability of medication abortion in rural and remote areas (Canadian Nurses Association, 2017; Norman et al., 2019). The optimization of the nursing role in abortion care has great potential for health equity and for meeting the needs of those facing significant structure and social barriers including Black, Indigenous and people of colour (BIPOC) and 2SLGBTQ+ individuals (Carson et al., 2022; Lathrop, 2013) because of the settings in which they work, training and nursing ethos (McCaffrey & McConnell, 2015).

The experiences of NPs with the recent implementation of medication abortion and the impact on their practices and communities require further exploration. NP provision of medication abortion has the potential to further normalize abortion in primary care, and support health equity and patient autonomy (Carson et al., 2022). In

what follows, we present qualitative findings from a study about NP implementation of medication abortion in Canada. We include perspectives from NPs who provide and do not provide medication for abortion and key stakeholders in government, health administration and advocacy. We take a critical feminist approach to understand: What roles have NPs played in the implementation of medication abortion in Canada? What value do NPs bring to abortion care and what are the ongoing challenges they face? We categorize our findings into three themes: (1) Facilitating implementation through informal education, mentorship and networking; (2) Navigating resistance to NP-provided medication abortion; (3) Promoting equity values and normalizing accessible medication abortion in primary care. We discuss the implications of these findings and provide recommendations for policy and organizational stakeholders and researchers to support the implementation of NP-provided medication abortion to improve reproductive health equity.

## 2 | BACKGROUND

The availability of medication abortion expands the options for those experiencing an unintended pregnancy and may mean more control for pregnant people over their abortions. In a review of qualitative literature about women/pregnant people's choice to terminate a pregnancy, Lie et al. (2008) found that for those who were concerned about negative judgements, social attitudes, and privacy about their abortions, medication abortion was appealing, albeit with some concerns about management and safety at home. Medication abortion may provide patients more autonomy and comfort during their abortions.

Like many health services, medication abortion access in Canada evolved during the COVID-19 pandemic, including improved availability of consultations and counselling through telemedicine and ordering prescriptions over the phone. Some propose taking abortions entirely out of the clinical realm. Prandini Assis and Larrea (2020) argue this is not a new practice and that women and pregnant people have used self-care methods to regulate fertility and prevent pregnancy for centuries. According to Joffe (2009), laws to regulate abortion were introduced in the nineteenth century and physicians were some of the loudest proponents of abortion regulation. This extended the medical purview to family planning from its prior location in intimate circles of care.

The integration of abortion into formal health care institutions and criminal law facilitated the development of a perspective that abortion outside formal clinical settings is less safe and a temporary measure until barriers and legal restrictions are removed and people can access formal facilities (Erdman et al., 2018). However, Erdman et al. (2018) argue that medication abortion outside formal facilities

is a form of harm reduction that allows people facing intersecting structural and social barriers to avoid surveillance and potential violence. In dozens of countries, feminist abortion hotlines exist where people and providers are joined together outside formal settings virtually or by phone. In countries with restrictions on pharmacies dispensing mifepristone/misoprostol, internet-based telemedicine services allow people to access information as well as medications via mail (Jelinska & Yanow, 2018).

There are scholars and health professionals who have advocated for autonomy in clinical decision-making and people having control over their health. Medicine has a long history of paternalism and violence, especially towards 'non-normative' bodies including women, people of colour, and people living with disabilities (Jewkes & Penn-Kekana, 2015; Page, 2020; Samra & Hankivsky, 2021). Altshuler et al. (2017) interviewed 21 women in the United States about their abortion experiences and found that their emotional needs during abortion care varied and that women valued being affirmed as 'moral decision makers' by their health providers.

Nurses are well-positioned to support pregnant people during their abortions. In the United States, a prospective observational study of over 9000 women about experiences with abortion care found that patients were very satisfied with abortion care from providers who were trained in abortion, including nurses (Taylor et al., 2013). In a scoping review of nurses' and midwives' roles in abortion care, Mainey et al. (2020) found nine studies identified that psychosocial aspects of care were important to nurses and midwives who provided abortions (e.g., non-judgmental counselling, interpersonal skills, developing therapeutic relationships, professional boundaries, awareness of patient comfort and emotional needs). Nurses who are trained in abortion care are well-suited to support harm reduction due to the identity and ethos of nurses which centres on engaging with patients from a compassionate perspective that considers the whole person and the needs of their families (McCaffrey & McConnell, 2015). Further, as primary care providers with a high presence in rural and remote communities in Canada (Martin-Misener et al., 2020), nurses and NPs may increase awareness of pregnancy termination options for people in the communities where they practice and facilitate informed decision-making (Mainey et al., 2020).

In this paper, we take a feminist qualitative approach to examine NP experiences of abortion provision. Lebold and MacDonnell (2020) call for the application of critical feminist lenses in nursing for a deeper reflection on the evolving practice of abortion in nursing care. A qualitative approach allows for in-depth and nuanced reflection on experiences and how broad policies and health systems structures affect the adoption of abortion into nursing practice. In this article, we describe the experiences of NPs with medication abortion implementation in Canada and explore how values, structures, and dynamics of power constrain and facilitate the implementation of mifepristone in NP practice. These findings contribute to advancing the international literature on nursing and abortion.

### 3 | THE STUDY

#### 3.1 | Aim/s

This study had two overarching aims: (1) To describe the experiences of NPs with medication abortion implementation—including those not currently providing. (2) To identify how to further support the implementation of medication abortion amongst NPs in Canada.

#### 3.2 | Design

In this article, we report on the qualitative findings of The CART NP Mifepristone Study, a nationally funded study about NP implementation of medication abortion in Canada. The study used a qualitative design and analysis informed by critical feminist theory. Critical approaches aim to investigate the meaning and taken-for-granted concepts and ideas that are shaped by our social structures, communication processes and language, which are ever-changing and historically situated (Campbell, & Bunting, 1991; Clarke & Braun, 2019). Broadly, feminist theories investigate topics or social issues in terms of their impacts and implications with respect to sex and gender. Feminist approaches engage with perspectives that elucidate power structures, often taking critical positions whilst pursuing social and political change (Grosz, 1990; Wigginton & LaFrance, 2019). Using a critical feminist approach (Campbell, & Bunting, 1991; Clarke & Braun, 2019), we explored NPs' experiences providing medication abortion care and how these experiences were shaped by sex and gendered dynamics of abortion and nursing, and social values and norms. This approach allowed us to unpack participants' experiences through a lens of health and social systems, policies and values.

#### 3.3 | Sample/participants

The sample included licensed NPs in any Canadian province or territory who provided medication abortion and NPs who were not providing medication abortion, as well as stakeholders including decision makers in the health policy system and related to medication abortion. Participants were recruited through: (1) health professional organizations and societies; (2) snowball sampling; (3) The CART NP Mifepristone Survey (<https://cart-grac.ubc.ca/np-mifepri-stone-study/>). An email invitation to participate in a qualitative interview was sent to potential NP and stakeholder participants through health professional organizations, societies, and networks. Snowball sampling (Given, 2008) was done at the end of each interview, by asking participants to share information about our study with NPs or stakeholders who they thought might be interested in speaking with us. Lastly, participants were recruited from a sample of NPs who responded to our study's quantitative survey component, and who indicated they would be willing to be contacted about participating in a qualitative interview. The following nursing associations assisted with survey distribution: British



Columbia Nurse Practitioners Association; L'Association des infirmières praticiennes spécialisées du Québec (AIPSQ); Newfoundland and Labrador Nurse Practitioners Association; Nurse Practitioners Association of Alberta; Nurse Practitioners Association of Canada; Nurse Practitioners Association of Ontario; Nurse Practitioners Association of Manitoba; Nurses Association of New Brunswick; Nurse Practitioners Association of Nova Scotia; Prince Edward Island Nurse Practitioners Association; Saskatchewan Association of Nurse Practitioners. Additionally, the survey was distributed amongst members of the National Abortion Federation of Canada and the Canadian Abortion Providers Support (CAPS) Network. The sample of survey respondents was purposefully selected (Coyne, 1997; Patton, 1990) to allow for a deeper understanding of perspectives across different settings and communities. Participants were not remunerated for their involvement in the qualitative interviews.

### 3.4 | Data collection

All participants were offered participation in English or French. We designed the NP interview guide to elicit participants' experiences with medication abortion, including their perceptions of the implementation process broadly and in their own practices, the impact on their patients and communities, ongoing challenges, and the value of NP provision of abortion care. For NPs who were not currently providing medication abortion, we asked questions about their motivation to provide or not provide, their practice settings and population challenges to provision and the priority level for the provision of abortion care in their practices. We asked participants about their training to provide abortion, including mentorship. The stakeholder interview guide was designed to capture the legislative, regulatory, scope of practice and/or health administrative landscape of medication abortion in Canada and included questions about the introduction and evolution of mifepristone in Canada, key facilitators and/or champions and barriers. The interview guides were developed iteratively. Co-investigators, including clinical and methodological experts, met several times to review and revise questions as needed. Four researchers trained in qualitative research conducted the interviews (including co-authors AC, ESC, MP).

### 3.5 | Ethical considerations

Ethics approval for this study was obtained in 2019 from Nova Scotia Health (previously Nova Scotia Health Authority) and the University of British Columbia. Participants were given the choice to be interviewed in English or French and emailed an informed consent document to review and sign prior to participation.

### 3.6 | Data analysis

The focus of our analysis was on participants' perspectives of, and experiences with, medication abortion and contextualizing these

stories within the socio-historical context in which they were told. This included the evolution of legislation and regulatory restrictions in each province/territory, health professional culture and norms and acceptance and/or stigma surrounding abortion care. We highlighted recurring ideas and concepts throughout and between interviews, including inconsistencies or contradictions. The analysis process was as follows: The interviewers wrote memos following each interview which included impressions and key takeaways from the conversation. Weekly meetings were held with members of the researcher team during the interview phase to debrief about the process and to make any adjustments to the questions or approach. Two researchers (AC, ESC) conducted multiple readings of each transcript. They then categorized the data into broad descriptive categories (e.g., descriptive of care process; motivation for providing abortion; collaboration with other health professionals) to understand the topics in the interviews. Following this descriptive categorization or coding, each researcher read through each transcript again whilst writing 'analytic memos' directly onto the transcripts using the footnotes and highlight features. These analytic memos were a way for the researchers to add their interpretive voice and reflections on what was going on in the text, in open-ended long-form. During analysis, regular weekly meetings were held with several members of the research team to discuss developing findings, raise questions and refine ideas.

### 3.7 | Credibility, dependability, transferability

We use the concepts of credibility, dependability and transferability to ensure the trustworthiness of findings. Credibility refers to the interpretation of experiences in a way that someone who shared that experience would recognize and relate (Lincoln & Guba, 1985). We ensured credibility through study design by co-developing the protocol with researchers, clinicians—including NPs—and stakeholders in government and advocacy. During analysis, we ensured credibility through reflexivity, peer examination and debriefing, and maintaining a closeness to participants' words during the presentation of findings. Reflexivity is a researcher's orientation toward any research endeavour in which they view themselves as an active and ongoing part of interpretation, one in which social location and assumptions should be continuously reflected on, including their role in shaping the production of knowledge (Kincheloe et al., 2017). As such, reflexivity is an active part of the research process. We held regular weekly meetings with team members (nurses, NPs, physicians, researchers), and quarterly meetings with the larger team, including knowledge users, to get feedback on data and the emergent categories and themes. This process involved questioning the findings and our interpretations such that the final themes would adequately reflect the data, the NP experience, and the context of medication abortion in Canada.

Dependability in qualitative research occurs when another researcher is able to follow the decision trail of the study including choice of participants, data collection, and recruitment, in a way that is logical and appropriate, and interpretation and analysis are



well-explained (Lincoln & Guba, 1985). We documented all decisions and any changes made to the original protocol were reviewed and approved by senior researchers on the team. Transferability refers to the degree to which findings or methods/theories from a qualitative study can be transferred to other contexts (Lincoln & Guba, 1985). As such, we thoroughly described and tracked our research approach (theory, methods, analysis) and participant demographics so as to be adapted by other researchers if desired.

## 4 | FINDINGS

Forty-three people participated in the qualitative study. Stakeholders ( $n = 20$ ) worked in the following settings: health administration, government, advisory roles, regulation, nursing advocacy and reproductive/sexual health advocacy. Of the 23 NPs who participated, 16 provided medication abortion at the time of participation and seven did not provide medication abortion at the time of participation. The number of years in practice since becoming an NP ranged from less than 2 years to over 20. We have included additional demographics of NP participants in Table 1. Interviews ranged from 30 min to 1 h in length. Pseudonyms were used for all participants.

We organized the data into three main themes that capture the NP role in medication abortion in Canada since mifepristone's approval, their leadership, and ongoing challenges: (1) facilitating the implementation of medication abortion through informal education, mentorship, and networking; (2) navigating resistance to the

implementation of medication abortion; (3) promoting equity values and normalizing accessible abortion in primary care.

### 4.1 | Facilitating implementation of mifepristone through mentorship and education

Provider NPs described ways they facilitated the implementation of medication abortion in their practices to make provision more efficient and to improve patient experiences. No participant reported having received abortion training as part of their initial NP education, outside of individually-sought practicums in reproductive and sexual healthcare. They came to abortion provision through independent pathways. They developed and tailored protocols for medication abortion; hired, supported and mentored colleagues to share the work of medication abortion provision; provided informal education to other health providers about Health Canada regulations and best practices; networked with lab technicians and allied clinics to expedite referrals and appointments for blood work or ultrasound dating. One NP, referred to as 'Chloe', describes her role in educating physician colleagues about mifepristone and becoming the 'spokesperson' for this care. This was common across interviews, where current NP providers were engaged in educating colleagues or health professionals in the community.

There's a lack of [provider] knowledge [about medication abortion]. I did a number of information sessions,

TABLE 1 NP participant demographics

Category	Sub-category	Total
Province	Atlantic Canada (NB, NS, PEI, NL)	5
	British Columbia	3
	Northwest Territories, Nunavut, Yukon	1
	Ontario	8
	Prairies (AB, SK, MB)	5
	Quebec	1
	Total:	23
Gender <sup>a</sup>	Female	20
	Male	3
	Total:	23
Community setting	Remote	1
	Rural	6
	Urban	16
	Total:	23
Practice type	Primary care	14
	Sexual and reproductive health	4
	Women's health	5
	Total:	23

Abbreviations: AB, Alberta; MB, Manitoba; NB, New Brunswick; NL, Newfoundland & Labrador; NS, Nova Scotia; PEI, Prince Edward Island; SK, Saskatchewan.

<sup>a</sup>NP participants were asked the open-ended question, "what is your gender?" The binary categories represented here reflect participants' responses.

I actually had a few physicians who came to the sessions, and I think that my role is just to try to teach them. I also did some one-on-one, answered some questions from a lot of doctors during medical meetings on the subject, so I remain the spokesperson and I really tried to take initiative in that sense. It's been a lot better since I've been able to inform them, getting my colleagues in line with that and orient them toward the best treatment for the patient. – Chloe, NP provider

Reflecting on their leadership and the informal education and mentorship in which they were engaged, participants discussed their impact on other health professionals. For example, Pamela, an NP abortion provider in an interprofessional practice in an urban setting, reflected on the eagerness of other providers to implement medication abortion in their practices after observing her role as a provider.

I found that since I've started doing this that it's been a bit infectious in our clinic. The other providers have been excited, like 'why is she doing it and I don't get to'. [...] There's been a really good uptake in people that are interested and we have even more providers that don't normally do it are like 'yeah, I want to' or I've had physicians that normally don't do it but they are seeing a patient that wants it and they were like calling me and saying 'could I start doing it? Can you tell me about it because I want to learn?'. That's been kind of cool. It might just be good for people to know that you might seem like you're the only one in your practice that does it but once other people see that it's actually pretty straightforward and very doable and a really helpful service for your clients that you might see some momentum come from that and that other people also want to get on board and provide that service as well. – Pamela, NP provider

In the account above, Pamela suggests being a source of support and a visible provider has increased interest in providing amongst other health professionals in her community and helped them to feel less isolated when beginning to implement mifepristone in practice. Similarly, NP providers of mifepristone stated that mentorship from colleagues was a key reason they started providing abortion and for their success in implementing it into practice.

[My colleague] made it really easy. I think if I didn't come into this clinic with her already having the trail blazed I may have found it overwhelming to put together the assessment and the education documents, but she very widely shared that and very graciously shares it with anyone that asks. At the presentation that we did last month, she shared everything. Take it, adapt it, do whatever you want. This is the education sheet. You can take off my logo and my name and put

on yours. [...] If it weren't for that I would probably feel a little overwhelmed with how to keep all the moving parts straight, but she's made it so brainless. – Lori, NP provider

Several participants expressed that mentorship was important for their confidence and feeling supported as new providers. Those without access to a provider mentor or colleague(s) found implementation more isolating. Some felt less confident troubleshooting more complex patient scenarios when they did not have a more experienced provider to consult. For some non-providers, lack of mentorship was one of several reasons for not providing. Erica, a stakeholder and physician abortion provider, emphasized the value of mentorship:

In terms of confidence and familiarity, I think having a mentor is so important. In my province, we're small enough that I don't mind being a mentor to anybody [...] What I'm finding now is that once people get experience, I don't hear from them. They're just off doing their thing and the medical abortion piece is just one small part of their general primary care practice whether they're an NP or family physician. – Erica, stakeholder

## 4.2 | Navigating resistance and lack of support for medication abortion provision

The stigma surrounding abortion continues to impact its integration and implementation in Canada's healthcare system. For the NPs in this study, the resistance and/or lack of support for abortion that most impacted their provision of care came from colleagues, employers and fellow health providers in their communities and workplaces.

One of the nurses that works here said to me that my patients don't deserve access to social work because they're choosing not to have their babies. So there definitely is that underlying culture of, you know, we're the bad guys. It creates extra stress and it also bubbles over into other programs and people's willingness to work with you on other things as well. There's definitely some cultural stuff in the clinic that's just always been here and I'm not sure if it will ever be completely avoidable. – Kristen, NP provider

For provider NPs, they tried to navigate resistance or hesitation from others by educating them about professional responsibilities, or, failing that, they decided to work around those specific health professionals. Whilst NPs suggested this was not a major ongoing barrier, some stated there were pharmacies in their communities that refused to stock the medication. NPs knew which pharmacies were efficient and supportive of stocking mifepristone reliably, and which refused to stock it: NPs did not attempt to maintain a relationship with unresponsive pharmacies. In Amanda's story, she describes one incident of

this explicit refusal to stock/dispense the medication from a local pharmacist and how they navigated this situation:

I did have partnership with some pharmacy. One of their part time pharmacists decided they were going to pull some moral bullshit with me and get on a high horse about you shouldn't be terminating pregnancies, this is not appropriate and as a healthcare provider I should not be doing it. I certainly let her know what I was thinking [...] I won't subject my clients to this which is too bad because the pharmacy is across the street from the clinic. The manager told the part time pharmacist either you never do that again or you quit. There are no other options because this is a service we provide, and we provide it for the community and we stock it on our shelves. You don't get to make any judgment call on it. Since then I've had no complaints and no concerns so that's been good, but there are some pharmacies who have declined. – Amanda, NP provider

Whilst Amanda states that these instances are not especially common, this was frustrating and required them to navigate a professional space in which a fellow provider was unwilling to do what was in their professional duty. However, this example demonstrates how, despite pro-choice medical professionals' attempts at normalizing abortion care as 'just another health service', it is still bound up with gendered value judgements and expectations.

Several participants described hiring practices in their clinics/workplaces that attempt to avoid future conflict or refusal to support or provide medication abortion, in situations where that is part of the clinic's day-to-day available services. For example, Pamela describes how during the interview process at their interprofessional primary care clinic, potential hires are asked about their position on abortion care and whether they are pro-choice:

Everyone now is super supportive and even our new locums, it's part of our interview process. We ask any new providers what their thoughts are on abortion, are they supportive of offering that option, would they consider providing medical abortion because we want to make sure we have the right people working that have similar views on pregnancy options and supporting youth. We actually have it as part of our interview process now to make sure that we have people with the right philosophy and stuff coming on board.

– Pamela, NP provider

In the example above, hiring providers based on values (i.e., pro-choice) was intentional and not necessarily something that is needed for a range of other health services in health professional scopes of practice. For others, these hiring practices do little to address prevailing hierarchies in medicine which impact NP's abilities to provide efficient care for patients. For example, Ben is an NP not currently prescribing

medication abortion, but who is heavily involved in the coordination of abortion care (e.g., counselling, referral to physician partner), who faces delays for services such as ultrasounds due to medical hierarchies which shape how lab technicians process their requests.

My colleague and I have said 'should we do it, shouldn't we do it?' Really it comes down to a multi-factorial reason. One is that, ideally you would have efficient access to ultrasound services and your population would be prioritized. I think your NP's would feel a lot more comfortable performing a medical abortion on a client who had a confirmed gestational age by an ultrasound which is recommended, but having that relationship with your Radiology Department where they're going to prioritize your patients in some reasonable fashion isn't necessarily there [for us]. There's different dynamics between a nurse practitioner calling and there's different dynamics between a physician calling asking for an ultrasound. We find we're not always prioritized well for access to dating ultrasounds in terms of needing it for a medical abortion whereas, if our physician calls it would be much more rapidly done so access to imaging. – Ben, NP, non-provider

Ultimately, such hierarchies and lack of acknowledgement of NPs' authority and expertise may jeopardize patient care and the efficiency at which they can provide abortions to patients. This is one factor as to why Ben does not prescribe medication abortion.

There were also stories from participants of less explicit examples of resistance from employers. For example, several NPs recounted that they did not advertise their provision of mifepristone or were careful about what they told funders so as not to compromise future financial support. For some NP providers, this was inconvenient but did not stop them from providing mifepristone. For other NPs, the potential to lose funding, in combination with a lack of employer support to implement medication abortion in their practices, and lack of mentorship or motivation to provide, impacted their decision not to provide mifepristone. Cindy, an NP providing medication abortion in a specialized clinic in an urban area, described the resistance she faced when it came to funding for a point-of-care ultrasound machine that would assist in their provision for abortions:

When we apply for funding, it's often around anti-violence, sexual assault, and those kinds of topics. We wanted to get a point-of-care ultrasound, but we can't figure out how to couch that, because as soon as we say it's for termination of pregnancy there's no one that's going to fund that. Nobody wants to put their name on getting an ultrasound to, you know, 'kill babies'. That's the way they see it [...] We're funded by [regional health authority] but sometimes we'll apply for grants for equipment like a point-of-care

ultrasound or if we need a new exam table or something like that and then you have to justify why you need it and what population you're seeing and that's where our hands get tied. We'd love to have a point-of-care ultrasound but we don't do prenatal care here and so it become sort of like 'why are you needing this?' – Cindy, NP provider

The above example is indicative of the politics which continue to surround medication abortion, despite it being a safe, common and normal healthcare service. Whilst no legislative restrictions exist in Canada around mifepristone, values and attitudes and employer/system priorities and dynamics impact NPs' ability to provide abortion care efficiently (e.g., hesitation to fund equipment being used for abortions).

### 4.3 | Promoting equity values and normalizing accessible abortion in primary care

All participants acknowledged the value that NPs bring to abortion care. Stakeholders specifically discussed the roles that NPs play in communities and how they fill a crucial gap in primary care across the country, especially in rural and remote areas. NPs improve accessibility by increasing the number of abortion providers, as well as providing care closer to home for people.

It's really hard to find a family doctor but nurse practitioners are increasingly involved in community health and they actually know their patients and people trust them and I think that when it comes to somebody seeking an abortion, including medical abortion, it's a huge difference to be able to speak to someone that you trust that you actually know from the community. It's kind of scary going to, potentially having to go a long way to go to a walk-in clinic, an ER room, talk to a stranger after investing a lot of money and time and effort into travelling. I think community health is really high-quality health and nurse practitioners seem to be on the leading edge of that. - Olivia, stakeholder

As Olivia describes, patient trust is particularly important when providing abortion care because it is a stigmatized service, there may be safety concerns for the patient, and time and efficiency are crucial to individuals who are pregnant and no longer want to be.

Participants discussed how, because they do not receive payment on a fee-for-service basis, NPs are able to spend more time with patients, providing information and answering questions. They described the trust that they had built with their patients and that there are many NPs working in primary care, which would allow them to see patients they already know them and with whom they had good relationships. Several participants also discussed the gendered component of the nursing profession and that, whilst there are certainly male abortion providers, pregnant patients may feel more comfortable with receiving

abortion care from a woman provider. Zachary sums up the value of NPs well:

As nurse practitioners, we fill a gap sometimes in the slightly more complicated areas. A fee-for-service, walk-in clinic is not going to do this because it takes a lot of work, but nurse practitioners often fill those gaps for more complicated types of things that require a bit more extended involvement. I think we want to be able to provide that comprehensive care wherever possible and not just refer out all the time and actually have really good conversations around what are the options and how do we approach each one. I think we have a bit of a different approach as well, partly, than medicine does sometimes and just accessibility, having more providers just makes it more accessible to people, especially in rural places, they don't really have other options. Nurse practitioners, nurses, it's a gendered profession as well, it's mostly women, so maybe it's having that large number of female providers might be useful as well rather than having the, I mean don't fit that obviously but just having that as a group that's predominantly female, maybe that would be useful as well. – Zachary, NP provider

Participants further described the value of NP provision of abortion in terms of patient emotional well-being. For example, time was not only discussed by participants in terms of longer appointments, but also in terms of the efficiency of the care process, which was a key factor in terms of mental health and compassionate care.

There is a tendency among our patients who are looking to access medical termination that the sooner the better. Once they've made that choice they want it to be done and they want it to happen now so delays in accessing service can be very hard on them mental health wise, I think and it's causing them anxiety. I get the feeling that they feel almost worst about terminating a pregnancy that's eight weeks versus six and a half. They just want as quick of access as possible. Having that kind of relationship, like I said, with our physician [partner] where usually I can get someone an appointment within two days. It is quite beneficial to the patient. – Ben, NP non-provider

Things change in a week very quickly. You weren't pregnant last week and now you're pregnant and now we're going in a completely different direction because you don't have alternatives and that's why abortion through pill, if it could possibly be feasible in the north, that would be really wonderful because I think that people do change their minds and if we have options available it can change people's lives dramatically. – Diana, NP non-provider

In both examples above, participants describe the need to have an efficient abortion care process, because being pregnant when you do not wish to be is hard on patients and can have mental health implications.

Further, Sophie, a clinic director, emphasizes the importance of including abortion [training] in primary care education from a health equity perspective, because the service potentially impacts at least half of NP patients—those capable of becoming pregnant.

I know that it seems wrong to me that one in three Canadian people capable of becoming pregnant will have an abortion in their lifetime and that half of, at least half of the patient load that any nurse practitioner or physician will see in their, especially in family practice will be capable of becoming pregnant that abortion care isn't an absolutely routine part of the education of nurse practitioners and family docs but it doesn't seem to be. I'm not surprised because abortion has historically been a woman's issue and women's issues are historically not prioritized so I think when I talk about reproductive justice that's another component is moving the needle on what is covered in family medicine education. – Sophie, stakeholder

Importantly, Sophie draws attention to the historical (and present) context of abortion in Canada and broadly, in which sexual and reproductive health services that predominantly affect women and people with a uterus, are not prioritized in healthcare training.

## 5 | DISCUSSION

Our study identified three themes about how NPs experienced the implementation of medication abortion and/or how they understood their roles in relation to medication abortion: (1) educating, mentoring, and networking with other health providers in the community about medication abortion; (2) working around resistance from colleagues/employers/the public to medication abortion provision; (3) integrating health equity principles into abortion provision and advocating for abortions in primary care. For those who were providing, they were often mentors and leaders in their communities. When they were knowledgeable about medication abortion and had the infrastructure and support to incorporate this service in their practice, NPs in this study were at the forefront of normalizing abortion as primary care and expanding access in their communities (e.g., coordinating stock with local pharmacies, hiring pro-choice employees, creating accessible abortion information materials for patients, advocating for sex and gender equity). The perspective of NPs not offering abortions provided important context about gaps in health professional abortion education, health system hierarchies that subordinate the NP role despite their advanced scope of practice and skills, and social norms and values (e.g., moral judgements

about abortion) that permeate clinical spaces through resistance to abortion care.

Our findings are consistent with previous literature which emphasizes the importance and potential impact of educational exposure to sexual and reproductive health training as a student or through an employer (McLemore & Levi, 2017). We found that when NPs possessed the knowledge and motivation to provide medication abortion (and the necessary resources required to provide the service), they were advocates and leaders of abortion provision in their communities. Feminist-informed approaches to medication abortion and patient care are timely and urgent to myth-bust around abortion in Canada, to make the case for abortion training in nursing and medicine pre-licensure education (Cappiello et al., 2017; McLemore & Levi, 2017; Paynter et al., 2019), and to justify the allocation of resources necessary to provide medication abortion in communities and clinics where gaps exist (e.g., timely ultrasound and emergency services closer to home). Programs that provide technical and emotional support to new providers are valuable for the implementation of medication abortion in communities (LaRoche et al., 2022). Such steps will further normalize mifepristone/misoprostol in primary care and destigmatize abortions, with the potential to reduce patient harm and make the process more comfortable—allowing individuals to end an unwanted pregnancy sooner, and with a provider they know and trust (Godfrey et al., 2010; World Health Organization, 2020; Yanow, 2013). Care that is closer to home and from a trusted provider is especially important for pregnant people who face intersecting oppressions and barriers to health system access (Baker et al., 2021).

This study explored the nurse practitioner's experience with medication abortion provision in Canada. We envision that further research will contribute to these findings by investigating patient experiences with abortion care provided by nurse practitioners and interprofessional care teams. We recommend that nursing educators integrate sexual and reproductive health, including abortion care, into curricula and in a way that is feminist and health equity-oriented to be inclusive of all genders, cognizant of intersecting oppressions, and prioritizes patient empowerment. Further, we recommend policymakers and health administrators partner with nurses, physicians, midwives, social workers and pharmacists, for comprehensive provincial/territorial sexual health strategies to reduce barriers for patients, improve care efficiencies, and increase public and provider knowledge of medication abortion.

### 5.1 | Limitations

This study focused on health providers. Future research about patient experiences with abortion, which are feminist-oriented, would enhance knowledge about this important service, including its potential impact on a diversity of patients and communities. Medication abortion via mifepristone/misoprostol is relatively new to Canada;



as the number of providers of medication abortions continues to increase, experiences with implementation and practice may evolve.

## 6 | CONCLUSION

In this study, we aimed to understand the recent implementation of medication abortion in NP practice and communities. Using a feminist framework, we found that NPs navigate social stigma, health system resistance to abortion and health professional hierarchies, to provide medication abortion. NPs are resilient leaders of abortion care in their communities and are trusted by patients to provide care that is inclusive and cognizant of their needs, they continue to confront socio-cultural barriers and power structures which prevent interested NPs from providing this service. NP provision of medication abortion can be supported at multiple levels including nursing education and policy to facilitate interprofessional collaboration and to meet community needs.

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## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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## DATA AVAILABILITY STATEMENT

The data that support the findings are described in detail within the manuscript. The data are not publicly available due to privacy or ethical restrictions.

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ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - QUALITATIVE

# Lived experiences of end-of-life communication among nursing home staff: An interpretive phenomenological study

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#### Abstract

**Aims:** To explore and understand lived experiences of end-of-life communication among nursing home staff.

**Design:** Interpretive phenomenological study.

**Methods:** In-person, semi-structured, in-depth interviews were conducted from May to August 2021 with 21 nursing home staff members involved in end-of-life communication (four managers, four chief nurses, three chief medical officers, three nurses, three psychologists, two occupational therapists, one chief nurse aide and one nurse aide). Data were analysed by van Manen's hermeneutic approach, which uses the life-world existentials of spatiality, corporeality, temporality and relationality to guide reflection on the human experience. Data were reported according to the Consolidated Criteria for Reporting Qualitative Research.

**Results:** Thirteen categories were identified and framed within the four existentials. Regarding spatiality, end-of-life communication took place in a physical, mental, socio-cultural and professional competence space. With regard to corporeality, interviewees reported difficulties in managing their own feelings and those of family caregivers. For temporality, interviewees reported delays in end-of-life communication due to staffing issues and an increase in urgent and temporary relief admissions to nursing homes. To compensate, they tried to assure that all interactions that did take place were of high quality. Finally, with regard to relationality, interviewees lived end-of-life communication through their relationships with family caregivers and colleagues. The supportive role of colleagues was expressed as teamwork, which helped promote reflexivity about how to tailor communication, manage challenging emotions and situations, set aside time for communication, and prepare family caregivers for death.

**Conclusion:** End-of-life communication was an all-encompassing experience for nursing home staff. The supportive role of colleagues was stressed across all existentials, suggesting that teamwork is essential in delivering effective communication at the end-of-life.

**Patient or Public Contribution:** There was no patient or public contribution to this study, which addresses the experiences of nursing home staff only.

## KEYWORDS

communication, end of life, hermeneutics, lifeworld existentials, nurse, nursing home, qualitative study

## 1 | INTRODUCTION

The literature provides several definitions of end-of-life communication in nursing homes (NHs), including (a) a “discussion” about life-sustaining treatments, care goals, advance directives, prognosis or the possibility to withdraw treatments or palliative care options; (b) “speaking” about symptom management or future care; (c) “talking” about how a resident is doing; or (d) “receiving information” about a resident’s health problems or what to expect (Gonella, Basso, et al., 2019). Thorough end-of-life communication has been associated with better quality of care in NHs and has been identified as essential to promote effective person-centred care. High-quality end-of-life communication helps fulfil the physical, psychological, spiritual and existential needs of residents and family caregivers (FCs), and promotes trust and therapeutic alliance (Towsley et al., 2015).

Despite these well-recognized benefits, end-of-life communication in NHs is often poor, delayed or simply absent (Morin et al., 2016). Few NHs enact end-of-life communication systematically, and only a minority have written procedures on the involvement of residents or their FCs in care discussions, or on how to communicate during clinical deterioration or after death (Gonella, Clari, et al., 2021). Missed conversations tend to occur when neither NH staff nor FCs recognize that a resident’s clinical condition is changing, or when either party assumes to know the resident’s end-of-life care preferences (Auriemma et al., 2022; Towsley et al., 2015). Studies have shown missed opportunities for end-of-life communication with physicians, who are often viewed by FCs as “missing in action” (Shield et al., 2005), and little inclusion of FCs in care plan meetings (Reinhardt et al., 2017).

End of life is complex and involves clinical, psychological, social, spiritual, legal and financial concerns. Therefore, proper end-of-life communication requires a multidisciplinary team with corresponding competencies (Anderson et al., 2019; Towsley et al., 2015). Moreover, as responsibilities can be divided by field, pressure on individuals is alleviated (van der Steen et al., 2014). As nurses are often the principle source of information for FCs in NHs, they also routinely coordinate end-of-life communication in multidisciplinary teams (Gonella, Di Giulio, et al., 2022). Indeed, satisfaction with nurse communication has been associated with higher satisfaction with end-of-life care (Liu et al., 2012) and less aggressive treatments in NHs (Gonella, Basso, et al., 2019). Moreover, transnational studies have assessed the effectiveness of training NH nurses to conduct meetings with and support FCs who are presented with difficult decisions about end-of-life care (Harding et al., 2022; Hartigan et al., 2019).

Although a number of studies have explored NH staff’s experiences of end-of-life communication, none has employed qualitative

methodologies based on a dynamic research process in which the researcher has an active role – such as interpretive phenomenology (IP) (Smith et al., 2009)—to provide a more comprehensive, in-depth understanding of the lived experience.

## 2 | BACKGROUND

There is consensus that NH residents and their FCs would benefit more from comfort-oriented care aimed at improving the quality of remaining life than from curative-oriented care meant to prolong survival (van der Steen et al., 2014). End-of-life communication allows residents and their FCs to reflect on and share their care preferences with NH staff. This communication facilitates partnerships, promotes understanding, allows NH staff to organize the care plan, and simplifies transitions in care goals as NH residents’ conditions worsen and death approaches (Anderson et al., 2019; Gonella, Campagna, et al., 2019). Indeed, most residents cannot make care decisions at the end of life, often causing NH staff to rely on FCs (Mitchell et al., 2012). In these situations, good end-of-life communication between FCs and NH staff is crucial, as it reduces FCs’ decision-making burden when a relative’s wishes are unknown (Fosse et al., 2014), counteracts NH staff’s fears of leaving something undone, and avoids legal problems (Furman et al., 2007; Gonella, Basso, et al., 2021). However, end-of-life communication is not always practiced or is delayed until a resident’s health deteriorates (Evenblij et al., 2019). This delay is often justified by fluctuating disease trajectories and a lack of predictive certainty, which add complexity to end-of-life care decisions (Evenblij et al., 2019; Firnhaber et al., 2020). However, the literature also highlights a wide array of staff-related barriers to end-of-life communication that may be anticipated and addressed, including lack of training and multidisciplinary collaboration, uncertainty about prognostication, time pressure, emotional discomfort, lack of confidence, feeling unprepared to initiate and sustain such conversations, and fear of a negative impact on residents (De Vleminck et al., 2014; Furman et al., 2007; Travers & Taylor, 2016; Young et al., 2017).

Understanding the experiences of end-of-life communication among NH staff is critical to better highlighting- and addressing-related challenges. In-depth exploration of these experiences may help identify personal, social, and professional needs, and underpin the development of context-specific strategies to help NH staff engage in these conversations. Moreover, this understanding may help identify difficulties in end-of-life communication that can be used to inform the design and implementation of appropriate services and interventions to improve this communication.

### 3 | THE STUDY

#### 3.1 | Aim

This study aimed to explore and understand the lived experiences of end-of-life communication among NH staff.

#### 3.2 | Design

This is an IP study based on van Manen's hermeneutic approach. IP was preferred because it aims to provide detailed examinations of a person's lived experience and gives an active, dynamic role to the researchers as they try to make sense of the interviewees, who in turn are trying to make sense of their own world. Moreover, IP is idiographic in its commitment to explore each interviewee's experiences deeply before moving towards more general claims (Smith et al., 2009). van Manen's approach is composed of four lifeworld existentials (i.e. lived space or spatiality, lived body or corporeality, lived time or temporality and lived human relations or relationality) and offers a heuristic guide for reflecting on the human experience without imposing predetermined themes (van Manen, 2015). This study is reported according to the COnsolidated criteria for REporting Qualitative research (COREQ) checklist (Tong et al., 2007) (Table S1).

#### 3.3 | Sample/participants

Forty-four NHs in different regions of Northwest Italy were purposively invited to the study to guarantee the greatest variation of data; six accepted to participate. Characteristics of participating NHs (e.g. public/private profile, number of beds, Alzheimer unit, staffing, written procedures on communicating clinical deterioration or bereavement management) have been published elsewhere (Gonella, Di Giulio, et al., 2022). Managers from participating NHs were contacted by telephone and received the study protocol by email.

NH staff were eligible for inclusion if they (a) had a clinical role; (b) had been employed in the facility for at least 6 months; (c) had worked at least 10 shifts in the previous month; (d) communicated with FCs and (e) were willing to participate in the study. Using these criteria, NH managers identified 26 staff members and sent them a preliminary invitation. Twenty-one agreed to participate (Table 1) and their names were given to the research team, who verified that NH staff met all eligibility criteria and then contacted them by phone to arrange an interview. Recruitment continued until no new analytical information was noted. Of the six participating NHs, two contributed with five interviews each, one contributed four, one contributed three and two contributed two interviews each.

TABLE 1 Interviewees' characteristics

Healthcare professionals (n = 21)	N
Female gender	17
Age, years, mean [range]	50 [25–73]
Education	
High school diploma	2
Bachelor's degree	10
Master's degree	9
Professional profile	
Nursing home manager	4
Chief nurse	4
Chief medical officer	3
Nurse	3
Psychologist	3
Occupational therapist	2
Chief nurse aide	1
Nurse aide	1
Overall working experience, years, mean [range]	16 [1–50]
Working experience in nursing home, years, mean [range]	8.5 [0.5–25]
Employment	
Permanent full-time	14
Freelance	6
Permanent part-time	1

#### 3.4 | Data collection

A topic guide based on relevant literature (Anderson et al., 2019) and on the research team's experience in qualitative methodology and end-of-life care was developed and piloted among two NH staff. Only minor amendments were made following the pilot, and the pilot data were not added to the final dataset.

Using the amended topic guide, one researcher (AA) with no relationship to the NH or to interviewees conducted in-person, semi-structured, in-depth interviews from May 2021 to August 2021, while COVID-19-related restrictions were in place. Interviews took place in a quiet, private room of each NH, and interviewees could choose to have the interview before, at the end of or during their work shift. No one other than the interviewee and the researcher was present at the interview. Interviewees could choose the language of the interview, and all chose Italian as the language in which they felt most comfortable expressing their experiences. Only one interview was performed per interviewee, which is deemed sufficient for IP analysis (Smith et al., 2009).

Interview questions included: (a) What has been your experience with providing end-of-life communication in your NH and what does it mean to you?; (b) What has been your experience with starting end-of-life communication?; (c) What has been your experience with

sustaining end-of-life communication? and (d) How have you experienced the relationships with FCs during and after end-of-life communication? The mean duration of interviews was 37 minutes (range 21–67). Audio recordings and field notes were maintained throughout the process.

### 3.5 | Ethical considerations

The Ethics Committee of the University of Torino approved the study protocol (number 0598416/2021). All interviewees received oral and written information about study aim and data collection procedures and provided written informed consent to participate in the study and for their interview to be audio-recorded. Interviewees could stop the interview at any time and for any reason. Transcripts were anonymised for both the NH and the interviewee.

### 3.6 | Data analysis

All audio recordings were transcribed verbatim into a Microsoft Word document alongside the corresponding field notes. One researcher (SG) randomly checked 10 transcripts for accuracy. Anonymised transcripts were exported to Atlas.ti version 8 for data management.

Data analysis involved the phases of data immersion, theoretical and open coding, creation of categories and thematic analysis. To ensure inter-rater agreement, two researchers (BA and SG) repeatedly read interview transcripts to get a full understanding (i.e. data immersion), did an independent analysis and finally met to share their coding sheets. Discrepancies were discussed, and a consensus list of codes was created. This consensus list was used by a third researcher (AC) to recode the full set of transcripts. Field notes were analysed concurrently with the interview transcripts to add more context to the interpretation of findings.

All researchers utilized the four existentials as a framework through which to begin data organization (i.e. theoretical coding), while simultaneously adopting open coding within each existential. All four existentials were explored simultaneously in each transcript. Statements reflecting interviewees' lived experiences of end-of-life communication were highlighted and their meanings were labelled. The same statements could be coded for more than one lifeworld existential since the existentials exist as interconnected facets of the single phenomenon "experiences of end-of-life communication" (Errasti-Ibarrondo et al., 2018). Once all data were coded, the same three researchers (BA, SG and AC) re-reviewed the data independently, to explore how the codes could be related to developing categories that connected the data logically and authentically. Once categories were created, the existentials were employed as

guides for thematical reflection on the meaning of experiences of end-of-life communication by moving beyond descriptions of categories and offering explanation and interpretation (Errasti-Ibarrondo et al., 2018). Repetition of words or synonyms across existentials provided guidance to identify a single overarching category. Then the three researchers engaged in a final discussion to enhance analytical rigour and achieve consensus. These outcomes were then discussed within the research team, so that all researchers could provide feedback and reach consensus. Existentials are illustrated by significant quotes, identified by a code that indicates the staff member's profile and the NH (e.g. nurse/NH1, NH manager/NH2). Quotes deemed illustrative by the research team were translated into English (target language) for the purposes of publication, and back-translated to ensure reliability in reporting. Two different team members (AC and SG) were engaged in the translation and back-translation processes for the purposes of rigour. Both translators understand not only the source and the target languages but also the two cultures (Chen & Boore, 2010).

### 3.7 | Rigour

Guidelines for trustworthiness and authenticity were followed (Lincoln & Guba, 1986). Several strategies were employed to attain credibility and dependability. The semi-structured interviews enabled an in-depth understanding of NH staff's lived experiences of end-of-life communication and were conducted by a graduate nurse who received additional training in conducting qualitative interviews. Moreover, interviewees could review their interview transcript. Two researchers independently analysed transcripts and then met to consolidate codes, which were further validated by a third researcher. The research team kept an audit trail and adhered to hermeneutic alertness over the entire study. Triangulation within the team helped to identify categories and significant quotes and offer explanations and interpretations of findings. All these strategies ensured confirmability. Transferability was pursued by describing the data collection process and sample characteristics and seeking data saturation. Finally, authenticity was sought in an impartial way by considering viewpoints that were representative of multiple NH parties engaged in end-of-life communication.

## 4 | FINDINGS

Overall, 13 categories that captured NH staff's experiences with end-of-life communication were identified and framed within van Manen's four existentials (van Manen, 2015). Communication, end of life, death and dying were recurrent words across all existentials, thus the overarching category "communicating at the end of life" was identified (Figure 1).



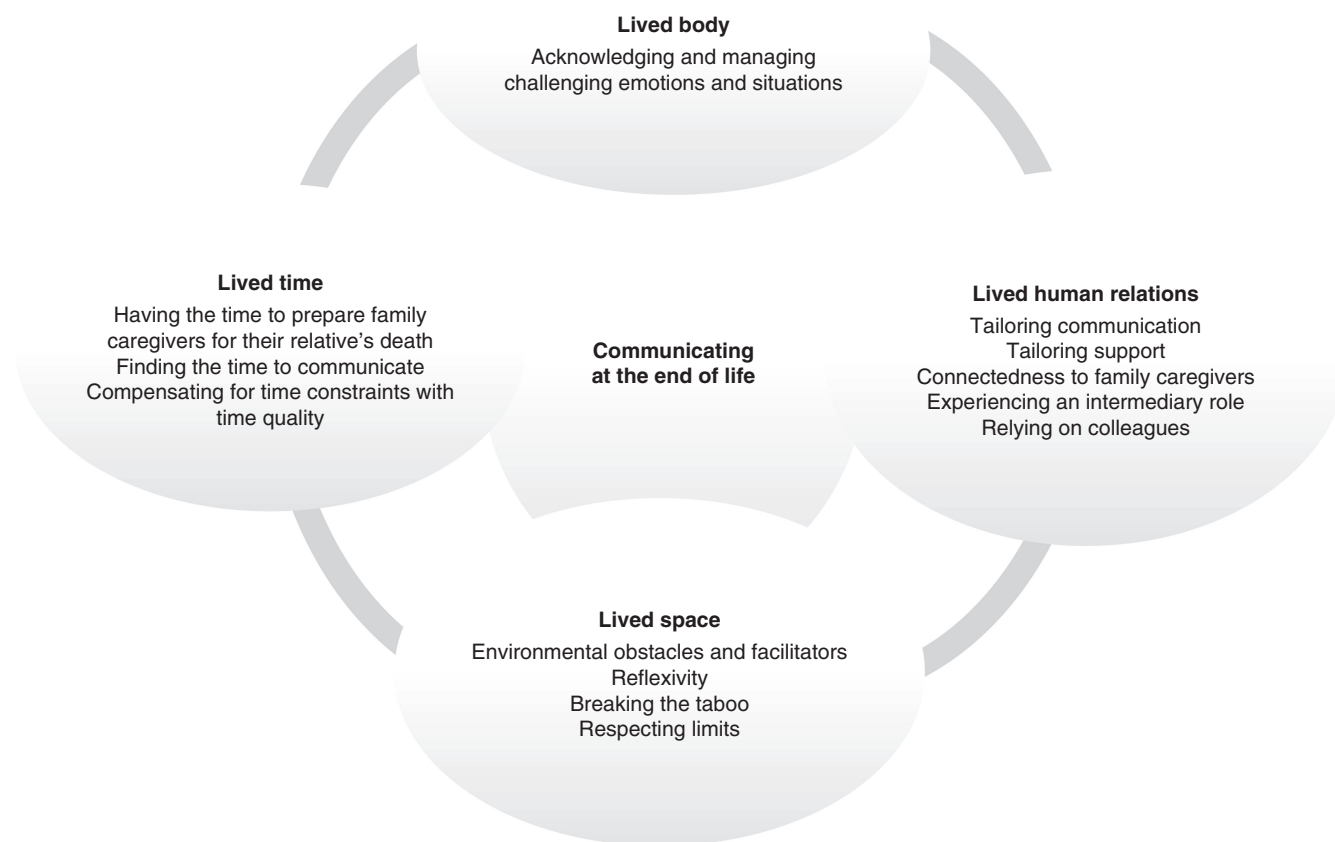


FIGURE 1 Lived experiences of nursing home staff with end-of-life communication: an interpretive phenomenological study.

#### 4.1 | Lived space (spatiality)

Lived space describes the place in which interviewees moved and found themselves during end-of-life communication. NH managers, nurses, occupational therapists and nurse aides mainly perceived this as a physical space, psychologists as a mental and socio-cultural space, and chief medical officers as a professional competence space.

##### 4.1.1 | Physical space: Environmental obstacles and facilitators

Interviewees reported that bulky personal protective equipment (PPE) and pandemic-related visitation restrictions, which imposed limited body communication and lack of physical contact, were physical obstacles to end-of-life communication. However, a familiar atmosphere, NH leadership that set communication among its priorities, and the physical presence of FCs in the facility were described as facilitators:

I miss the physical contact with FCs, even just a hand on the shoulder to help them not feel alone.

(Nurse aide/NH6)

The NH becomes a kind of home. Relationships [between staff and FCs] are much closer than in acute care settings, and this facilitates communication.

(NH manager/NH6)

I can't stand this bulky equipment and physical distance. I used to rely on body language and physical contact when communicating with FCs (...) this is no longer possible.

(Nurse/NH1)

##### 4.1.2 | Mental space: Reflexivity

Staff were often unsure how to initiate end-of-life communication with FCs. Reflexivity in the form of self-reflection and team meetings helped staff identify the best way to approach sensitive topics. Interviewees commonly reported reflecting on experiences with end-of-life communication and related feelings alone and with colleagues:

As a team, we always ask ourselves about the best way to start difficult conversations, and how to tailor them to each FC.

(Psychologist/NH4)

#### 4.1.3 | Socio-cultural space: Breaking the taboo

End-of-life was experienced as a taboo subject and had rarely been discussed in advance, so FCs usually did not know their relative's care preferences. Therefore, staff considered it essential to discuss end-of-life care options and preferences with FCs immediately upon their relative's admission to the NH. Such conversations became the responsibility of staff members who were judged most capable due to their educational background, like psychologists:

Sometimes I feel like a vulture who has to start a taboo topic. When we realise that death is nearing, colleagues often tell me 'The floor is yours because you know how to say it.'

(Psychologist/NH2)

#### 4.1.4 | Professional competence space: Respecting limits

Interviewees reported the need to establish and respect the limits of their professional competencies during end-of-life communication. They also acknowledged the risk of exceeding these limits. Some learned from experience not to violate colleagues' field of competence and most referred FCs to appropriate colleagues when questions were outside their competence. Some interviewees perceived a hierarchy of competencies in communication, while others perceived that their role was minimized:

Everyone should recognise their role and limits, and communicate within their area of competence. (...) physicians and nurses are responsible for discussing health-related issues, nurse aides can provide information about activities of daily living, while administrative staff is in charge of bureaucracy.

(Chief medical officer/NH6)

I frequently hear that it is nurse aides who most often notice changes in health status, since they spend the most time with the residents. However, we can only mention changes we see to our superiors; we are not supposed to discuss them [with FCs]. For the most part, we are not allowed to contribute to end-of-life communication.

(Nurse aide/NH5)

### 4.2 | Lived body (Corporeality)

Lived body describes how interviewees perceived their own bodies and emotions during end-of-life communication.

#### 4.2.1 | Acknowledging and managing challenging emotions and situations

Interviewees found end-of-life communication emotionally difficult and highlighted the need to acknowledge FCs' emotions to manage the communication adequately. FCs' emotions varied over the care period, from hostility to anger or suffering. Each experience was unique, influenced by the degree of FCs' awareness of their relative's deterioration, the uncertainty of the prognosis, and the personal situations of the NH staff themselves, such as a recent death in their own family. Interviewees often struggled to explore how well FCs understood their relative's condition, manage prognostic discordance and denial, and prepare FCs for their relative's death:

I had several end-of-life communication experiences, and they have all been different. Communication changes based on who you have in front of you, and you need to adapt your manner and content accordingly.

(Psychologist/NH6)

FCs often ask me, 'How much time is left?' I never know what to answer, because it is difficult to make accurate predictions. It might be 2 days or 2 months.

(Nurse/NH1)

Staff experienced strong emotions, and they found it helpful to discuss cases with colleagues to manage these emotions:

Discussing cases with colleagues was an opportunity to reflect on and exchange challenging personal experiences.

(NH5/nurse aide)

The COVID-19 pandemic made remote end-of-life communication more common, but interviewees found it distressing. Remote communication was defined as limiting, incomplete, biased, sterile and unsatisfactory, with a high risk of misunderstanding. Interviewees felt that end-of-life communication requires in-person contact to be sensitive:

Remote communication comes across as false and sterile. The medium carries news but no emotion. I give updates but with little idea of how the person is taking them (...). It makes it impossible to rely on body language to determine how much information the FC can handle.

(NH manager/NH5)

### 4.3 | Lived time (temporality)

Temporality refers to the passage of time in relation to experiences of end-of-life communication.

### 4.3.1 | Having the time to prepare family caregivers for their relative's death

NHs were perceived as places where there should be enough time to prepare FCs for their relative's death since death usually occurs after a medium to long stay. Cognitive, behavioural and emotional preparation for death required exploring FCs' acceptance of upcoming death and responding to any doubts that their relative's condition was worsening. Continuous communication and regular meetings between staff and FCs helped FCs understand what to expect:

NHs are a place where people usually die after a long stay, so we should have time to prepare FCs. (NH manager/NH6).

Most cases degenerate slowly, and communication is a gradual journey.

(Psychologist/NH4)

### 4.3.2 | Finding the time to communicate

Communication was perceived as a priority, particularly end-of-life communication. Staff knew they were responsible for initiating communication with FCs about residents' clinical condition and for providing regular updates so as to avoid unpreparedness in case of a sudden downturn. Staff were cognisant of the importance of taking time to answer FCs' questions and of avoiding hurried responses that might leave FCs without a full understanding of the situation. However, setting aside time for communication was not easy; staff had to work together to create timetables that squeezed in family meetings among all their other care tasks:

I had to establish a timetable for family meetings to provide FCs enough time to share their doubts. Family meetings had to be squeezed in somewhere, and we had to check with colleagues (...) to avoid overlap with their other activities.

(Occupational therapist/NH5)

### 4.3.3 | Compensating for time constraints with time quality

Staff viewed end-of-life communication as part of their care tasks, but they complained that there was too little time for it, even when residents had longer stays, due to the low staff-to-resident ratio mandated by regional staffing regulations. Moreover, urgent and temporary relief NH admissions were becoming more common than traditional, long NH stays, leading to the postponement of

communication until times of crisis. Staff tried to compensate for time constraints with high-quality interactions:

We are really short of time. If we had more time, we could talk more with FCs, and care decisions would be made earlier.

(Chief nurse/NH6)

Unfortunately, communication is often initiated only in times of (...) emergency. Moreover, regional staffing regulations allocate minutes of nursing care for certain categories of residents. However, we also have to provide nursing care to people who fall outside these categories.

(NH manager/NH2)

Now, [end-of-life] communication often is done in times of crisis, because people move into NHs only when their conditions are already severely compromised. It is no longer a scheduled entry as it was in the past.

(Chief nurse aide/NH2)

The essence of caring is not only the amount of time you provide, but also the quality of the time you offer.

(NH manager/NH1)

## 4.4 | Lived human relations (relationality)

This existential describes the connectedness between staff and FCs, and among NH staff.

### 4.4.1 | Tailoring communication

Staff valued personalized, comprehensive, truthful, and empathic communication to establish relationships with FCs. Communication strategies varied according to the situation: silence, body language or even remote communication (e.g. long-distance FCs and urgent communication). Generally, interviewees considered it essential to use simple language and avoid medical jargon and technical terms; informal approaches and direct communication were not advised when strong, trusting relationships were not present:

You don't always communicate in the same way; communication depends on the person you have in front of you.

(Chief medical officer/NH2)

A hug, a hand on the arm, a smile, you can talk without using words.

(Chief nurse/NH4)

#### 4.4.2 | Tailoring support

Staff listened to FCs to understand their needs and tailor support accordingly. Some FCs wanted detailed clinical information, others needed guidance in making decisions, and others needed reassurance that their relative was not suffering. Finding the right words to support FCs was not easy:

Some need to know little, others a lot; some want details, others just want a general overview; some need support and reassurance. Understanding which of these is needed to be truly supportive is hard.

(Chief medical officer/NH2)

#### 4.4.3 | Connectedness to family caregivers

Staff experienced communication as a mutual exchange which benefited and satisfied FCs. Connectedness was hindered when staff perceived FCs as pretentious, insistent, rude, or intrusive and in case of distrust or prognostic discordance. Trust was slow to develop and could be threatened by events like a confusing phone call, poorly informed staff members or alternative sources of information. Establishing connectedness was harder and extremely stressful when families were fragmented and in conflict. COVID-19-related visitation restrictions also negatively affected connectedness. Even when FCs were allowed in the facility, PPE allowed for limited body communication and physical contact, which hindered relationships. Frequent, in-person meetings that started at admission, explaining each staff member's role to FCs, attention to body language, guidance in and making shared care decisions, and free access to the facility promoted connectedness. Caring attitudes such as availability, closeness, kindness, patience, presence and professionalism were also essential in developing connectedness with FCs:

I have given and my reward has been the satisfaction of seeing FCs at peace.

(Chief nurse aide/NH6)

Trust strengthens over time and leads to mutual esteem. As death approaches, everything is easier if good relationships have been established.

(Nurse/NH3)

I have difficulties listening to FCs who want to do everything to prolong a relative's life. One son had us place a feeding tube for his mum, though she is cachectic, she is dying. This makes me angry. Then I give up and say, 'Do as he wants, even if I disagree.'

(Chief nurse/NH6)

When you have to communicate with siblings who don't talk to each other or are at odds, it's awful, especially when important decisions need to be made.

(NH manager/NH4)

#### 4.4.4 | Experiencing an intermediary role

The staff experienced an intermediary role in communication between FCs and residents, and between FCs and hospital services. This intermediary role was expanded during the COVID-19 pandemic due to visitation restrictions which prevented FCs from accessing facilities and care services freely:

We have always been a conduit, but this pandemic has made us more aware of this role.

(NH manager /NH1)

I regularly offer FCs video-calls with their relative, because it's important to keep them in touch despite pandemic-related restrictions.

(Occupational therapist/NH6)

#### 4.4.5 | Relying on colleagues

Colleagues were a precious source of support to manage difficult end-of-life communication and promote FCs' awareness about their relative's clinical situation and evolution of disease. Moreover, discussion and consensus within the team was essential to communicating a single, common message to FCs when residents deteriorated. Unfortunately, such discussions were not always possible due to limited time:

FCs often don't accept the situation, so multidisciplinary meetings involving the general practitioner, palliative care physician, chief nurse, and the NH manager are arranged to promote awareness. These meetings are extremely useful because everyone has their role, and an effective communication balance is maintained.

(Chief nurse/NH2)

All staff members meet periodically, discuss cases and establish a common response to FCs' questions. Once we determine this response, I am confident in rebutting FCs when they say, 'your colleague told me...'

(Chief nurse/NH6)

We should have weekly team meetings to discuss difficult cases, but this is not always possible because there is not enough time.

(Nurse aide/NH5)

## 5 | DISCUSSION

The dynamics of end-of-life communication vary across care settings and may affect how this communication is experienced. In acute care settings, physicians usually manage these conversations, while other social and health professionals offer emotional support and help FCs understand complex information (Anderson et al., 2019). However, on-site physicians are rare in Italian NHs, making NH staff responsible for timely, honest, compassionate end-of-life communication (Gonella, Clari, et al., 2021). This study sought to explore and understand the lived experiences of end-of-life communication among NH staff by employing the lifeworld existentials of spatiality, corporeality, temporality and relationality as a reflective strategy.

### 5.1 | Spatiality

End-of-life communication was experienced as a physical, mental, socio-cultural and professional competence space. End-of-life communication took place both in real and virtual settings. Interviewees experienced PPE and remote communication modalities as obstacles and highlighted the role of physical contact in supportive end-of-life communication. Sensitive physical contact helped demonstrate emotional closeness, belonging and attachment, which FCs have deemed essential to establishing relationships and providing person-centred care (Lopez et al., 2013). In agreement with a previous study (Gonella, Basso, et al., 2022), a familiar atmosphere was favoured by FCs' presence in the facility and promoted clear and thorough communication. NH staff also experienced end-of-life communication as a mental space in the form of reflexivity on an individual and team level. Similar to previous results (Olson et al., 2021), reflexivity in the form of self-reflection and team meetings fostered continual language adjustment that was also influenced by staff's personal feelings. Multidisciplinary team meetings played an important role in deciding how to interact with FCs and in promoting tailored, person-centred communication that addresses sensitive issues, which is a core element of palliative care delivery at the end of life (van der Steen et al., 2014).

This suggests that NHs must create an open environment in which staff, residents and FCs feel safe and comfortable sharing their feeling and thoughts. Indeed, FCs have reported that they experienced higher-quality communication and felt more involved in care planning when a team-based approach to end-of-life communication was employed (Frey et al., 2020). NH staff experienced end-of-life communication as a socio-cultural space, in which both staff and FCs felt some resistance to frank communication about death. End-of-life communication was a "hot potato" that was passed within the care team, as FCs were often unaware of their relative's end-of-life care preferences (Gonella et al., 2020), and not all staff felt prepared to sustain such a discussion (Harrison Denig, 2016). Our findings confirm the need to continue to break the taboo surrounding death and dying (Thulesius et al., 2013), particularly in

majority-Catholic countries such as Italy, where the model of maintaining FCs' hope often results in missed or delayed communication (Toscani & Farsides, 2006). Breaking this taboo and providing transparent, timely, thorough communication could help FCs better accept the transition from curative-oriented to palliative-oriented care (Gonella, Basso, et al., 2022).

Finally, NH staff experienced communication as a professional competence space, in which their professional profiles had an influence. As in previous studies (Anderson et al., 2019), our interviewees recognized the need to respect the limits of their professional competencies when conducting end-of-life communication. Nurses reported mainly physical nuances during end-of-life communication. However, nursing education emphasizes self-reflection and caring for a person as a whole as pillars of nursing practice. As such, nurses may take these aspects for granted and thus not report them (Coffey et al., 2019). It is also possible that chronic understaffing, compounded by the pandemic, forced NH nurses to focus on more practical issues when communicating (Campagna et al., 2021). This issue deserves further investigation.

### 5.2 | Corporeality

As in earlier reports (Olson et al., 2021), staff acknowledged challenges in managing their own emotions and those of FCs during end-of-life communication. End-of-life communication was particularly demanding for NH nurses, who often represent FCs' main point of contact for discussing prognosis. Indeed, prognostication is complex in the elderly, which can increase the emotional burden of end-of-life communication (Yourman et al., 2012). Training and resources on how to conduct conversations about serious illness could be integrated into the curriculum and continuing education of healthcare professionals to increase their confidence in end-of-life communication (Buckman, 2017). Interprofessional training regarding diagnosis and prognosis-related communication is also essential to promote collaboration and to better empower nurses in this practice. Finally, having the flexibility to respond to different situations and individuals, and to discuss with colleagues in structured, peer-facilitated informal groups may allow healthcare professionals to normalize their emotions and learn coping strategies (Borghi et al., 2021). Our findings suggest that healthcare professionals should be provided emotional support, social support and communication training in an environment that allows time for reflective practice.

### 5.3 | Temporality

Interviewees perceived NHs as privileged places for end-of-life communication. Indeed, NH residents usually have longer stays, which should leave time for multiple conversations that introduce and reinforce information, facilitate FCs' gradual acceptance and understanding, and prepare them for death and bereavement (Hebert et al., 2009). However, despite the recognized benefit of early

end-of-life communication, about one-third of conversations occur within 1 month of death (Reinke et al., 2017). In our study, NH staff ascribed delays in communication to staffing issues and increases in urgent and temporary relief admissions. Interviewees perceived communication as a priority and made great collective efforts to schedule time for this activity without compromising other care tasks. To compensate for the lack of time, staff tried to engage in high-quality interactions with FCs.

## 5.4 | Relationality

End-of-life communication experiences usually included FCs and colleagues, not residents. This confirms the tendency to postpone such communication until recovery is impossible and residents have lost cognitive capacity (Gonella, Basso, et al., 2019). Interviewees reported that tailoring communication and support to the situation and to each FC's individual needs favoured connectedness and had mutual benefits. Our findings confirmed well-known barriers to (distrust and prognostic discordance) and facilitators of (clarifying each staff member's role, staff members' caring attitudes and frequent, in-person meetings) end-of-life communication (De Vleminck et al., 2014; Travers & Taylor, 2016). Our interviewees also experienced relationality as an intermediary role between FCs and their relatives, and between FCs and hospital services. The role of intermediaries in improving the quality of care, particularly at the end of life, has been already highlighted (MacDonald et al., 2011). Our findings suggest that restrictions strengthen the intermediary role of NH staff. For example, restrictions aimed at containing the spread of COVID-19 expanded the role of NH staff in ensuring timely communication with FCs (Hado & Friss Feinberg, 2020). Finally, NH staff's lived experiences of end-of-life communication was one of teamwork: they sought and relied on colleagues' support to manage difficult conversations with FCs, to promote FCs' understanding of their relative's prognosis, and to handle mismatched expectations. These findings confirmed that teamwork is essential to providing end-of-life communication according to palliative care guidelines, which recommend multidisciplinary teamwork to ensure person-centred communication and high-quality care (van der Steen et al., 2014).

Our findings may serve to guide healthcare policymakers who wish to invest in communication skills training that focuses on conversations about serious illness and may guide the planning and structure of such training. Finally, our findings highlight the need to make psycho-social, supportive services available to healthcare professionals to safeguard their well-being, due to the emotionally demanding nature of end-of-life communication.

## 5.5 | Limitations

This study was conducted during the COVID-19 pandemic, which may have emphasized some nuances of end-of-life communication experiences, such as challenges in establishing trusting relationships and

managing emotions due to limited in-person communication, increased staff shortages and turnover as extra nurses were called into hospitals. However, we believe that our findings apply beyond the COVID-19 timeframe, as the challenges highlighted are well-known in the end-of-life literature. Moreover, it is possible that the data analysis we adopted (i.e. exploring all four lifeworld existentials simultaneously in each transcript) privileged the existential of relationality over the others since end-of-life communication is a sensitive phenomenon that is influenced by relationships among parties. The existential of lived human relations was indeed the most grounded. A different analytical approach, such exploring each lifeworld existential consecutively in all transcripts, may have provided different results (Rich et al., 2013). However, during the theoretical coding process, the use of lifeworld existentials should have amplified each existential equally across the interviews. In addition, "a phenomenological description is always 'one' interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer or deeper description" (van Manen, 2015). Finally, this study was performed in the Italian long-term sector. Because this sector is managed on the regional level, staff-to-resident ratios and the organization of internal processes vary largely by region. None of our NHs had in-house physicians to whom FCs could turn for information at the end of their relative's life, and high staff turnover also had an adverse effect on communication experiences. This study characteristic may limit the transferability of our findings to other jurisdictions and health systems.

## 6 | CONCLUSION

End-of-life communication was an all-encompassing experience for NH staff, with spatiality, corporeality, temporality, and relationality features. A highlight of the study was the central role of teamwork in communicating at the end of life, as suggested by the ubiquity of this concept across all lifeworld existentials. Discussion during team meetings promoted reflexivity about the best way to tailor communication to individuals and situations (spatiality), helped manage challenging emotions and situations (corporeality), helped plan time for communication (temporality), and promoted FCs' awareness about disease progression based on a shared plan (relationality).

### AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE: <http://www.icmje.org/recommendations>): (1) substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content.

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## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# A conflicted tribe under pressure: A qualitative study of negative workplace behaviour in nursing

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## Abstract

**Aim:** This study explored workplace interactions of Australian nurses in regional acute care hospitals through an examination of nurses' experiences and perceptions of workplace behaviour.

**Design:** This research is informed by Social Worlds Theory and is the qualitative component of an overarching mixed methods sequential explanatory study.

**Methods:** Between January and March 2019, data were collected from 13 nursing informants from different occupational levels and roles, who engaged in semi-structured, in-depth, face-to-face interviews. Data analysis was guided by Straussian grounded theory to identify the core category and subcategories.

**Results:** Theoretical saturation occurred after 13 interviews. The core category identified is *A conflicted tribe under pressure*, which is comprised of five interrelated subcategories: *Belonging to the tribe*; *'It's a living hell'*; *Zero tolerance—'it's a joke'*; *Conflicted priorities*; *Shifting the cultural norm*.

**Conclusion:** This study provides valuable insight into the nursing social world and the organizational constraints in which nurses work. Although the inclination for an individual to exhibit negative behaviours cannot be dismissed, this behaviour can either be facilitated or impeded by organizational influences.

**Impact:** By considering the nurses' experiences of negative workplace behaviour and identifying the symptoms of a struggling system, nurse leaders can work to find and implement strategies to mitigate negative behaviour and create respectful workplace behaviours.

**Patient or Public Contribution:** This study involved registered nurse participants and there was no patient or public contribution.

**Clinical Trial Registration:** Study registration Australian New Zealand Clinical Trials Registry (Registration No. ACTRN12618002007213; December 14, 2018).

## KEYWORDS

acute care, bullying, health services research, leadership, nurses, organizational behaviour, workforce issues

## 1 | INTRODUCTION

Conflict related to negative workplace interactions in the nursing profession has deep historical roots and despite extensive research into the problem it continues to persist and has been recognized as a global phenomenon (Hartin, 2021; Minton et al., 2018). Nurses are reported to face a greater risk of exposure to negative workplace behaviours due to the high-stress environments in which nursing work is situated and the high level of personal involvement nurses have in their work (Shorey & Wong, 2021; Waschglar et al., 2013). A prevalence review indicated that up to 87% of nurses worldwide have experienced negative workplace behaviour over the course of their careers (Bambi et al., 2018) and up to 60% of nurses will leave their first job due to the negative behaviours of their co-workers (Clarke et al., 2012).

Negative workplace behaviour in nursing has been described as a 'silent epidemic' (Murray, 2009, p. 273) due to the acceptance of behaviours as the cultural norm in the profession and victims, therefore, being hesitant to report the behaviour (Hartin et al., 2020; Hawkins et al., 2019). Victims' hesitance to report may be due to a perceived lack of action by management and fear of consequences, such as an escalation of the behaviours in retaliation, and exclusion from work groups (Arnetz et al., 2019; Hartin et al., 2020). Victims of negative workplace behaviour have described feeling unsupported by management to report the behaviours and experienced dissatisfaction and mistrust when the complaints are not acted on (Hallberg & Strandmark, 2006). Over time, this contributes to a reluctance to report and tolerance of negative behaviours (Hawkins et al., 2019). As a result, negative workplace behaviours have become accepted as a 'rite of passage' (Birks et al., 2018, p. 48) and an accepted part of nursing socialization (Birks et al., 2018; Moore et al., 2013). Studies indicate that nurses who have previously been subjected to negative workplace behaviour often then treat others in the same way, perpetuating cyclic negative behaviour in the profession (Hawkins et al., 2021a; Lee et al., 2013).

### 1.1 | Background

Negative workplace behaviours can be classified into three categories: work-related bullying (e.g. unmanageable workloads or withholding information); person-related bullying (e.g. being humiliated or ignored); physically intimidating bullying (e.g. being shouted at or even threats of violence) (Einarsen et al., 2009). Previous studies have found that nurses are more likely to experience work-related bullying acts, such as unsafe workload allocation (Hawkins et al., 2021a; Palaz, 2013; Yun et al., 2014). Power differentials are also a key aspect of negative behaviour, particularly work-related negative acts, with the most commonly identified perpetrators being either supervisors or colleagues (Arnetz et al., 2019; Hawkins et al., 2021a; Johnson & Rea, 2009). These behaviours have been found to occur in numerous workplace settings in the nursing profession, ranging from front-line service provision to senior executive leadership (Edmonson & Zelonka, 2019; Johnson & Rea, 2009).

Individuals exposed to negative behaviours often report psychological distress, poor physical and mental health, decreased job satisfaction, increased absenteeism and intention to leave (Ortega et al., 2011; Trépanier et al., 2016; Wilson, 2016; Wolf et al., 2021). The effects of negative workplace behaviours also place at risk the quality and safety of patients' care, with reported increased incidents of errors, reduced work productivity and avoiding asking for help (Berry et al., 2012; Johnson & Benham-Hutchins, 2020; Wolf et al., 2021; Wright & Khatri, 2015). Negative workplace behaviour is a barrier to collaborative teamwork and has negative implications for organizations, having been shown to impact staff morale, staff retention and recruitment (Johnson & Benham-Hutchins, 2020; Ortega et al., 2011; Wolf et al., 2021). For non-metropolitan health care organizations already faced with difficulties in recruiting and retaining nurses, negative behaviours may impact an organization's employment reputation (Edmonson & Zelonka, 2019; Katrinli et al., 2010; Marufu et al., 2021).

Although there has been extensive research into negative workplace behaviours in the nursing profession, they have been generally in metropolitan settings. Due to the nature of smaller regional locations, health care organizations are often the largest employers in the community (Bushy, 2002; Smith et al., 2019) and nurses working in these locations have limited employment options (Whiteing et al., 2022). Nurses working in regional settings work with limited resources (Smith et al., 2020) in an environment where 'informal social structures predominate' (Bushy, 2002, p. 105) and close relationships amongst the community can lead to distortion between professional and personal roles (Bushy, 2002; Mills et al., 2010). Such social intricacies should be considered when examining nurses' experiences of negative workplace behaviour in non-metropolitan locations.

### 1.2 | Theoretical framework

The theoretical framework for this research project is Social World's Theory, which originally emerged from the Chicago School of Sociology (Clarke, 1991). Social world theorists perceive social structure as being shaped and defined by repeated interactions between individuals (Carter & Fuller, 2015), so that society is conceptualized as a mosaic of neighbouring social worlds, which may intersect with each other (Clarke, 1991; Strauss, 1978). Thus, individuals can simultaneously not only belong to but also construct multiple social worlds (Maclean et al., 2021). These social worlds refer to groups where there is 'a set of common or joint activities or concerns, bound together by a network of communication' (Kling & Gerson, 1978, p. 26).

Each social world is associated with one primary activity (e.g. delivery of nursing care). There are sites where those activities occur (e.g. in the hospital) and technology applied to carry out the social world's activities (e.g. technical and clinical nursing skills). Unruh (1980) termed the individuals in social worlds as either strangers or tourists or as regulars or insiders based on their 'social proximity to activities and knowledge vital to the ongoing functioning of a



social world' (Unruh, 1980, p. 280). Each individual in a social world is associated with its activity (e.g. nursing care); however, some individuals are recognized or believe themselves to be more *authentically* of that world. *Authentic* individuals are regarded as most representative of the social world (Strauss, 1982) by those considered to have the 'power' to authenticate (Strauss, 1978, p. 123). Power generally resides with those with seniority, authority or longevity in the social world (Strauss, 1978).

Social worlds uphold ideologies about how their work should be completed and in each social world a set of standards of performance are used to evaluate an individual's actions and their degree of *authenticity*, that is, whether an individual belongs in that world (Strauss, 1982). Claims of the *authenticity* of some members and denial of a claim to authenticity of others often lead to conflict in social worlds (Strauss, 1982). The degree of socialization and acceptance felt by individuals who enter a social world impact on how individuals enter and leave (Strauss, 1978). If individuals do not feel fully accepted or are not viewed as being authentic this can lead to conflict and the segmenting of the original social world and the creation of subworlds (Strauss, 1982). Strauss (1982) suggested that the study of conflict and power relationships are crucial aspects of research into social worlds, including the allocation, assigning and depriving of resources (Strauss, 1978).

## 2 | THIS STUDY

The overarching research study design is a mixed methods sequential explanatory study with an embedded experimental component. The aim of the overarching study is to investigate the self-reported exposure to and experiences of negative workplace behaviours of nursing staff and their ways of coping in regional acute care hospitals before and after workshops have been implemented in the organization. The study protocol is described elsewhere (IRRID: PRR1-10.2196/18643, Hawkins et al., 2021b).

### 2.1 | Aim

This article reports on the qualitative strand of the overarching study, which aimed to explore the workplace interactions in the social worlds of nurses working in acute care settings of regional hospitals in New South Wales (NSW), Australia and, thus, enhance the understanding of their experiences and perceptions of negative workplace behaviour. The Consolidated Criteria for Reporting Qualitative Studies (COREQ; Tong et al., 2007) has been applied in reporting this study (Table S1).

### 2.2 | Participants and recruitment

The overarching research included 12 medical/surgical wards across four NSW regional acute care hospitals. The hospitals were selected

due to being similar in size, with the similar provision of services and case mix. Their co-location in the same Local Health District meant that all four hospitals were under the same executive leadership and were subject to the same bullying and negative workplace behaviour policies, as well as the same human research ethics governance. The primary author (NH) visited each of the hospitals and the wards to present the study's overall aim and recruitment process. Participants were invited to participate in the quantitative survey component and/or a qualitative, one-on-one, in-depth interview. Recruitment flyers were placed in each ward's tearoom, along with recruitment packages, which contained the participant information statement, the various questionnaires and consent to be contacted for an interview. Study participants who met one of the following criteria were invited:

- New graduate nurses in the first 12 months of practice following completion of a Bachelor of Nursing degree.
- Registered nurses who had been employed for more than 1 year at a minimum of 0.6 full-time equivalents.
- Nurses in leadership roles, including nurse unit managers, clinical nurse educators and clinical nurse specialists employed at a minimum of 0.6 full-time equivalents.

For the qualitative strand, the intention was to purposively sample the volunteers to ensure a representative sample of nursing roles and hospital sites. Initially, 46 nurses returned consent forms to participate in an interview. They were all sent a further two follow-up emails seeking confirmation. A total of 13 informants responded to follow-up emails, who then became the volunteer sample for the qualitative strand. Data saturation was reached with the 13 interviews, therefore, no further recruitment was undertaken.

### 2.3 | Ethical considerations

Ethics approval was obtained from the Hunter New England Local Health District Human Research Ethics Committee (NSW HREC Reference No: HREC/17/HNE/596). All informants were provided with study information on the consent form and were free to decide to participate in the research and to withdraw at any stage without any adverse consequences. Due to the sensitive nature of the research topic, informants had the option to bring a support person with them to the interview and the contact details of the free Employee Assistance Program counselling service were provided. Written consent was sought from informants before audio-recording the interviews. Data collected were de-identified to ensure confidentiality.

### 2.4 | Data collection

In 2019, semi-structured, in-depth interviews were conducted with informants by the primary author at an agreed, private location. The



TABLE 1 Interview schedule

Background and demographic questions	Attitude and feelings questions
Approximately how many years have you been a Registered Nurse?	How do you feel about how other members of the nursing profession support new graduate nurses?
Approximately how many years have you worked at your current workplace?	What do you think could be changed to better support new graduate nurses?
What role do you currently have?	Do you feel accepted and like you belong as a member of the nursing profession? If so, why? If not, why not?
	Do you agree with the statement that all nurses are accepted and feel like they belong as a member of the nursing profession? If so, why? If not, why not?
	What suggestions do you have for improving the workplace culture in the nursing profession?
Knowledge questions	Respectful workplace workshop questions
What do you know about the NSW Health policy on bullying and incivility?	Have you attended the respectful workplace modules 1 and 2?
What do you understand bullying to be?	No... Have you heard about these workshops? Where did you hear about them?
Can you give me an example of bullying?	Do you have any intention of attending these workshops in the future?
What do you understand incivility to be?	Yes...
Can you give me an example of incivility?	Could you please describe how you felt about the respectful workplace workshops?
Is there any difference between incivility vs bullying?	Do you feel that the workshops were beneficial? If yes, what aspects? If not, why not? What should be done differently?
	After attending the respectful workplace workshops what changes (if any) did, or will you implement?
	What changes (if any) have you observed in the wards you have been working?
Opinion and values questions	Experience and behaviour questions
What are your thoughts about bullying and incivility in the nursing profession?	What negative behaviours have you experienced or observed in your workplace? Tell me about how you dealt with negative workplace behaviour?
What can you tell me about the organizational culture in your current workplace?	Do you feel that this negative behaviour had any effect on your work? Do you feel like this impacted on patient care you deliver?
Do you think that new graduate nurses are more likely to be the victims of bullying and incivility?	<input type="radio"/> If yes, tell me about how this impacted on your patient care?
Why do you think this is/is not the case?	What positive behaviours have you experienced or observed in your workplace? Have you ever observed negative workplace behaviour towards new graduate nurses?
	<ul style="list-style-type: none"> <li>• If yes, please tell me about the situation</li> <li>• How did you respond?</li> </ul>
	How did they respond?
Final questions	
Do you have anything further you would like to say about workplace culture?	
Do you have any questions for me about this research?	

initial interview schedule was informed by a published literature review and by the preliminary results from the quantitative strand of the overarching study (Hawkins et al., 2021a) (Table 1). Data collection and analysis occurred concurrently (Corbin & Strauss, 2015). Although limited to a volunteer sample of 13 informants, at the conclusion of the final two interviews the primary author noted that no new information was obtained (Moser & Korstjens, 2018; Roy et al., 2015) and no new theoretical insights or categories were emerging. Therefore, no further sampling was undertaken (Corbin & Strauss, 2015; Trotter II, 2012).

Memos and notes were kept by the researcher during the process (Corbin & Strauss, 2015). The audio-recorded interviews lasted between 32 and 70 min. All but one interview was audio recorded and transcribed verbatim. One informant chose not to consent to audio recording due to fear of reprisal, but that informant consented to note-taking by the researcher. Demographic information such as

nursing role, years in the current position and total years in nursing were collected during recruitment on the participant consent form and confirmed at the beginning of each interview.

## 2.5 | Data analysis

The first two interviews were transcribed by the primary author and the remainder by a commercial transcribing service with which the university had a confidentiality agreement. The primary author reviewed all transcripts, by checking them whilst listening to each audio recording. The transcripts were also sent to all participants to review and verify the contents.

Data analysis was guided by Straussian Grounded Theory (SGT; Corbin & Strauss, 2015; Strauss & Corbin, 1990), which is the method of choice when researching in the Social Worlds Theory

framework (Clarke, 1991). Although debated by 'purist' grounded theory researchers, there have been numerous examples where theoretical frameworks have been utilized and analysis has been guided by grounded theory methods (Edwards & Jones, 2009; Mitchell Jr., 2014; Rosa, 2010; Sen & Spring, 2011; Vasconcelos, 2005, 2007; Vasconcelos et al., 2012). The combination of social worlds theory as a framework with the analytical tools of grounded theory was combined to uncover the social relationships and behaviours of nurses and construct a new understanding of the phenomenon of the negative workplace behaviours occurring in the nursing social world.

To ensure collaboration and reliability in the data analysis process, the interview transcripts were uploaded into NVivo for all members of the research team to access. To validate the data analysis and interpretation, both the second and third authors (S.Y.-S.J. and T.S.) reviewed several transcripts, and the findings were discussed with N.H. to reach a consensus. Throughout the data analysis process, the research team met frequently, allowing for comparison and meaningful discussions about how the coding was approached (Harding & Whitehead, 2013; Saldaña & Omasta, 2016).

Data analysis in SGT is undertaken using a three-stage approach: open coding; axial coding; and selective coding (Bryant & Charmaz, 2019; Corbin & Strauss, 1990). In the initial stage of open coding, the research team immersed themselves in the transcribed interview data, coding line-by-line (Bryant & Charmaz, 2019). The researchers undertook constant comparison, reading and re-reading transcripts and sorting conceptually similar data into concepts. Memos were also kept and dated during data analysis (Corbin & Strauss, 1990; Harding & Whitehead, 2013; Strauss & Corbin, 1998). The axial coding stage involved the identification of relationships between the concepts (Strauss & Corbin, 1990), utilizing a coding paradigm to assist with analysing, refining and aligning codes (Corbin & Strauss, 1990; Vollstedt & Rezat, 2019). Corbin and Strauss' (2008) coding paradigm consists of three components: conditions, actions/interactions and consequences. The research team 'put the data back together' (Corbin & Strauss, 1990, p. 97) by first grouping concepts into those three components. By examining the individual concepts

and their interplay, a detailed explanation of the phenomena was developed (Strauss & Corbin, 1998, p. 124; Figure 1). This allowed the researchers to then consider relationships between concepts and link them into broader categories. In the selective coding stage, data categories were refined and integrated to develop a single-story line (Corbin & Strauss, 1990; Starks & Brown Trinidad, 2007) (Table 2). During that final stage, the research team completed diagramming, as recommended by Corbin and Strauss (1990), as a useful tool for assisting in the integration of categories (Figure 2). A core category and five subcategories were identified that summarize the main ideas of the study.

## 2.6 | Rigour and Trustworthiness

The research team used a series of techniques to improve credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). To ensure credibility, the primary author reflected on her own experience as a nurse in a rural setting to capture a true reflection of the social reality of the participants. Throughout the study design, data collection and data analysis, a reflective journal was maintained by the primary author, which outlined reasons for methodological decisions. This assisted the researcher to identify and minimize any researcher bias that may have impacted the data collection, analysis and interpretation. To enhance transferability, the authors have provided a rich description of the research context, informant characteristics and the processes involved in the design, data collection and data analysis stages of this study. This description allows readers to evaluate the applicability of the results to other contexts (Forero et al., 2018; Johnson et al., 2020). An audit trail and memos were kept throughout the analysis to demonstrate the dependability in the decision-making process (Table S2). To ensure confirmability, the research team also met and debriefed regularly, allowing for peer scrutiny of the analysis and interpretation, thus ensuring that the findings remained true to the informant's accounts of their experience of negative workplace behaviour.

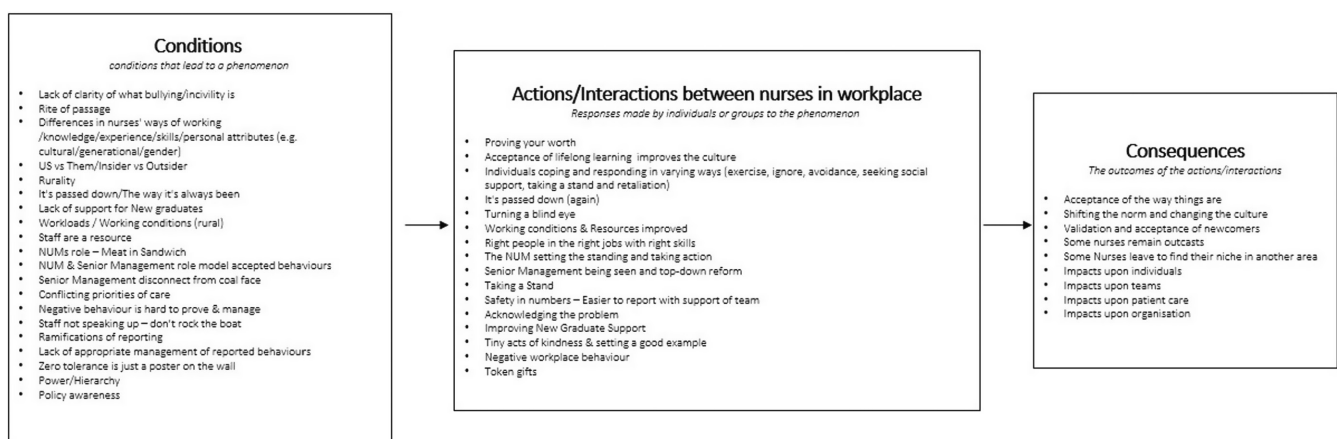


FIGURE 1 Axial coding using paradigm.

TABLE 2 Overview of categories and subcategories

Core category	Subcategories	Concepts	Coding paradigm
A conflicted tribe under pressure	Belonging to the tribe	Us vs. Them	Condition
		Rurality	Condition
		Rite of passage	Condition
		Power and Hierarchy	Condition
		Ways of Working	Condition
		The way it's always been	Condition
		Proving your worth	Action/Interaction
	'It's a living hell'	Validation and acceptance of newcomers	Consequence
		Remain as outcasts or leave the ward to find their niche	Consequence
		What is bullying and incivility	Condition
		Negative behaviours	Action/interaction
		Impact on individuals/teams/patient care and Organization	Consequence
		Individuals' way of coping	Action/Interaction
		It's passed down again	Action/Interaction
	Zero Tolerance—'It's a joke'	Policy awareness	Condition
		Zero tolerance is just a poster on the wall	Condition
		Reporting and its ramifications	Condition
		Do not rock the boat and do not speak up	Condition
		Safety in numbers	Action/Interaction
		People turn a blind eye and it's accepted as the norm	Action/Interaction
		Lack of management of reported behaviours	Condition
		Token gifts	Action/Interaction
		Negative behaviours are hard to prove and manage	Condition
		Staff are a resource	Condition
		Management role model accepted behaviours	Condition
		NUM sets the standard	Action/Interaction
	Conflicted priorities	Working conditions (staffing and workloads)	Condition
		Lack of support for new Graduates	Condition
		Conflicting priorities of care	Condition
		Senior management disconnect	Condition
	Shifting the cultural norm	Num—meat in sandwich	Condition
		Tiny acts of kindness	Action/Interaction
		Shifting the norm	Consequence
		Setting a good example	Action/Interaction
		Acceptance of lifelong learning	Action/Interaction
		Improving new graduate support	Action/Interaction
		Setting the standard and taking a stand	Action/Interaction
		Acknowledgement of problem	Action/Interaction
		Right people right jobs	Action/Interaction
		Management to be seen and need for top-down reform	Action/Interaction
		Working conditions and resources improved	Action/Interaction

### 3 | FINDINGS

A total of 13 informants (4 males and 9 females) participated in this study. They consisted of three New Graduate Nurses (NGNs), one Registered Nurse (RN), six Clinical Nurse Educators (CNEs) and three Nurse Unit Managers (NUMs). They had worked in their current

workplace for an average of 10.5 years and had been nursing for an average of 17.4 years. Table 3 gives a detailed overview of informants' characteristics.

The core category that emerged was *A conflicted tribe under pressure*, which represents the conflict in the nursing profession and the internal and external stressors impacting workplace interactions.

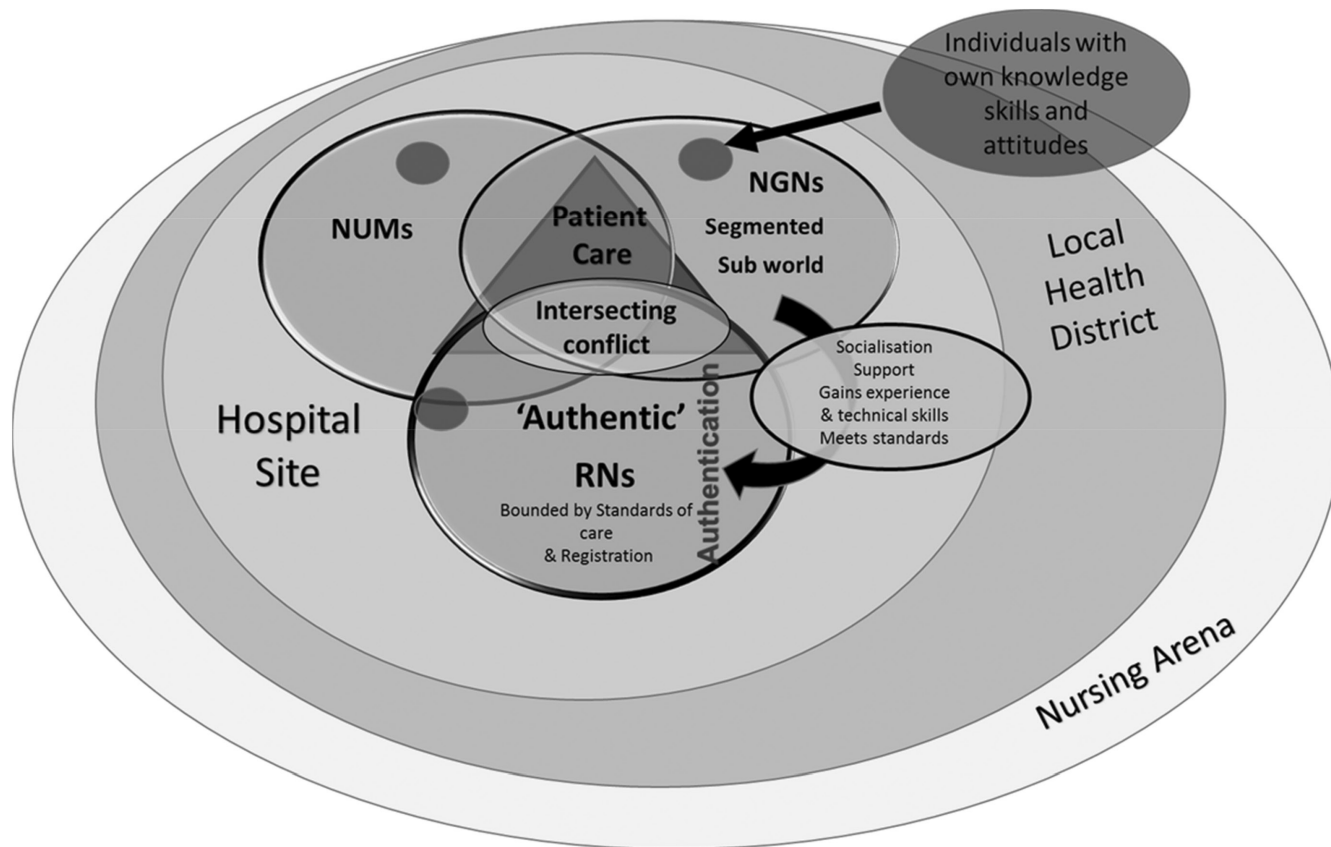


FIGURE 2 Working diagram of the nursing social world.

TABLE 3 List of the informants in this study showing their characteristics

Participant	Gender	Ward type	Site of employment	Years in current workplace	Total years in nursing profession
NUM1	M	Medical	C	24	37
CNE1	F	Medical	C	8	8
NUM2	M	Medical	C	7.5	7.5
CNE2	F	Medical	C	25	25
NGN1	M	Surgical	C	1	1
RN1	M	Medical	B	5	5
CNE3	F	Surgical	B	25	38
CNE4	F	Medical	A	14	37
CNE5	F	Surgical	A	11	34
NGN2	F	Surgical	C	1	1
NGN3	F	Medical	C	1	1
NUM3	F	Medical	D	1	19
CNE6	F	Medical	D	13	13
Mean years				10.5	17.4

Abbreviations: CNE, clinical nurse educator; NGN, new graduate nurse; NUM, nurse unit manager; RN, Registered nurse.

That core category is comprised of five subcategories: *Belonging to the tribe*; *'It's a living hell'*; *Zero tolerance—it's a joke*; *Conflicted priorities*; *Shifting the cultural norm*. Each is described below with relevant examples of informants' quotations.

### 3.1 | Belonging to the tribe

This subcategory represents the socialization and validation process of newcomers into the existing 'tribe' or social world. Informants

described their tribes as having an *us vs. them* (CNE1) attitude, where existing staff were described as territorial and new staff had to prove they were worthy of being included. CNE6 described it as *being like a pack*. It was identified that due to their rurality and, hence, a less transient workforce, long-term personal relationships and alliances often developed amongst staff, leading to cliques in the workplace. These pre-existing cliques impacted newcomers' socialization into the tribe, and it was acknowledged by informants that new staff to a ward were more likely to be the victims of negative behaviour, as perpetrators saw them as being vulnerable and weak. The negative workplace behaviour they experienced was viewed as a rite of passage, as described in existing literature (Birks et al., 2018, p. 48) and informants spoke about there being an obvious hierarchy.

Informants also identified barriers to the acceptance of individuals on the ward, such as being part of a casual workforce, being from a different cultural background, gender (being male) and different personal attributes, such as *being a little bit left of the norm* or being *quirky* (CNE3), as well as the level of confidence and the pliability of the individual to fit into the wards culture. The ability to do the job and an individual's way of working also emerged as a major contributing factor to belongingness. Informants identified that nurses who did not cope and could not complete the expected workload were often excluded from the team and faced negative workplace behaviours as a consequence. Time management was identified as being a critical capability. There were, however, different opinions amongst informants as to whether completing the allocated workloads was in fact an achievable task. There was also a discrepancy between informants as to the priority of care for patients, with some indicating that traditionally all showers should and would be completed on a morning shift, whereas others viewed this as an outdated model of care.

Informants identified that these expectations and ways of working were ingrained, and things were done a certain way because *that's the way it was always done* (CNE4). CNE5 described it as like a tribal culture:

We come historically from a background that was a military sort of background. There's a lack of critical thinking and a task orientated style of nursing that does not allow a person the freedom to think critically and to explore other ways of doing things. It regiments and expects a person to conform to a way of doing things because that is how it has always been done. If a person questions that they're maybe stepping out of that tribe.

There were noted consequences for individuals stepping out of that tribe and questioning the way it has always been done. Informants described instances where questioning practice or practising in a different way than *what has always been done* (CNE5) led to bullying and uncivil behaviour. CNE1 suggested *It's not until nurses display practice that doesn't fit within the team that it turns nasty*.

Informants reported having to take action and *put in the hard yards* (CNE3) to achieve acceptance and validation and prove their worth to the team. As a result of their actions, demonstrating to the rest of the team that they could be trusted and accountable for their workload, some participants reported they began to feel accepted and like they belonged in the tribe. That feeling of belonging and validation as an individual was reported to occur when they were being asked for their opinion and when they were approached to help, instead of needing help. NUM1 stated they started to feel really accepted in the profession:

I was being asked for my opinion. If somebody else valued my opinion, they obviously felt that I belonged and I knew what I was talking about and to think that I knew better than they did, I might know something they didn't, that made me feel really like part of the profession then, that I was actually contributing something to the profession.

Other informants reported that they remained on the ward not yet feeling accepted. RN1 described *Well for me it's not the profession that I thought it was going to be. Whether or not—I've not found my niche*.

### 3.2 | 'It's a living hell'

Because negative workplace behaviour can be subjective and based on the victim's personal perception and experiences, it was important to explore the informants' understanding of what constitutes negative workplace behaviour. When informants were asked about their experiences of negative workplace behaviour, every informant identified they had experienced and witnessed negative behaviours whilst working in regional acute care hospitals. All informants in this study, at all occupational levels, believed they had experienced negative workplace behaviours, although they had varied conceptual understandings of negative workplace behaviour. Informants described that bullying behaviour occurred in various forms, which was a higher level than incivility. Three informants (NGN1, NUM3 and CNE6) identified that negative behaviour had to be occurring on a regular basis or be repeated behaviour to be termed bullying. Incivility, on the other hand, was described as a more common, lower-level behaviours, akin to lack of manners.

The behaviours that informants were exposed to in their workplace included unfair rostering and workloads, being made to work outside of their skill level, isolation and exclusion, information being withheld, being undermined and contradicted in front of the team and being singled out and made to look incompetent. One informant described it as a *living hell* (NUM1) and others shared feelings of embarrassment, fear, sadness, tiredness and feeling physically sick. They describe lacking self-confidence and the motivation to come to work, feeling burnt out and considering leaving, with new graduates questioning their career choice. NGN1 recalled feeling like 'I didn't

know what I was doing, maybe it wasn't for me, maybe I wasn't cut out for this'. RN1 recalls how he felt as a result of negative workplace behaviours:

It absolutely made me feel terrible. I broke down. I cried because I was just so {long pause}. I think it was a combination of just being so tired and being so worried. I felt saddened and disappointed in the profession.

The behaviours also impacted the informants home life with reports of increased irritability at home, increased alcohol consumption and lack of sleep due to thinking about incidents that had occurred. NUM3 described how the impacts of negative behaviours coupled with personal stressors led to changes in her normal behaviour.

I had a lot going on and this on top of it was just horrible. So yeah, I just - I was probably more cranky at home. But I definitely drank more alcohol. I gained more weight.

Informants also reported that these negative behaviours impacted the team overall, because it affected the ward's culture and working environment. It also led to some nurses avoiding seeking help with patient care, although it was really needed. NGN1 reported that he often avoided asking for help during his graduate year, 'If it was a minor thing, I just wouldn't worry about it, and I just wouldn't ask any questions'; however, he also conceded that 'I didn't really know what I was doing. At the time I guess it felt minor'. The negative behaviours also impacted nurses' attitudes and ability to care with many reporting that they were not able to smile at work or even think, which led to a lot more mistakes being made. CNE5 surmised: 'If you haven't got your needs met, how can you possibly look after someone else?'. Informants indicated that negative behaviours directly put patients at risk as they did not get the care they deserved.

In response to their exposure to negative behaviours, informants reported using various ways of coping, ranging from exercising, avoidance of the person/workplace, keeping work/life separate, giving up and acquiescing to fit in, or formulating a plan to deal with the negative behaviour. Informants also reported seeking support from others including family, mentors and also from Employee Assistance Programs. Although some informants reported taking sick leave or considered leaving their job, several informants reported that due to personal reasons they just had no choice but to just keep going to work. CNE1 reported, 'I think a lot of nurses are already burnt out, but we just keep going because we've got mortgages'.

It was also evident that retaliation became a mechanism for coping. Informants reported that in response to negative behaviour experienced they began to withhold information, do the bare minimum and refuse to help others if they had been rude or uncivil in the past. This endemic, cyclical nature of negative behaviour was highlighted by NUM1: 'It's kind of handed down. It's a that's how I got treated,

so that's how I'm going to treat you'. This cyclic negative behaviour was cited by informants as a reason that nurses leave the profession and had implications for recruitment. It was acknowledged that good people were leaving the profession and that staff retention and recruitment was an ongoing issue. CNE2 asked, 'If we bully our staff how are we going to get new staff?'. She suggested that if you are known in the community as having a culture of bullying, people will be less inclined to apply to work there.

### 3.3 | Zero tolerance—'It's a joke'

The informants confessed to minimal knowledge of their organization's bullying policy; nevertheless, all informants recognized that a zero-tolerance stance was the expected standard. Informants also expressed disillusionment with zero tolerance, with many stating that 'it's a joke' and just an ideal, a poster on the wall, a box to tick and never actually enforced. NUM2 asked, 'It's zero tolerance but I know somebody who's been here for umpteen years, and it's well known that they're a bully, so why is that allowed? If there's zero tolerance, why is that allowed to continue?'

There were many barriers to zero-tolerance policy enforcement identified by informants, ranging from a lack of reporting to ineffective management. Several informants reported that there was often a lack of confidentiality when reporting, especially in these relatively small rural locations. They considered it brave to speak-up, due to fear of ramifications and ongoing consequences. They regularly tolerated the behaviours and attempted to ignore it as they did not feel safe and did not want to be seen as obstructive. Informants who had reported behaviours described the consequences, which included further abuse, exclusion from the ward, unfair workload allocations and a decrease in rostered hours. Having colleague support in the ward to report the behaviours empowered informants to engage in the formal reporting process. When the experience was shared instead of an informant feeling like they were the only one being targeted, there was a sense of safety in numbers to stand up and report the behaviours. As NUM3 stated:

I found another person that he was bullying. So, I only reported it because I was encouraged by her to do so and she had also reported it. So, she told me about her experience and she had also been talking to another person that he had been bullying and they had also reported their experience. So, I felt like I wasn't alone and that I potentially might be believed. Because I wasn't sure if I'd be believed.

However, this collective support did not occur in every ward, with informants stating that often people would turn a blind eye, ignoring the problem and leaving informants feeling alone and unsupported. NUM1 described an occasion where he was the victim of negative behaviours in front of others, as follows:



I looked around the room at those who had in private supported my concerns, but they were just sitting there with their heads in their hands. I was left alone and unsupported to cop the heated abuse. I felt awful. On that day no one had my back.

When negative behaviours were reported, informants felt a lack of confidence in management to act. They reported feeling disappointed and disheartened after speaking to management about negative behaviours on multiple occasions with no outcomes or resolution, CNE5 reported: 'I have been over to management a number of times over the years to various managers and it's just not managed up above'. Informants suggested that senior management had very little accountability, took little action and instead gave token rewards to staff to improve culture, such as barbeques, pizza days and bacon and egg rolls. Informants described those actions as 'insulting' (CNE1) and 'having little effect upon culture' (CNE2).

Nurse Unit Manager informants also spoke about the difficulties managing negative workplace behaviours from their perspective and, even if staff reported the behaviours, little was often done in response. They acknowledged the huge amount of effort and time that went into the performance management of perpetrators and felt that their workloads did not allow time for this. They referred to a difficult process, plagued by an onus of proof on the victim over a long period of time, multiple strike rules allowing the behaviours to continue and what they perceived as nursing union interference and representation of the perpetrator, making it difficult to actually remove anyone from the ward. NUM3 explained that, due to political reasons and an upcoming state election, one staff member was not performance managed by a NUM 'Because they were a very unionized staff member, they would bring the unions in. They [NUM] were advised not take it any further'.

Nurse unit manager informants spoke about how, if they did actually bother to undertake the performance management process, it was often disregarded by senior management as it was too much work to address the issues at hand and due to staffing issues, they could not afford to lose anyone. Multiple informants shared the view that negative behaviours were ignored and tolerated because staff were a valuable resource and that often that person and their experience were needed despite their behaviours.

They [*perpetrators*] get away with everything because their clinical skills are excellent. They're a resource, they're an asset, you couldn't possibly lose them despite their particular personality traits. So, in that regard it is a bit frustrating because you know no matter what happens, they will find a way out of it (NGN1).

In another case, NUM1 stated, 'Realistically I'm not going to put in the work to get someone fired. And let's be honest short of stealing drugs or doing something illegal it is impossible to be sacked in this organisation'.

Informants also reported that negative behaviours were often role modelled by those in leadership positions, with demonstrations of power over those below. The NUMs role in the ward was identified as being crucial in setting the tone and standards of behaviour. For example, NGN2 stated, 'It's the attitudes and actions of the Nurse Unit Manager that set the standard of what's accepted on the ward'. Informants spoke fondly of NUMs who set a clear standard of expected behaviours and enforced that standard.

Our current NUM I think is the best one that we've had that's sorted things out because she really - from the day that she started, made it clear what she will and won't tolerate on the ward and the values expected. She emphasised that we're a team (CNE6).

One informant (NGN2), however, reported difficulties in her ward as the nurse unit manager displayed negative workplace behaviour, which impacted her management of behaviours of other staff in the clique. That reportedly led to those behaviours being 'accepted as the norm on that ward as that was the precedent being set from management' (NGN2).

### 3.4 | Conflicted priorities

Informants identified that poor workplace conditions such as short staffing and heavy workloads had negative effects on nurse's workplace interactions. Informants reported increased feelings of stress and defeat as they were unable to complete their allocated workloads. The increasing pressure to complete unachievable workloads reportedly led to irritability, sadness and an inability to help other nurses (such as new graduates) with their workloads. NUM3 described negative workplace behaviours as 'a symptom of a struggling system'.

Informants suggested that nurses on the ward and senior management had conflicting priorities of care, and informants felt like there was a disconnect between the 'coal face' (NUM1) and those making decisions. Senior management was accused of never being seen and hiding in their silos, making decisions based on budgets, tick boxes and key performance indicators rather than seeing patient care as the priority. Informants perceived that senior management lacked empathy and did not appreciate how stressful the work environment was. NUM3 explained:

I think from an executive level and a very high executive level, I don't think they really understand what it's like to work on the floor. Nurses are now working in an environment we've created for them, and I don't think those people understand what they've created. There is no respect for what ward nurses do.

The NUMs also identified that they often felt like the 'meat in the sandwich' (NUM1, NUM2, NUM3), caught between senior leadership

decisions and expectations and providing ward leadership. The NUMs acknowledged that there was a flow on effect from decisions made above them. NUM3 said:

It's really hard because I have a circle of influence and I can't influence what happens above me and there's so many steps above me that really impact down. I mean when we look at morale and we look at the culture of our unit, I can obviously lead with positivity, I can set examples. But I don't necessarily agree with the things that are pushed on the floor staff with their workloads.

### 3.5 | Shifting the cultural norm

Although informants spoke about the occurrence of negative workplace behaviours being embedded in nursing culture, they also spoke about instances of individual tiny acts of kindness and positive workplace practices. Simple things such as pleasant introductions, orientation to the ward environment, knowing where the staff toilet and tearoom were located and someone offering to be the person to help if needed, were identified by informants as enabling newcomers to feel welcome. They described how social events, staff morning teas, holiday celebrations or birthdays with cake all helped build camaraderie and help the team to get to know one other. Some informants suggested that it did not have to be anything big, just simply telling people they are doing a good job, building them up or asking how their shift was going was enough to make a difference in someone's day. Informants identified that by setting a good example and displaying respectful workplace behaviour, they hoped to make a difference. For example, NGN 3 described the acts of kindness that made a difference in her feeling like she belonged:

Certain team leaders used to come round and make sure you were okay, to see if they could help. On my birthday they also made me a cake, so that was really nice. When I had to leave one level for another ward, they all gave me a hug because they didn't want me to go, that was also really nice.

The acceptance of learning as a lifelong process was also viewed as a crucial underpinning to positive workplace culture. Informants spoke about having empathy and insight for new staff coming to a ward and suggested there needed to be improved mentoring, support and workload allocations, especially for NGNs.

Informants identified that by standing up for the victims by shutting down gossip, reporting negative behaviours themselves and empowering victims to stand up to and report negative behaviours they were often able to halt negative behaviour. Informants spoke about instances where they had found the courage to stand up for themselves, 'prove that they weren't going to be walked over' (NGN2) and call out the negative behaviour, which had led to

improvement in their situation. Aside from the individual actions, informants described organizational actions that could transform the cultural norms of the profession and enhance respectful workplace practices. Informants described that for there to be a shift in the culture of the nursing profession, there needed to first be an acknowledgement of the problem. There were suggestions that the often-hidden negative behaviours needed to be spoken about more openly amongst the workforce, such as by sharing victims' stories and experiences and educating the future nursing workforce about the issues they may face.

Informants also described how having the right people, in the right jobs and with the right skills in the profession would modify behaviour and culture.

We need those people with the skills and personality to lead by example and manage behaviours and those who are approachable to speak up! We need people who truly have a zero tolerance. It needs to be more than just the poster on the wall (NUM1).

Informants felt that the presence of senior management and NUMs in the wards would allow for rapport building and improvement of respectful relationships between management and staff and permit firsthand experience of the poor working conditions. Informants identified that nurse-to-patient ratios, more staff and increased resources would improve morale, working conditions and, therefore, improve workplace interactions. NGN1 explained:

I honestly think if we just had more staff and more resources, if we reduced the stress levels, that in itself would reduce instability and bullying drastically. Because if you do that, people are less stressed and people are respecting each other more.

## 4 | DISCUSSION

The presence of negative workplace behaviour in nursing is not new (Hartin et al., 2018; Hawkins et al., 2021a, 2022). There has, however, been a shift over the years from the perception that negative behaviours are only attributable to individuals' interpersonal conflict to now recognizing the importance and influence of organizational factors (Hawkins et al., 2021a, 2022; Hutchinson et al., 2008; Johnson, 2015). Strauss et al. (1963), have previously conceptualized the features of a hospital organization such as work groups, rules, hierarchies, policies, organizational goals, ideologies, divisions of labour and career lines in which staff interrelate on a daily basis (Maines & Charlton, 1985; Strauss et al., 1963). These organizational features have implications for the workplace interactions of nurses and were apparent in the experiences shared by informants in this study.

During the interview process, informants described the socialization process of becoming an insider and *Belonging to the tribe*.

The Informants spoke about work groups being 'us vs. them' and depicted an authentication process of perceived strangers in the nursing social world. Conflict and social world segmentation was evident from the informants' descriptions of individual's attempts to be seen as being worthy to be an insider. They shared their experiences of negative behaviours in their workplace and described the impact on their lives as a *living hell*. There was also a view by informants that the standard of *Zero tolerance*, was a joke and suggested that negative behaviours were often not reported or managed. Various components of a *struggling health care system* such as heavy workloads and a lack of staff and resources compounded by conflicting care priorities between management and front-line staff were recognized as impacting negatively on workplace interactions. Informants highlighted the need for change at various levels to *shift the cultural norms* of the profession.

The study informants described an obligation by individuals to conform to the rules to be accepted. Achieving acceptance required having a certain standard of knowledge and skills but also having attitudes that aligned with the ward's culture and values. Although the explicit standards of performance for nurses in Australia are enshrined in the Registered Nurse Standards for Practice (Nursing and Midwifery Board of Australia, 2016), it was clear that there were also implicit standards in each ward. Strauss (1982) outlined that every social world has standards of performance along with methods of judging whether the standards are met. Informants identified that insider nurses were the authenticators who judged whether standards of performance had been met and they were responsible for deciding who was authentic and accepted. In this study, there were disagreements in the nursing social world, particularly between younger and older generational nurses about the degree of 'achievability' of the implicit social world standards of performance and the priorities of nursing care. This disparity, according to Strauss, indicates social world segmentation (Strauss, 1978). It also raises questions as to how new graduate nurses can ever be 'practice ready' (Masso et al., 2022) or 'hit the ground running' (Wolff et al., 2010, p. 7). They are educated in the university according to the explicit nursing standards of practice but may graduate having little understanding of the implicit standards of practice and ways of working expected in the nursing social world. The informants in this study outlined that implicit, in-world standards of performance and ways of working were common areas for conflict to occur. The inability to achieve and complete the workload or work in a different way fueled conflict and negative workplace behaviour. In their observational study of 120 hospital employees, Taylor and Taylor (2017) identified that it was common for negative behaviour and 'tough-love' teaching to occur between colleagues with disparate ways of working. These behaviours were often 'self-justified' (Taylor & Taylor, 2017, p. 3115) by perpetrators as a means of patient advocacy and improving colleague performance.

Informants also highlighted a mismatch between the organizational goals and the ideology of nursing care, which also led to conflict. For the informants, the need for management to meet key performance indicators and budgets was perceived to impact the

allocation, assigning and depriving of resources. Deprivation of resources can contribute to excessive workloads and inadequate staffing and, along with a lack of overall support from management, was identified as contributing to negative workplace behaviours. The deprivation of resources is emphasized by Strauss as a 'power feature' (Strauss, 1978), and has been reported in previous studies (Hutchinson et al., 2009; Vickers, 2014), where misuse of authority, processes and resources (including human resources) was labelled 'organizational corruption' (Hutchinson et al., 2009, p. 217). Despite the acknowledgement of organizational corruption and organizational negative behaviours in the literature of the past 13 years, zero tolerance policies remain targeted towards the management of individual behaviours and appear devoid of any framework for responding to and managing negative organizational behaviours. 'Organizational corruption' (Hutchinson et al., 2009, p. 217) and tolerance of negative behaviours increase levels of stress on nurses, which creates the perfect environment for the perpetuation of such behaviours. Those behaviours have persisted throughout the years and have become entrenched in the profession, becoming the cultural norm, as reported elsewhere (Hartin et al., 2018). Unfortunately, where acceptance and tolerance of negative behaviours are the cultural norm, there is a tendency for those behaviours to be underreported (Mckenna et al., 2003). Informants in this study identified that often negative workplace behaviours were accepted as the norm in their organization and, so as not to be seen as being obstructive, they often did not report behaviours. Without first fostering a workplace environment that discourages negative behaviours and establishing a culture that encourages reporting as the norm, the true extent of negative behaviours in an organization will remain hidden, thereby impeding attempts at mitigation.

Informants in this study who had reported negative behaviours expressed disappointment in the lack of action taken by management and viewed zero-tolerance policies as ineffective due to a lack of enforcement. It has been reported previously that many workplaces react inadequately to negative workplace behaviours, leaving workers disappointed by their inaction (Hallberg & Strandmark, 2006). In relation to social worlds, 'house rules' may be viewed as fluid and 'stretched and negotiated as well as ignored or applied at convenient moments' (Strauss et al., 1963, p. 130). The shortage of nursing workforce in regional areas was referred to frequently as an excuse as to why a zero-tolerance stance could not be enforced. Staff were viewed as a valuable resource that organizations could not afford to lose, so negative behaviours were tolerated. Regrettably, by conveniently not adhering to the zero-tolerance policy, recruitment and retention may be further impacted by the perpetuation of the behaviours, contributing to the ongoing nursing shortage.

Given the influence of organizational factors such as workload and staffing, the impact of the global COVID-19 pandemic on workplace behaviours since this data was collected warrants further consideration. Nurses have been essential to the healthcare response to COVID-19 (Fernandez et al., 2020) and many around the world have been infected or died in the line of duty (Turale et al., 2020). During the pandemic, whilst attempting to care for higher acuity

patients with increased workloads, nurses have endured reported staffing shortages and lack of resources (Chen, 2020; Manzano García & Ayala Calvo, 2020; Turale et al., 2020). Recent research has quantified the impacts on nurses due to the pandemic, with increased reports of fatigue, stress, burnout and intention to leave the nursing profession (El Ghaziri et al., 2022; Falatah, 2021; Raso et al., 2021). With previous research indicating an association between incivility and burnout (Oyeleye et al., 2013), it is hardly surprising that, in a study of 526 nurses in the United States of America, El Ghaziri et al. (2022) found that 37.4% of nurses experienced increased levels of incivility at work during the COVID-19 pandemic. In the qualitative component of that study, the informants reported feeling 'on edge', 'short tempered and more stressed than usual' (El Ghaziri et al., 2022, p. 150). Those informants reported that conflict occurred between nurses in relation to clinical skills, COVID patient assignments and heavy workloads (El Ghaziri et al., 2022). The increased pressure that the COVID-19 pandemic has placed on an already struggling health care system will continue to have ongoing implications, with experts warning that the true extent of the nursing exodus will not be fully felt until after the end of the pandemic (Falatah, 2021; Raso et al., 2021).

#### 4.1 | Study limitations

There are some limitations to this study that should be considered when interpreting the results. Firstly, this study was limited to a volunteer, convenience sample of 13 nurses located in one regional area of NSW, Australia. Care should be taken if generalizing the results to other countries and cultures, where there may be differing views of negative workplace behaviour and what is acceptable. Additionally, although this study included only registered nurse informants of varying levels (NGNs, RNs, CNEs and NUMs), the intention was not to underrate the role that other levels of nurses (e.g. endorsed enrolled nurses and assistant nurses) play in the delivery of patient care and workplace interactions. The decision to focus primarily on registered nurse informants' experiences was due to the overarching mixed methods design of the study and time, workload and funding constraints. It is acknowledged that the inclusion of informants from the various levels of nursing roles would provide a more comprehensive picture of the whole nursing social world.

## 5 | CONCLUSION

Negative workplace behaviours continue to persist in nursing and remain detrimental to individuals, patients and the nursing profession as a whole. This study has given valuable insight into the nursing social world and the organizational constraints that regional nurses work in on a daily basis. Although the inclination for an individual to exhibit negative workplace behaviours cannot be dismissed, this behaviour can either be facilitated or impeded by organizational influences. The mitigation of negative workplace behaviours requires not

only the management of individual behaviours but also the consideration and alleviation of associated organizational causative factors.

To decrease turnover and ensure a strong nursing workforce in the future, it is essential that nursing leaders make it a priority to transform regional nursing work environments to be conducive to respectful behaviours. Organizations should consider the profound ripple effect of under-resourcing and poor staffing on nurses' workplace interactions. Individual nurses also have a responsibility to demonstrate care and respect for one another and should integrate *tiny acts of kindness* towards others into their daily routines.

#### AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE [<http://www.icmje.org/recommendations/>]): (1) Substantial contributions to conception and design, acquisition of data or analysis and interpretation of data. (2) Drafting the article or revising it critically for important intellectual content.

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The authors declare no conflict of interest.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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# Managers' perception of older nurses and midwives and their contribution to the workplace—A qualitative descriptive study

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## Abstract

**Aims and Objectives:** The aim of this study was to explore healthcare managers' perceptions about older nurses' and midwives' and their contribution to the workplace.

**Design:** A qualitative descriptive methodology.

**Method:** Twenty healthcare managers working in Australia participated in semi-structured interviews. Data were collected between April 2019 and April 2021. Interviews were recorded, transcribed and then analysed using thematic analysis.

**Results:** All healthcare managers said older nurses and midwives contributed to the workplace through their experience and knowledge. Managers viewed them as a different type of worker and while there were some positive aspects to this, it was mostly negative. Although managers identified a broad age range for the older nurses or midwives, there was a common perception that if they were no longer able to perform their duties, they should leave the workforce.

**Conclusion:** Healthcare managers' perceptions towards older nurses and midwives are mostly negative, and their understanding of older workers' contribution is contradictory and poor. These negative views co-exist with the lack of agreement on who is the older worker, which explain the reluctance of healthcare organizations to invest in their older workforce. Future research is needed to better understand the unique contribution of older nurses and midwives in healthcare and how they can be supported at work.

**Impact:** The global ageing population will result in a rise in complex age-related health issues and will require an experienced and knowledgeable workforce. Given the greater experience of older nurses and midwives they are an important part of the health workforce. Yet managers' perception of the contribution by older nurses and midwives were often negative. The findings of this study highlight the need for organizational change so that the contribution of older nurses and midwives is recognized and supported by managers.

## KEYWORDS

ageing workforce, healthcare, manager, midwife, nurse, older workers

## 1 | INTRODUCTION

The world population is ageing, and many older workers remain in the workforce (Appannah & Biggs, 2015; United Nations [UN], 2019). Older nurses and midwives are also continuing to work (United Nations Population Fund (UNPF), 2021; World Health Organisation (WHO), 2020). While the older nurses and midwives can be valued by their managers for their experience and knowledge, they often encounter unfavourable opinions about their ability to contribute fully to the demanding healthcare workplace due to their age (Kleissner & Jahn, 2020; Ryan et al., 2017). There is little research on how older nurses and midwives are perceived by healthcare managers. This paper explores managers' perception about their contribution to the workplace.

## 2 | BACKGROUND

The implications of population ageing on healthcare systems are twofold. On one hand, with an ageing population, there is a projected rise in healthcare demand due to the complexity of age-related health issues (United Nations (UN), 2019; World Health Organisation (WHO), 2020). On the other hand, despite being in a physically demanding healthcare environment, many older nurses and midwives choose to stay in the workforce even though they may experience age-related challenges (Durosaiye et al., 2016; Organization for Economic Co-operation & Development [OECD], 2019; Schofield et al., 2017). The nursing and midwifery workforce appears to be growing in many countries, however, forecasts suggest this growth will be insufficient to meet the rising healthcare demands (United Nations Population Fund (UNPF), 2021; World Health Organisation (WHO), 2020). Retaining older nurses and midwives are recognized as one important strategy to help meet the increased demands of healthcare organizations (Fackler, 2019; Markowski et al., 2020). However, the negative perceptions about older nurses and midwives may hinder efforts to support and retain this group of workers.

### 2.1 | Managers of older nurses and midwives

Managers have the responsibility for staff organization (United Nations Population Fund (UNPF), 2021; World Health Organisation (WHO), 2020). Managers' perceptions about older nurses and midwives are important because they influence the older workers' work experiences (Garcia-Sierra & Fernandez-Castro, 2018). Older workers are more productive when a manager creates a supportive work environment (Salmela et al., 2017), however, managers often have negative opinions about older nurses and midwives, resulting in different treatment in the workplace (Ryan et al., 2017). Research suggests they are sometimes bullied for being slow workers (Clendon & Walker, 2016), or denied access to ongoing education and promotion (Ang et al., 2016; Durosaiye et al., 2016). Some older nurses and midwives have reported they are being asked to leave the workplace

to make room for younger colleagues (Clendon & Walker, 2016; Denton et al., 2021). The literature reinforces the impact that managers' perceptions can have on older workers.

### 2.2 | Older nurses and midwives in healthcare

Many older nurses and midwives cannot remain in the workforce because they struggle to cope with age-related physical challenges such as increased tiredness and fatigue, mobility impairment or onset of chronic diseases (Ang et al., 2016; Clendon & Walker, 2016). They experience stereotypical behaviour towards them where they are seen as outdated, irrelevant or limited in work output and their experience and knowledge are often not respected (Clendon & Walker, 2016; Durosaiye et al., 2016; Ryan et al., 2017). So, support from managers becomes a significant factor for retaining them in the workforce (Ericson-Lidman & Ahlin, 2017; Harrington, 2013). Previous literature has focussed predominately on older nurses and midwives' perception about their workplace challenges. However, there has been little exploration of how healthcare managers perceive older nurses and midwives and their contributions to the workplace. These managers' perception of older nurses and midwives is important if healthcare workplaces are to better support and retain older experienced workers.

## 3 | THE STUDY

### 3.1 | Aim

The aim of this study was to explore healthcare managers' perception of older nurses and midwives and their contribution to the workplace.

### 3.2 | Design

A qualitative descriptive methodology informed by Sandelowski (2000, 2010) was used to acquire and record the narration from managers. Qualitative description stays nearer to the primary data through a simple sorting and coding approach. It allows the participant's information to be communicated in their own language, which permits simple acceptance and understanding (Caelli et al., 2003; Neergaard et al., 2009).

### 3.3 | Participants

Healthcare managers who co-ordinate unit and staff administration in Australia were invited to participate in this study. A broad sampling strategy was adopted that sought to recruit managers from all health settings so that perceptions about older nurses and midwives in Australian healthcare could be widely explored. For the purpose of this study, a manager referred to a person in a supervisory or

charge position irrespective of their designated role. Inclusion criteria were as follows:

- Healthcare manager in any type of healthcare facility in Australia.
- Self-identifying as actively working in healthcare.
- Supervising older nurses and/or midwives.

A dedicated Facebook book page and Twitter account were created to promote the study. A professional nursing and midwifery organization provided further promotion. The recruitment occurred between April 2019 and April 2021. Snowballing and purposive sampling strategies were also adopted.

### 3.4 | Data collection

Data were collected using a semi-structure interview in person or via telephone due to the wide geographic distribution of participants. Semi-structured interviews enabled 'conversations with a purpose', allowing the interviewer to be flexible, and expand on any point raised from the participant's own words (Doody & Noonan, 2013; Sandelowski, 2010). Interview questions were informed by a scoping review and a previous study that involved interviews with older nurses and midwives (Denton et al., 2020; Denton et al., 2021). An interview was arranged at a mutually convenient time and each manager was asked:

1. When does a nurse or midwife become an older worker?
2. What is the contribution of the older nurse and midwife to the workplace?
3. Are there aspects about the workplace that are different for the older nurse and midwife compared with the younger group?
4. Does the contribution of the nurse or midwife change as they become an older worker?

The interviews were audio recorded and transcribed verbatim by the first author. To maintain anonymity, the researcher assigned pseudonyms to all managers prior to transcription.

### 3.5 | Ethics

This study was granted approval by the University of South Australia Human Research Ethics Committee (no. 201389). Participation was voluntary and prior to commencement, consent for interviews and audio recording was obtained. Participating managers were assured of confidentiality that they nor their organization would not be identified.

### 3.6 | Data analysis

To explore patterns and themes in the responses from managers, thematic analysis proposed by Braun and Clarke (2006) was used to

analyse the data. A staged approach was followed in the coding of data. (1) Reading and marking the interview transcripts aided familiarization of the managers' responses to the questions. (2) Recurring topics were assigned primary codes. (3) The primary coded data were searched for common themes. (4) A re-examination of the datasets occurred to ensure nothing relevant was overlooked and to ensure validity of themes and accuracy of the meanings. (5) Principal themes were then formed. The essence of each theme was identified, defined and named (Table 1).

### 3.7 | Rigour

To address the research aim and to ensure a rigorous process, a straightforward methodological framework was followed for acquiring and recording participant's own experiences using uncomplicated descriptive data (Sandelowski, 2000). A broad sampling strategy was used to recruit participants from a range of different healthcare settings and locations to help capture a variety of managers' perceptions about older workers. Independent coding of a sample of interview transcripts was undertaken by all members on the research team and the outcomes were compared and contrasted (Camfield, 2019). As analysis proceeded, to ensure emerging findings were credible and grounded in the data, regular meetings were held by the team to review the data, reflect and discuss the results (Graneheim & Lundman, 2004; Johnson & Rasulova, 2017). The written report was completed in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007).

## 4 | FINDINGS

Twenty managers responded to the recruitment process. All participants were included in the analysis of data (Table 2).

The interviews with managers captured different views about older nurses and midwives in the healthcare workplace. Based on the data collected, four themes and two sub-themes were identified.

- More than just age
  - Chronological age
  - Capacity to work
- Different type of worker
- Past their prime
- Experience and knowledge

### 4.1 | More than just age

The first theme was about how managers identified older nurses and midwives. Findings of the study show that older workers were mostly commonly recognized by their chronological age, but also their capacity to do the nursing or midwifery work.

TABLE 1 Data analysis

Question	Expressions	Primary code	Theme
1. When does a nurse or midwife become an older worker?	<p>Their age and physicality decline</p> <p>Being older was to be somewhere in their 60s because a lot them have limitations in that age group</p> <p>Their body starts giving out and physically falling apart</p>	<p>Age</p> <p>Physicality</p> <p>Limitations</p> <p>Inability to fully function</p> <p>Can they do the work?</p>	<p>More than just age</p> <p>Sub themes</p> <p>Chronological age</p> <p>Capacity to work</p>
2. What is the contribution of the older nurse and midwife to the workplace?	<p>They have that knowledge base and life experiences. Especially in a ward with a lot of younger people but you know that voice of reason and leadership and education.</p> <p>A lot to offer—a lot of prior knowledge and skills—Experience/Global knowledge</p> <p>Experienced, wealth of knowledge</p> <p>Older nurses have the experience and because they are more mature, they have good decision-making skills, and they are very reliable</p>	<p>Knowledgeable</p> <p>Life experience</p> <p>Leadership</p> <p>Educator</p> <p>Knowledgeable</p> <p>Skilled</p> <p>Experience</p> <p>Global knowledge</p> <p>Knowledgeable</p> <p>Experienced</p> <p>Mature</p> <p>Reliable</p> <p>Know what they are doing</p>	<p>Experience and knowledge</p>
3. Are there aspects about the workplace that are different for the older nurse and midwife compared with the younger group?	<p>They have different skills to the younger nurses</p> <p>They become older when they cannot hack the pace of the younger ones</p> <p>Older nurses challenged by IT with the younger ones it is usually just second nature</p> <p>Less flexibility in their willingness to take on new challenges</p>	<p>Skills are different</p> <p>Do not work as well as the young</p> <p>Not as tech savvy</p> <p>Inflexible</p> <p>Different to the young ones</p>	<p>Different type of worker</p>
4. Does the contribution of the nurse or midwife change as they become an older worker?	<p>Past their best when they reach their 50s, as people in their 40s are still able to function</p> <p>When you reach 60 you are not able to perform as well as when you are in 30 or 40s, so tend to be relegated to the side</p> <p>They get overlooked for in charge roles</p> <p>Older nurses and midwives were on their 'way out' and new applicants would not be employed if they were over 50 years old</p>	<p>Past their best at 50</p> <p>Pushed aside</p> <p>Past consideration</p> <p>Nearly gone</p> <p>Not useful anymore</p>	<p>Past their prime</p>

#### 4.1.1 | Chronological age

Managers often referred to chronological age when identifying older nurses or midwives, but it was obvious there was no precise age when a worker became older. Some managers considered nurses and midwives in their 60s to be older, because they were of a different generation. Fern said, 'I guess 60 is an age where things are changing a little bit.' Other managers said that being older was someone reaching retirement age. Lucinda said:

I think that when they get to 58 years generally, because when you get to that age you have to consider in the next 10 to 15 years people are going to retire.

However, workplace expectations about retirement have changed, Greta spoke of retirement goal posts progressively moving

over the years. Previously, workers from their mid-50 to 60 years were classified as older, but due to the changes in retirement policy, older workers were currently 60–70 years old. Two managers said being older was someone in their 40s and another said to be older was someone from 35 years upwards. Based on these perspectives about age, it is apparent that the term 'older' applies to a wide range of different ages when describing older nurses and midwives in the workplace.

#### 4.1.2 | Capacity to work

Managers also considered a nurse's or midwife's physicality as a factor when determining who was older. Some managers stated there are often age-related health problems or physical changes for workers which develop in their 50s. Bridgit said being older was: 'When they

TABLE 2 Participant demographics

	n
Role of participants	
Exec Officer/Director of Nursing/midwifery	5
Nurse Unit Manager	12
Clinical Manager/Clinical Nurse specialist	3
Workplace settings	
Metropolitan	5
Regional	11
Rural/Remote	2
Not specified	2
Type of healthcare facility	
Acute care	12
Aged care	2
Community care	2
Mental health services	2
Other	2
Australian State/Territory	
New South Wales	4
Victoria	5
South Australia	4
Western Australia	1
Queensland	4
Tasmania	1
Northern Territory	1

reach their 50s, as people in their 40s are still able to function.' Phoebe said: 'Being older was reaching 55 years, as by their 60s, their body starts giving out and physically falling apart. Managers spoke of identifying an older nurse or midwife when the ageing process restricted their capacity to work. Isolde said: 'Being older was to be somewhere in their 60s because a lot of them have limitations in that age group.' Physical decline can affect a nurse's or midwife's performance, and this can influence how they are viewed in the workplace. Greta said:

Once women hit 50, they are hitting menopause and undergoing physiological changes and with men, they are at a higher risk of heart disease. When you reach 60 you are not able to perform as well as when you are in 30 or 40s, so tend to be relegated to the side.

Age-related physical changes and fatigue can also make it increasingly difficult for older nurses and midwives to cope in the busy healthcare environment and this contributed to them being viewed as an older worker. Micaela said:

The ageing process takes a lot out of their bodies and they are not capable of doing fulltime work on a ward that is really heavy.

Managers thought older workers struggled with the busy pace of the healthcare environment.

Layla said:

Some of the older nurses when they are on the run all day, they struggle with that physical side of the work.

Isolde found older nurses and midwives 'become a little slower in thinking and work output' and Kiera said they tend 'to become more tired, fatigued and jaded'. So being 'older' was considered to be more than just age, it also involved their capacity to work.

## 4.2 | Different types of worker

The second theme was about how managers considered older nurses and midwives' workplace contributions to be different when compared with younger colleagues. While there were some positive aspects to the perceived difference, most aspects were negative. Isolde said, 'they think differently so they appear to be quite different'. Some managers believed older workers had a poorer understanding of technology. Greta said, 'with the younger ones it is usually just second nature.' Callista said:

Some of them are finding working a computer quite challenging. If you ask, 'are you reading your emails?' Some of them will say they don't know how to do it.

There was also a perception that older workers were reluctant to take on new tasks. Kiera said, 'There is less flexibility in their willingness to take on new challenges'. Additionally, managers said the older nurses and midwives had received training in a hospital setting, and therefore had a different approach to healthcare when compared with their younger colleagues. Isolde said:

Even with years of experience, learning through a different style from the university stream, a lot of them have got limitations in that older age group.

There was a common perception among the managers that older nurses and midwives were slower workers. Layla said, 'They become older when they can't hack the pace of the younger ones'. Managers also said they struggled with new technology and had a different approach to healthcare, so were often overlooked for higher duties. Isolde said:

Their work output is definitely less, they take more time to do what a younger nurse does, the more vibrant nurses

Community services manager Odette said:



We have so much IT these days and I think sometimes the older nurses are a little bit challenged by this. We have some nurses taking computers out to the homes, whereas the older nurses are not that keen. The willingness of the older nurse to make a change from what they are used to doing is not always there.

However, when compared with younger colleagues, Calista said, 'Hospital trained nurses are valuable, show more resilience, have good basic training, and good critical thinkers'. Fern said older workers, 'are more committed, engaged and less distracted'. Genevieve thought older nurses and midwives 'are more committed to work and give 100%, and that the younger workers were more about 'work life balance'. Micaela said:

Older nurses have a strong sense of duty and responsibility to the organisation, their colleagues and to their patients. They have been in the workforce a long time and are hardworking, responsible and have different skills to the younger nurses. They are reliable, they are going to turn up and do the job they are paid to do.

Although there were some positive commentaries about older workers, it was perceived by most managers that the workplace contributions of older nurses and midwives were not as valuable as those of younger workers.

### 4.3 | Past their prime

The third theme is about how different the workplace is for older nurses and midwives. The managers' perceived older nurses and midwives to be struggling to cope with the busy workload and thought they were past their prime. They believed the older workers often had an unrealistic view about how busy the healthcare workplace was and failed to appreciate it was a busy environment with little flexibility in the work roles. The older nurse or mid-wife struggling with their work tasks were seen to be past their usefulness. Charmaine said:

A lot of people still struggle to accept the fact that it is a 24/7 role' and those that struggle with attendance are in the older range of the workforce.

Isolde said, 'obviously as they get older their body is not as it used to be' so they have to be truthful about their own level of fitness. Odette said:

We are very mindful if they are starting to feel the effects of getting older, got aches or memory is not so good. They need to be honest about what their capabilities are.

Managers said individuals who were struggling with workplace challenges could be encouraged to consider change if they were prepared to step outside their comfort zone. Micaela said:

There is probably opportunity for staff to look around for other jobs that aren't so heavy, but you know nursing is still fairly structured around set hours and there is not a lot of flexibility.

Due to this limited flexibility of healthcare workplaces, managers said many older nurses and midwives were not given the option to redeploy to a less demanding area or change their role. Gemma said, everyone does the same job regardless of age:

If they want to do lighter duties, they need to leave the ward. There is not an option to reduce the duties. You do not get to do a different workload just because you are an older nurse.

Some managers said there was an attitude in their organization that the older workers should retire because they were too old for the healthcare workplace. Calista said, 'They get overlooked for in-charge roles' and Allegra said older nurses and midwives were often not considered for promotion with comments such as 'Oh, do you really want to do this job at this stage in your life?' This suggests the busy workplace was not older worker friendly and often not conducive to them remaining in their job. Kylie said:

Older nurses and midwives were on their 'way out' and new applicants would not be employed if they were over 50 years old.

Despite the common view that older nurses and midwives should leave if they could not do their job, many were unable to leave the workforce. Fern said:

Staying is often related to life circumstances rather than to age. Financially they need to work, or they work because they enjoy the work itself.

Moving to a different healthcare workplace was not always successful. According to Odette, when some older workers moved to community nursing thinking it will be a steppingstone to retirement, they are disappointed:

Some of the older nurses really struggle to retire because I think it is more the financial side of things. They are worried because the work becomes too much and some of the older staff just find that exhausting. It's quite a shock for some to realize they are working just as hard in the Community as they would be in an aged care facility or hospital.

Another manager noted that older nurses and midwives who enjoyed their work did not want to leave healthcare. Phillipa said:

I have a couple of nurses who have no intention of retiring. We will be taking them out in a 'box'.

#### 4.4 | Knowledge and experience

The fourth theme was in contradiction to the commentary above, in that managers valued the older nurses and midwives' changing contribution due to their knowledge and experience gained over the years. They recognize that older experienced workers make an important contribution to healthcare. Isolde thought older workers 'have a wealth of knowledge or experience'. Keira said they have 'knowledge and skills that never tire'. They often became mentors and guides for younger colleagues. Gemma said:

They become a 'go to' person, someone who is experienced, someone who gives advice to other people.

Iris had similar views about experienced older workers:

They are the 'valuable rocks,' the 'go to' person. They've got it altogether because they have been around for a long time.

Allegra recognized older nurses and midwives to be 'the ones with practical knowledge that the younger ones do not have'. One manager said they had a comprehensive knowledge of the healthcare environment and were recognized to have a 'gut feeling' or 'intuition'. Iris said, 'these people know what they are doing'. Kylie said: 'They have life skills and experience which helps them make the right decision, especially with patient care'. Phillipa said:

We need to acknowledge they have a lot of skill and knowledge and it takes some time to hand that over, you can't lose people and bring in new people and expect them to be at the same level.

Despite positive commentary about experience and knowledge, this contribution by older workers did not seem to be well utilized in many workplaces. The common perception seemed to be that older nurses and midwives were just waiting for retirement, which limited their usefulness in the workplace. This highlights the complexities for older nurses and midwives in healthcare, and the contradiction that exists between being having great experience while also being past their prime.

## 5 | DISCUSSION

This study sought to determine how managers perceived the contribution to the workplace of older nurses and midwives. As managers

sought to identify older nurses and midwives they looked beyond age, it was also the older worker's capacity to work. Consistent with earlier studies, when age was used to classify a worker as being old, there was little agreement on what that age should be (Austen et al., 2016; Harris et al., 2018; Utraiainen et al., 2016). This ambiguity about who are the older workers in healthcare is of concern, because if workplace practices are to be modified to better support older workers, then it is critical to know who are the target population (Buchan et al., 2020; World Health Organisation (WHO), 2020).

The managers in this study perceived older nurses and midwives differently to younger workers. Some managers acknowledged the positive attributes of older workers, saying they were hardworking, more resilient, less distracted, committed, engaged and more reliable. They were also perceived to be critical thinkers with a practical knowledge that was gained through years of experience. This view is supported by the literature which suggests older nurses and midwives are valuable to the organization because of their reliability, skills and experience (Clendon & Walker, 2016; Fackler, 2019; Ryan et al., 2017). But most often in this study, managers perceived older nurses and midwives negatively. They were often perceived as slower, inflexible, resistant to change and producing less output than younger workers. Their contribution to the workplace was seen to be limited, so they were often not considered for promotion or education opportunities. There was a view among managers, that because older nurses and midwives were approaching retirement, so they were not a good investment for the organization. This negative perception corresponds to earlier studies which reported older nurses and midwives were becoming tired more easily due to shift work and heavy patient loads therefore, were seen as slow workers who do not 'pull their weight' (Ang et al., 2016; Kirgan & Golemski, 2010; Spiva et al., 2011). While managers recognized the positive attributes of older workers, their different skills sets do not appear to be utilized in the workplace. Instead, older nurses and midwives were often considered to be a second-class worker compared with the younger more 'vibrant' workers.

Managers said the older nurses and midwives were often overlooked for senior roles or were not considered for promotion because they were past their prime. One manager said she asked older workers, 'do you really want to do this job at this stage in your life'? This is similar to previous findings where many older nurses and midwives were found to experience a lack of respect, diminished workplace value and were viewed as a poor investment for ongoing education or promotion due to their perceived impending retirement (Voit & Carson, 2012; Warburton et al., 2014). Ang et al. (2016) reported that it was common for older nurses and midwives to be asked when they were going to retire and Clendon and Walker (2016) reported older nurses and midwives had a short 'shelf life' and would not be chosen over a younger person for the same job. These negative perceptions about older workers have important implications for a workforce that continues to age, and this will likely add to the challenges that are faced by older nurses and midwives. Despite managers' negative perceptions about older nurses and midwives, managers recognized

experience is the older workers most important contribution. Many other reports in the literature suggest more experienced workers are needed to ensure high-quality care (Fackler, 2019; Reinhardt et al., 2020; Ryan et al., 2017). Therefore, older nurses and midwives should be considered key workers for the healthcare workplace (Szalmasagi, 2018) because they carry the knowledge, skills and traditions of the profession. However, findings suggest many managers tell older nurses and midwives to retire, despite their considerable knowledge and experience. In a small number of workplaces, the older nurse and mid-wife are seen as the 'wise worker' of healthcare (Denton et al., 2021). In these workplaces, older nurses and midwives said their managers valued their contribution because they were considered to be more committed and less distracted than the younger workers (Clendon & Walker, 2016; Denton et al., 2021). This contradicts the common view from this study that older nurses and midwives are past their prime. However, positive attributes of older nurses and midwives are often ignored (Dahlke & Hunter, 2022; Ryan et al., 2017) and negative perceptions may discourage healthcare organizations from implementing workplace change to better utilize the knowledge and skills of older nurses and midwives. These findings highlight contradictions that exist in healthcare workplaces, that older nurses and midwives are seen as both an asset and a poor investment by managers. This explains the reluctance of organizations to invest in the older workforce in healthcare.

## 6 | STRENGTHS AND LIMITATIONS

While the participation of 20 healthcare managers from a broad range of locations and settings allowed the different perceptions about older nurses and midwives to be explored, a larger more diverse sample with greater representation from rural and specialty services may result in different findings. Although the characteristics of gender, age, ethnicity, clinical specialty or background were not taken into account all managers involved participated voluntarily in this study and some may have become interested in the topic because they were older workers themselves. Therefore, their perception about older nurses and midwives may have been influenced by their own experience as an older worker. Mindful that ageing of nurses and midwives in the workplace is a global issue, this study was limited to one country. Due to the healthcare variations when compared with other countries, a manager's perception of older nurses and midwives in Australia might not be in accord with other healthcare systems.

## 7 | CONCLUSION

The findings of this study highlight the contradictions that exist in healthcare about older nurses and midwives, managers recognize their experience and knowledge, but also view them as a poor investment because of their age. Managers' perceptions about older workers in this study were mostly negative. However,

some managers recognized that older nurses and midwives were more committed and engaged, and less distracted while at work. Managers also recognized the greater experience and skill that older workers had to offer the workplace. But the negative perceptions about older nurses' and midwives' contribution to the workplace were far more prevalent than the positive views. These negative views help explain the reluctance of organizations to invest in their older workforce in healthcare. It also highlights the need for more research to better understand the unique contribution of older nurses and midwives in healthcare and how they can be supported to continue to contribute.

### AUTHOR CONTRIBUTIONS

All authors have agreed on final version. Julie Denton: Conceptualization, investigation, data curation, formal analysis, methodology, writing—original draft, review and editing, visualization. David Evans: Supervision, validation, review and editing. Qunyan Xu: Co-Supervision, Validation, review and editing.

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### CONFLICT OF INTEREST

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### DATA AVAILABILITY STATEMENT

Author elects to not share data.

### PATIENT OR PUBLIC CONTRIBUTION

No patient or public contribution. Neither the research question nor the outcome measures were determined by patients or the public, nor was the study designed or implemented by them. No patients or public were asked to advise on interpretation or the writing up of the findings.

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**ORIGINAL RESEARCH: EMPIRICAL  
RESEARCH - QUALITATIVE**

# The impact of the COVID-19 pandemic on the perioperative transition to specialty practice program

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## Abstract

**Aim:** To understand how the COVID-19 pandemic impacted nurse educators' and novice nurses' experience with the perioperative transition to specialty practice program.

**Design:** A qualitative descriptive study.

**Methods:** Semi-structured interviews were conducted with five perioperative nurse educators and five perioperative transition to specialty practice program participants from a major metropolitan health service in Melbourne. Data were collected between April and July 2021. Interviews were audio-recorded and transcribed verbatim, and data were analysed using reflexive thematic analysis.

**Results:** Five themes were identified. The value of the perioperative transition to specialty practice program in supporting novice nurses was recognized in the theme 'Nurturing our novices'. Widespread changes to clinical practice were demonstrated in the theme 'Every day is different', including changes to elective surgery, redeployment of staff and the transmission risk of COVID-19. 'The perils and joys of online learning' revealed both challenges and benefits of transitioning theoretical education from face-to-face to online delivery. 'Roller coaster of emotions' represented the heightened emotions participants experienced due to the COVID-19 pandemic. 'Looking back to move forward' encompassed participants' reflections on the year, considering the challenges, adaptive strategies and the future of perioperative nursing education.

**Conclusion:** The perioperative transition to specialty practice program was significantly impacted by the COVID-19 pandemic. Participants needed to adapt to rapid and frequent changes, which contributed to feelings of emotional distress, affected consolidation of clinical learning and reduced engagement with theoretical education.

**Impact:** Perioperative nurses should acknowledge that opportunities for learning were decreased for transition to specialty practice program participants during the pandemic. Ongoing support and education should be provided, to nurture the future generation of perioperative nurses.

No patient or public contribution. This study only involved staff from the participating health service, purposefully recruited as they had the required knowledge and experience to address the research aim.

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## KEYWORDS

COVID-19 pandemic, novice nurses, nursing education, operating suite, perioperative nursing, transition to specialty practice

## 1 | INTRODUCTION

The outbreak of coronavirus disease (COVID-19), caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has caused significant disruption to healthcare systems around the world (Nicola et al., 2020). Around 15% of individuals who contract COVID-19 become seriously ill, and a further 5% become critically ill, requiring intensive care support (World Health Organization, 2021). Considering that there have been over 600 million cases of COVID-19 reported worldwide, it is not surprising that there has been an increased demand for healthcare services, which has caused a diverse range of challenges for those working in healthcare (Stucky et al., 2020; World Health Organization, 2022).

Perioperative clinicians have faced unique challenges as widespread changes occurred to surgical practice because of the COVID-19 pandemic. Surgical procedures were reduced or cancelled, clinicians were redeployed to other areas of the hospital, surgical education was impacted, and perioperative practices needed to evolve to manage viral transmission risk (Al-Jabir et al., 2020; Elliott et al., 2021). In this specialty practice area, perioperative nurses form a unique subset of healthcare workers who experienced significant change because of the COVID-19 pandemic. Perioperative nurses provide care to patients through all stages of surgery, including preoperative, intraoperative and postoperative care, ensuring patient safety, both physical and psychological (Gül & Kılıç, 2021; McGarry et al., 2018).

Appreciating the complexity of the perioperative environment, nurse educators are integral to the specialization and ongoing professional development of perioperative nurses, which in turn facilitates the delivery of safe, quality patient care (Thornton, 2018). For this paper, the term *nurse educator* refers collectively to clinical nurse educators and clinical support nurses who work in healthcare services. Nurse educators also provide support and mentorship to novice perioperative nurses, defined as 'any registered nurse who has not worked in the perioperative environment before, including a new graduate, an experienced nurse from another area of nursing, or a nurse with previous perioperative experience who has not maintained basic competency' (Association of periOperative Registered Nurses, 2018, p. 5). While the impacts of the COVID-19 pandemic on the perioperative environment have been identified, little is known about how the COVID-19 pandemic has affected the education of novice perioperative nurses.

## 2 | BACKGROUND

Nurses and midwives account for 55% of the total workforce in Australia (Australian Institute of Health and Welfare, 2022a), with

most employed in acute settings in public hospitals, including the operating suite (Australian Institute of Health and Welfare, 2016). Despite an increasing number of healthcare workers in Australia, it has been predicted that the nursing workforce will face a shortage of up to 123,000 nurses by 2030. Unless the situation is addressed, this shortage creates a risk of current and future demands of healthcare systems not being met (Health Workforce Australia, 2014).

Transition to specialty practice (TSP) programs provide theoretical education, clinical support and professional development to facilitate the transition of nurses into specialty practice areas (Considine & Hood, 2004). These programs are aimed at supporting novice registered nurses with limited post-registration experience or experienced nurses wishing to develop their expertise in a different area of specialty nursing practice (Morphet et al., 2015). In Australia, TSP programs are facilitated by hospital-based nurse educators, with programs delivered over 6 or 12 months. TSP programs were first implemented in Australia in 2000, as a successful recruitment strategy to combat staffing shortages in the emergency department (ED; Considine & Hood, 2004). Subsequent research in both the ED and the intensive care unit (ICU) highlighted the positive effect of TSP programs on nursing recruitment and retention, while also facilitating the professional development and clinical progression of nurses in specialty practice areas, and leading to formal postgraduate education (Madhuvu et al., 2018; Morphet et al., 2015). A similar foundational educational program is offered in the United States of America, with demonstrated effectiveness for both recruitment and retention of perioperative nurses (Nissen, 2020; Vortman et al., 2019). However, there is currently no literature describing or evaluating TSP programs for Australian perioperative nurses.

Nursing education has been significantly disrupted by the COVID-19 pandemic (Ramos-Morcillo et al., 2020; Wallace et al., 2021). Student attendance was limited at many nursing schools and university campuses due to government restrictions, prompting a rapid transition from face-to-face campus education to online remote learning (Langegård et al., 2021; Ramos-Morcillo et al., 2020; Wallace et al., 2021). This transition to online learning has been challenging in many ways, for both nursing students and educators (Langegård et al., 2021). Various teaching methodologies have been used to foster student engagement, however overall, most nursing students have indicated their preference for regular campus-based face-to-face education due to the social interaction and enhanced learning experience (Langegård et al., 2021; Ramos-Morcillo et al., 2020). Students' performance, motivation and discipline have also been negatively affected by the abrupt transition to online learning, with decreased social interaction identified as a contributing factor (Langegård et al., 2021; Ramos-Morcillo et al., 2020).

While the experience of university nursing students has been explored in detail, studies considering the impacts of COVID-19 on nursing education in the workplace are limited.

Perioperative nurses have experienced widespread changes in response to the COVID-19 pandemic. Many elective surgeries were cancelled or postponed, to support surge capacity, by potentially repurposing perioperative departments into temporary ICUs, and creating a surplus of staff. For many, this has constituted a change in role as they have been redeployed to assist in other clinical areas, therefore requiring further education in preparation for their new role (Al-Jabir et al., 2020; Lee et al., 2020; Stannard, 2020; Stucky et al., 2020). Perioperative nurse educators played a vital role in redeployment, ensuring staff were appropriately reallocated and suitably prepared for their area of redeployment by providing education on any identified knowledge gaps (Peneza et al., 2021). Perioperative nurses needed to rapidly adjust to frequent changes in their clinical work environment because of the COVID-19 pandemic, with evolving knowledge, evidence, policies and practice guidelines often creating conditions of uncertainty (Elliott et al., 2021). Considering the vast array of changes to perioperative nursing practice, no research has specifically examined the experience of novice nurses working in such a dynamically changing environment during a pandemic.

Restrictions on elective surgery have resulted in a backlog of surgical cases, potentially impacting patient outcomes (Matava et al., 2022). In Australia, waiting times for most elective procedures increased during 2019–2020 and 2020–2021, and the proportion of patients waiting more than a year for their elective surgery increased from 2.8% to 7.6% in the same period (Australian Institute of Health and Welfare, 2022b). Similar increases in waiting list numbers and waiting times have been reported internationally (Matava et al., 2022; Uimonen et al., 2021). The drive to deal with this ever-growing backlog of elective surgical cases has resulted in an increased demand for specialized perioperative nurses. Sustained funding to expand the perioperative workforce is necessary to achieve significant reductions in the elective surgery waitlist (Matava et al., 2022). By supporting novice registered nurses with hospital-based education, the perioperative TSP program bridges the gap between general undergraduate nursing education and specialized postgraduate education at university. Given the importance of growing the perioperative nursing workforce to help combat the growing elective surgical waiting list (Matava et al., 2022), it is imperative to consider the impact of the COVID-19 pandemic on the perioperative TSP program.

## 3 | THE STUDY

### 3.1 | Aim

The aim of this study was to understand the impact of the COVID-19 pandemic on nurse educators' and novice nurses' experience with the perioperative TSP program.

### 3.2 | Design

A qualitative descriptive design was used to provide a rich description of participants' experiences (Sandelowski, 2000). Data were collected from nurse educators and participants involved with the 2020 perioperative TSP program. This study is reported according to the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007).

### 3.3 | Participants

This study was conducted in the perioperative departments of two acute hospitals which are part of a major metropolitan health service in Melbourne, Victoria, Australia. Participants were purposefully recruited. The eligible sample included 12 potential participants; hospital-based nurse educators and TSP participants who had experience with the perioperative TSP program during 2020 were eligible to participate in the study. Participants were invited to take part in the study via a workplace email, distributed by a senior member of the Learning and Teaching Directorate at the participating health service. Attached to the email was the participant information sheet, which provided detailed information about the study. Interested participants then contacted a member of the research team to arrange an interview time.

### 3.4 | Data collection

Data were collected between April and July 2021 via semi-structured interviews, using the interview questions shown in Table 1. A pilot interview was conducted with an ED nurse educator, to determine the clarity of the initial interview questions. The interview guides were iteratively refined after each interview, and prompts and probes were used to further explore participant responses. The first author, a Master's prepared researcher, conducted online interviews via Zoom at a time convenient to participants, adhering to COVID-19 restrictions on face-to-face meetings. The participants and interviewer were known to each other, as the interviewer had previously worked in the perioperative education team, providing the impetus for the study. All interviews were audio-recorded and transcribed verbatim by the interviewer. Interview recordings were replayed afterwards, and field notes were taken at this time. Participants were given the option to review their transcript; six participants chose to receive theirs, however, no amendments were made.

Guest et al. (2006) suggest that data saturation, the point at which no new themes are observed in the data, is likely to occur after 12 interviews in a relatively homogeneous sample. Considering the maximal sample size for this study was 12 participants, spread across two distinct cohorts, the decision was made not to rely on the concept of data saturation; rather, data were collected and analysed for each consenting participant, recognizing the unique contribution each individual could make to the overall dataset.

TABLE 1 Examples of interview questions

No.	Nurse educator	TSP participant
1	Demographic Questions: How long have you been working as a Registered Nurse? How many years have you worked in the operating theatre? How many years of experience do you have as a nurse educator in the operating theatre? Do you hold any professional qualifications required to work as a nurse educator?	Did you commence TSP straight after completing your graduate year? Did you have any prior experience in the operating theatre before commencing TSP?
2	What do you feel is the value for learners participating in a TSP program?	What do you feel is the value of participating in a TSP program in the operating theatre? What motivated you to apply?
3	How did COVID-19 impact practices in the operating theatre?	
4	What impact did COVID-19 have on the 'hands-on' training of the program?	
5	What impact did COVID-19 have on the specialty rotations?	
6	What challenges did you face as an educator due to COVID-19?	What challenges did you face as a TSP participant due to COVID-19?
7	What changes and adaptations were you required to make to your delivery of theoretical education during this year?	What was your experience of the theoretical education provided during your TSP year?
8	Considering the cohort as a whole, have you noticed any widespread impact on the learners in 2020 compared with previous years of TSP programs?	How did COVID-19 impact your ability to complete the academic requirements of the TSP, such as the learning package, case studies, and assignment?
9	Considering that TSP aims to increase recruitment and retention of staff into specialty areas and act as a pathway for postgraduate study, what impact do you think COVID-19 has had on the future workforce?	What were your intentions/goals when you applied for the TSP program? Have those intentions/goals changed at all because of COVID-19?
10	What strategies helped you adapt to the changes presented by COVID-19?	
11	Overall, what have you learnt from the past years' experience?	

Abbreviation: TSP, transition to specialty practice.

### 3.5 | Ethical considerations

Ethical approval was granted by the Human Research Ethics Committees at Eastern Health (LR20-113-70099) and Deakin University (2021-096). Participants received the participant information and consent form (PICF) via email, which explained the purpose of the study, what participation involved, possible risks and benefits of participation and privacy and confidentiality arrangements. Participation was voluntary, and participants provided verbal consent at the beginning of the interviews. Participants were able to freely withdraw at any time. Information on available support services was provided in the PICF and reiterated to participants at the conclusion of the interview.

### 3.6 | Data analysis

Interview transcripts were analysed using reflexive thematic analysis, which is commonly used in qualitative research to identify, analyse and report patterns or themes in the data. The reflexive thematic analysis involves a six-phase approach, resulting in a richly detailed account of data (Braun & Clarke, 2006, 2019, 2021). (i) Familiarization began when the interviews were transcribed and was augmented by re-listening

to audio recordings, re-reading transcripts and making field notes. (ii) Codes were developed through an inductive process, organically recognizing what the data were saying. The first author coded the data semantically, staying close to the participants' language and meaning. (iii) Themes and subthemes were actively constructed from codes, collating those that held shared meaning and collectively told a story about the data. (iv) Themes were subsequently reviewed with the research team, ensuring clear distinctions between each theme, and that all data related back to the central concept of each theme. A thematic map was used to visualize the relationship between themes and subthemes. (v) Themes and subthemes were named, ensuring the essence of each theme was embodied in the name. (vi) Finally, the analysis was written into a narrative, telling the story of the data in and across each of the themes. Data analysis was supported using NVivo 12 (QSR International). Participants were not invited to provide feedback on the findings.

### 3.7 | Rigour

Lincoln and Guba's (1985) four criteria for trustworthiness were followed to establish rigour. Credibility was upheld by the interviewer establishing rapport with participants at the beginning of the interview, supporting a willingness to exchange information;

and participants were given the opportunity to verify the accuracy of their interview transcripts. Confirmability and dependability were maintained by keeping an audit trail, which comprised any changes made to the interview guide, casual notes about interviews, and notes about coding decisions and the development of themes. Finally, transferability was ensured through a purposive sample, providing rich descriptive data and verbatim quotes. Acknowledging the researcher's prior experience with the perioperative TSP program, reflexivity involved critically questioning her role and reflecting on how this influenced the study (Braun & Clarke, 2021). This was managed with the use of a journal and regular meetings with the other authors, from study design, through to data analysis.

## 4 | FINDINGS

Of the 12 potential participants approached, 10 consented to take part in the study, including five perioperative nurse educators and five TSP participants. All participants were female. Interviews lasted between 24 and 51 min, with a mean duration of 33 min. Experience as a perioperative nurse educator ranged from 1.5 years up to 16 years. All TSP participants began the program immediately after their graduate year, and participants had varying levels of prior perioperative experience. Five themes and eight subthemes were constructed from the data (see Figure 1).

### 4.1 | Theme 1: Nurturing our novices

Perioperative nursing is a unique and complex area of specialty practice, described as 'a very niche area of nursing' (TSP Participant #4), and the perioperative TSP program provides an introduction to the specialty practice area for novice nurses. 'For a lot of people, it's their sort of first exposure to theatre ... it's a really good opportunity to get some exposure to the area' (Educator #3). The 12-month program combines didactic teaching and hands-on learning to offer an 'all-round experience of theatre' (TSP Participant #4), allowing novice nurses 'to learn in a supportive environment' (Educator #2), and teaching participants 'what to expect in terms of the job itself, and the responsibilities that you have [as a perioperative nurse]' (TSP Participant #5). The TSP program also facilitates recruitment into the operating suite and acts as a pathway for postgraduate study. 'It feeds into any EFT [equivalent full time] deficits ... it grows the nursing population in theatre' (Educator #4). 'It gives them a really good foundation ... it's almost equivalent to the first 6 months of a grad [graduate] certificate' (Educator #1).

### 4.2 | Theme 2: Every day is different

Participants described widespread changes to clinical practice in the operating suite because of COVID-19, affecting an array of policies and procedures. 'The constantly changing environment

was challenging' (Educator #5). 'Everything from infection control to patient transport, patient selection for procedures ...' (Educator #5); 'changes to processes, changes to policy ...' (Educator #1). This theme included three subthemes.

#### 4.2.1 | Urgent cases only

Elective surgery was significantly impacted by the COVID-19 pandemic, with only the most urgent procedures permitted to be scheduled. Participants perceived that the reduction in surgical procedures adversely affected their ability to consolidate their clinical learning. 'Because there wasn't as many surgeries happening, there wasn't exposure to, to repeatedly learn skills and ... cement those skills' (TSP Participant #1). TSP participants described 'missing out on some of those really simple foundational cases' (TSP Participant #3), and instead were often 'thrown in, into complex cases' (Educator #1). The reduction in elective surgery also resulted in missed learning opportunities for TSP participants, particularly in certain surgical specialties, such as orthopaedic surgery. 'They didn't get to experience a lot of stuff that they may have, towards the end of their rotations' (Educator #2). 'I feel I've been short-changed in that area [specialty rotations] ... I do think my learning has really been impacted' (TSP Participant #4).

#### 4.2.2 | Changing roles

Redeployment of perioperative nurses to other clinical areas was necessary during the COVID-19 pandemic. 'I think management did a pretty good job of trying to avoid [redeploying] the TSPs, but ... there were obviously times where they did have to be redeployed' (Educator #3). Redeployment impacted learner rotations and the overall skill mix of junior and more experienced perioperative nurses in the department. 'Their rotations were impacted. Skill mix was impacted' (Educator #4). This disruption to rotations was challenging for TSP participants. 'Going into your day ... you're not really sure what to expect: what your role is for the day, what rotation you'll be in for the day, what sort of surgeries you'll be in for the day' (TSP Participant #5). Educators also described how their role was broadened beyond providing education. 'A lot of anxiety management'; 'A bit of a mediator ... a buffer between other disciplines, and the staff, and the management' (Educator #1).

#### 4.2.3 | Keeping safe during the pandemic

Personal protective equipment was made available to protect participants from COVID-19. However, advice surrounding safe and effective use was constantly changing throughout the pandemic. 'The advice was always evolving, whether or not we used N95s or face masks; or double gloved or not double gloved; room resting, not room resting' (TSP Participant #1). Even experienced perioperative

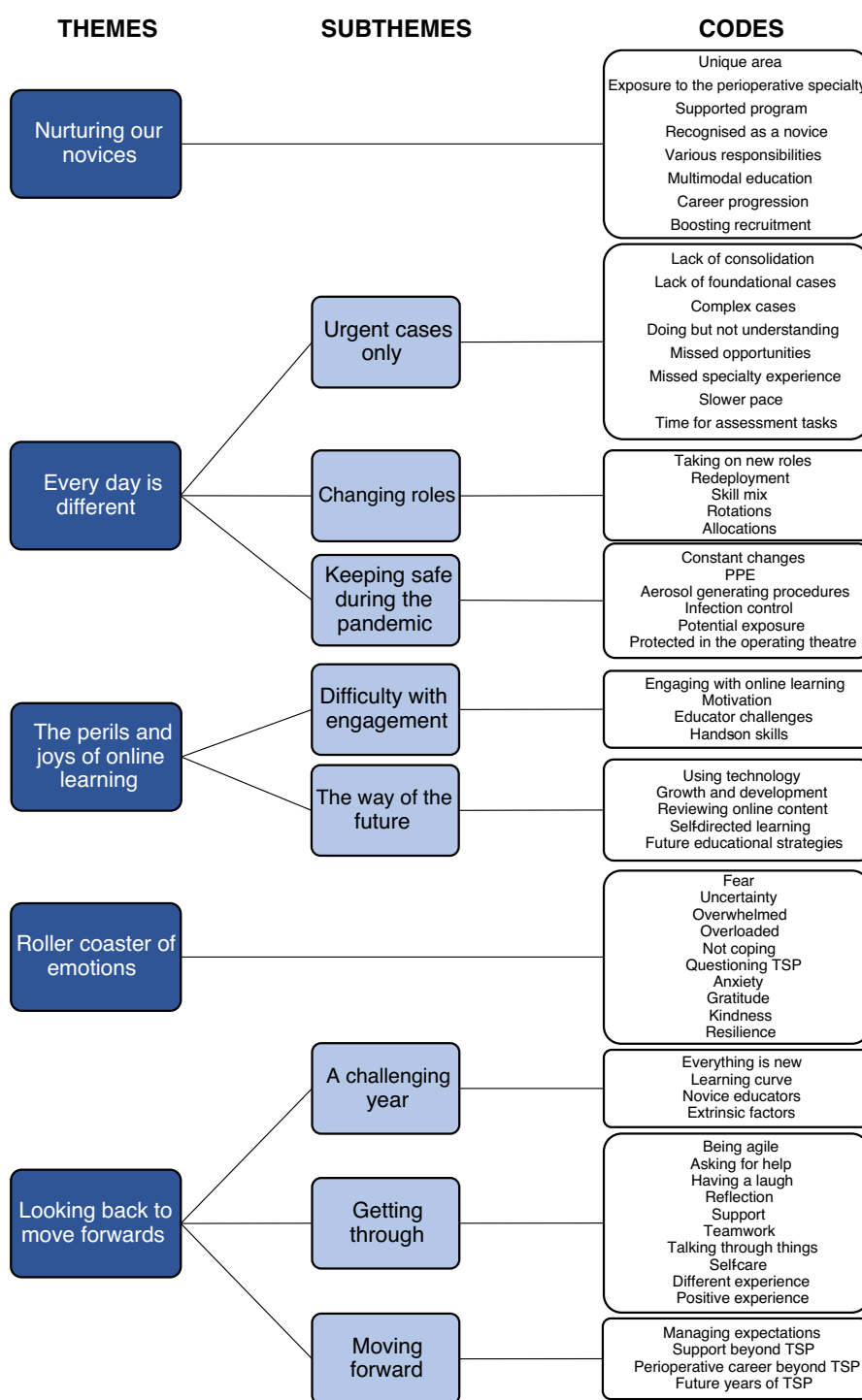


FIGURE 1 Development of themes and subthemes from codes.

nurses were often unsure of current advice, leaving TSP participants without clear role models. 'You want to follow the direction of everyone and look up to these people who you're learning from, but then they don't know what's going on' (TSP Participant #1). A general sense of anxiety around contracting COVID-19 was noted. 'Everyone was a little bit scared ... to have the virus themselves ... you're in an area where your risk is increased as well, because you're a healthcare worker' (TSP Participant #5). However, participants felt more protected due to the screening processes that occurred in the operating suite. 'Nearly all of our patients were screened, and they

were COVID tested prior to coming to theatre. So, I felt relatively safe that most of the precautions were taken' (TSP Participant #1).

### 4.3 | Theme 3: The perils and joys of online learning

The theoretical component of the perioperative TSP program shifted rapidly from face-to-face sessions to an online format because of COVID-19 restrictions. 'Like everybody else delivering ...

theoretical education, we had to pivot to online [learning]' (Educator #1). 'At the beginning, the study days were in person [face-to-face], and they were all fine, but the mid-year study days were disrupted' (TSP Participant #1). This online transition resulted in both challenges and benefits for participants.

#### 4.3.1 | Difficulty with engagement

Overwhelmingly, TSP participants expressed challenges associated with online learning and a preference towards face-to-face education. 'No matter what I'm doing, online learning is already, like, a barrier, and like, already impacts my learning straightaway' (TSP Participant #2). The engagement was compromised, not only with theoretical content, but also between the learners and educators, and with fellow learners. 'Not getting together with their group and touching base ... that was a deficit' (Educator #4). 'They couldn't, you know, bounce ideas off each other with an educator' (Educator #2). Without having an opportunity to complete any formal training in digital technologies, creating online content in a short time frame was challenging for the educators, also impacting TSP participants' learning. 'It was a big learning curve for me, and quite stressful' (Educator #4). 'It was just kind of, a bit of a throw together, quick, let's get some stuff up online ... there was probably things that were missed, or things that weren't covered in as much detail' (Educator #3). TSP participants also missed the opportunity to learn certain hands-on skills. 'You can't do hands-on, you can't do role play, you can't do tangible things and touch like on the other [face-to-face] days that we did' (TSP Participant #4).

#### 4.3.2 | The way of the future

Despite the challenges associated with online learning, several benefits emerged. 'Developing that online content has been a benefit ... it's the way of the future' (Educator #4). Both nurse educators and TSP participants agreed that the study days were intensive, and some of the content was overlooked or forgotten. 'They're big days, there's a lot of information, and it's all very new to take in. So, a lot of it just goes over their heads' (Educator #4). The significant benefit of having online theoretical resources is that TSP participants were able to review the content at a later date, which was not possible with traditional face-to-face education. 'They can revisit it when, if they need to ... because it doesn't align with their rotation, or they just need a refresher' (Educator #4). Looking forward, nurse educators felt the online component would continue for future cohorts of TSP participants, using a hybrid approach. 'I certainly see the online content carrying on, and, you know, we're developing new ways of doing that' (Educator #3).

### 4.4 | Theme 4: Roller coaster of emotions

Participants experienced heightened emotions during the COVID-19 pandemic, above and beyond the usual stress of delivering or

participating in the TSP program. 'There's been an absolutely understandable anxiety and stress level of doing a job that you previously have not known, but I definitely noticed a difference in the presentation of that stress last year' (Educator #5). 'There was ... a general heightened anxiety across the department and that was also affecting the TSP students' (Educator #4). These feelings of fear and anxiety were exacerbated for novice TSP participants. 'I was overwhelmed as it was, going into a program, plus this [COVID-19] on top of it, it was a bit amplified' (TSP Participant #4). Educators observed TSP participants feeling overwhelmed and overloaded. 'I don't think they coped well during COVID' (Educator #2). They were 'so overloaded with information that they just couldn't ... take on anything else' (Educator #1). Positive emotions of gratitude and kindness helped participants find meaning in an otherwise challenging situation. 'I had a lot of team members also come and say thank you ... so that made it all worthwhile' (Educator #5). Participants also felt stronger for overcoming the challenges of the year. 'Thinking about COVID itself ... it taught me how resilient I am, how patient I am, how independently I learn ... you do teach yourself how to overcome these things' (TSP Participant #5).

### 4.5 | Theme 5: Looking back to move forward

The COVID-19 pandemic was a novel situation and one that participants navigated through progressively, as changes occurred. 'Everyone was just trying to do their best in the situation that we were in, I don't think I could fault people for being in that situation' (TSP Participant #1). Participants reflected on the challenges they faced during 2020, considered adaptive strategies, and contemplated the future, which was depicted in three subthemes.

#### 4.5.1 | A challenging year

The COVID-19 pandemic impacted on the novice nurses' ability to adjust to a new clinical environment, intensifying the usual learning curve. 'We are just so new to this environment ... we don't know what's going on and how the system works' (TSP Participant #3). 'I didn't know what I was doing when I walked in, and then you threw Corona at me' (TSP Participant #4). The challenges of being a novice were felt amongst the education team as well. 'We were the blind leading the blind essentially ... we did well, but definitely I think people who were in the system a little bit longer than us probably did a hell of a lot better than we did' (Educator #2). Workplace challenges were also exacerbated by the impact COVID-19 was having on participants' personal lives. 'You've got the lockdown, not being able to see family members, and all these things impacting you emotionally as well' (TSP Participant #5).

#### 4.5.2 | Getting through

Participants identified several adaptive strategies that helped them cope with the stressors of the COVID-19 pandemic. Teamwork,



support, and peer debriefing were beneficial for participants. 'I relied on my team a lot to help me through' (Educator #3); 'talking to my colleagues ... debriefing a lot' (Educator #5); 'getting in touch and having a conversation ... peer support was actually really important' (TSP Participant #3). Humour was also used to relieve some of the stress and fear surrounding COVID-19. 'It was cathartic, the non-sense at times became beneficial' (Educator #4). Reflection was also a valuable tool for TSP participants. 'I used reflection a lot last year ... reflection's really, really important and a very, very good tool too, for a learner' (TSP Participant #5). The overall experience of the TSP program was different, but TSP participants still felt positive about getting through the challenges of the year. 'It was a tough year, but like, it toughened me up in my career, so yeah, it was a great experience' (TSP Participant #3).

### 4.5.3 | Moving forward

Expectations needed to be managed at the end of the TSP program. 'I think the expectation of being in a program and coming out 100% confident ... I felt disheartened at the end on a personal level' (TSP Participant #4). Additionally, the expectations of the wider perioperative workforce needed to be adjusted. 'The expectation of the staff in the operating suite is that they will be at the same level as other TSP years ... that has to be managed post their program as well' (Educator #1). Despite the impacts of the COVID-19 pandemic, all TSP participants from 2020 were offered ongoing employment in the operating suite, with 60% progressing to postgraduate studies in perioperative nursing. 'They're all driven to stay, because that's where they want to be ... they still want to be theatre nurses ... it's the getting there that's proving to be a bit difficult for them' (Educator #2). Nurse educators highlighted the potential future implications for the TSP program, as a result of reduced undergraduate nursing student placements in specialty practice areas. 'They [undergraduate students] didn't go into high-risk areas, so ICU, ED, periop ... the recruitment of our future TSPs I think is going to be impacted' (Educator #5).

## 5 | DISCUSSION

This study has contributed essential background information about the perioperative TSP program in an Australian context, not yet found in any existing literature. Earlier research suggests that many undergraduate nursing students do not gain exposure to perioperative nursing during their clinical placements (Callaghan, 2011). The TSP program, therefore, offers participants a supported introduction to the unique area of perioperative nursing. Being supported as a novice perioperative nurse was important for TSP participants and was recognized as an essential component of the program by the educators. By providing education and clinical experience, the TSP program facilitates the first stages of advancement through the novice-to-expert skill acquisition model (Benner, 1982).

TSP programs have been previously demonstrated as an effective recruitment and retention strategy for both ED and ICU nurses in Australia (Considine & Hood, 2004; Madhuvu et al., 2018; Morphet et al., 2015). The results of the current study support these findings, with educators believing the TSP program effectively boosts recruitment for the perioperative department. The perioperative TSP program also facilitated career progression, with 60% of participants progressing to specialist perioperative postgraduate study in 2021. This finding is consistent with prior literature from the ICU TSP program (Madhuvu et al., 2018).

The findings of this study are underpinned by the notion of change, and how participants adapted to change. Participants described rapid and frequent changes to clinical practice in the operating suite, a finding supported by the international literature (Elliott et al., 2021; Ike et al., 2019). Keeping abreast of the latest changes was difficult for participants, as advice was constantly evolving. COVID-19 protocols and practices have changed continuously around the world, with contradictory information often confusing staff (Elliott et al., 2021; Juvet et al., 2021; Nelson et al., 2021). Constant workplace changes contributed to feelings of emotional distress, including anxiety and fear. Moderate levels of anxiety have been reported in perioperative nurses since the onset of the COVID-19 pandemic (Gül & Kılıç, 2021). Novice nurses in this study also reported feeling overwhelmed, as they struggled to adjust to not only the changes brought about by the COVID-19 pandemic but also a new specialty practice environment. This finding has been reported in other specialty areas of nursing, where the stress of role transition was heightened by the added burden of the pandemic (García-Martín et al., 2021; Naylor et al., 2021). Peer support and teamwork have been identified as supportive strategies when adapting to change (Elliott et al., 2021; Juvet et al., 2021; Nelson et al., 2021). Participants in this study described how valuable teamwork and supportive relationships were in adapting to changes brought about by the COVID-19 pandemic.

Perioperative nurse educators were required to make significant adjustments to the delivery of education to TSP participants. Digital content was created and uploaded to the health service's pre-existing online education platform for online delivery of the course rather than face-to-face study days to align with COVID-19 restrictions. The transition from face-to-face to online education has been extensively studied in the context of university-level nursing education (Hill & Fitzgerald, 2020; Langegård et al., 2021; Madhavanprabhakaran et al., 2021; Ramos-Morcillo et al., 2020; Wallace et al., 2021). However, the present study contributes a unique perspective as the educators were based in a hospital, with differing access to resources and supports compared with educators from university settings. Creating pre-recorded lectures for repeated online use requires planning and preparation and is labour-intensive for educators (Madhavanprabhakaran et al., 2021). Nurse educators in the current study reflected that some educational content may have been overlooked due to time pressures. Undergraduate nursing students have perceived the faculty's unfamiliarity with online learning platforms to be a barrier to their learning (Wallace et al., 2021).

Participants in this study reported reduced engagement with online learning, contributed to in part by the steep learning curve experienced by the educators.

Despite the challenges associated with online learning, silver linings have emerged for health professionals' education (Erlich et al., 2021). The ability to revisit recorded online content at a later stage is a major advantage, benefiting TSP participants in this study, as well as university nursing students (Wallace et al., 2021). With support from local information technology teams in the individual healthcare organization, nurse educators in the current study felt better prepared to continue with online learning, anticipating a hybrid approach in the future. Opportunities for further growth and development include exploring and incorporating technology to enhance student engagement, such as discussion boards and interactive problem-solving activities (Hill & Fitzgerald, 2020; Wallace et al., 2021).

Perioperative TSP participants' overall experience of learning was disrupted due to the COVID-19 pandemic, impacting both the practical and theoretical components of the program. Reductions to elective surgery at the study site were consistent with international reports (Al-Jabir et al., 2020; Ike et al., 2019; Stannard, 2020), resulting in reduced opportunities for learning in certain surgical specialties, and impacting TSP participants' ability to consolidate their learning. Redeployment of perioperative nurses during the pandemic occurred around the world (Al-Jabir et al., 2020; Ike et al., 2019; Stannard, 2020; Stucky et al., 2020). TSP participants in the current study also experienced brief periods of redeployment, affecting their learner rotations, and further impacting their ability to consolidate their learning. This study contributes to our understanding of how the COVID-19 pandemic may impact novice nurses' ability to consolidate their clinical skills. TSP participants described feeling overwhelmed with the COVID-19 pandemic, whilst also navigating the challenges of being a novice nurse in an unfamiliar environment. Even senior perioperative nurses were noted to feel overwhelmed, which affected their ability to provide leadership and support to participants. Similar findings have been reported in a qualitative study examining the experience of early career nurses in acute-care settings (Sessions et al., 2021). The current study found that the combination of reduced elective surgery, redeployment, and decreased support from preceptors all contributed to a diminished clinical learning experience for TSP participants.

In addition to the learning challenges experienced in the clinical domain, TSP participants also experienced learning difficulties with the theoretical component of the program. TSP participants expressed a preference for face-to-face study days, finding the online study days to be less interactive and engaging. This experience has also been noted by undergraduate nursing students (Langegård et al., 2021; Ramos-Morcillo et al., 2020; Wallace et al., 2021). Engagement with educators and peers was also impacted by online education in the current study, and participants missed the opportunity of networking with each other and openly sharing their experiences. Similar findings have again been reported in the

university context, with nursing students reporting a deterioration in student-teacher communication and reduced discussions with classmates after transitioning online (Langegård et al., 2021; Wallace et al., 2021). The present study has contributed a novel perspective, considering the experience of both the teacher and learner simultaneously in the hospital context, a teaching domain rarely studied.

## 5.1 | Strengths and limitations

This study addressed a major research gap, contributing valuable knowledge about the perioperative TSP program in Australia, while also identifying the impacts of the COVID-19 pandemic on hospital-based nursing education. As the COVID-19 pandemic continues to evolve, the results of this study have implications for both current and future novice perioperative nurses. This study uniquely combined the experiences of both nurse educators and TSP participants, providing a breadth of understanding and a comprehensive overview of the impact the COVID-19 pandemic has had on the perioperative TSP program.

While offering a new and unique perspective, the present study has several limitations that should be considered when interpreting the study findings. The participants were all female and recruited from two acute hospitals in one public health service in Melbourne, Victoria. The results, therefore, need to be interpreted in this context and may not be transferrable to other clinical areas. Similarly, the burden of COVID-19 in Australia has been modest compared with some other countries, so the impacts described by participants may not be relevant in some international contexts. Finally, it is recognized that the interviewer was previously known to the participants, however, recruitment was facilitated by an independent source, mitigating the perception of coercion.

## 6 | CONCLUSION

The perioperative TSP program was significantly impacted by the COVID-19 pandemic. Disruptions to clinical practice notably affected TSP participants' ability to consolidate their hands-on learning. Whilst adapting to frequent clinical changes, TSP participants were also required to adjust to an entirely new specialty area of practice, creating a complex learning environment. Online study days were challenging for both nurse educators and TSP participants, resulting in reduced engagement. Despite the challenges, the pandemic has been a catalyst for change, with educators planning to incorporate an online pedagogy into future TSP programs, building on strategies to foster engagement. Teamwork was identified as an integral supportive strategy for participants, and all perioperative nurses should continue to support each other to overcome workplace challenges. Perioperative staff need to be aware that opportunities for learning were decreased for TSP participants during the pandemic, and expectations about the level of competence in specialty procedures may need to be adjusted.

Ongoing support and education may be required to continue to nurture the future generation of perioperative nurses.

## AUTHOR CONTRIBUTIONS

Amy Skiller, Julie Considine and Patricia Nicholson contributed to the design of the study. Amy Skiller collected the clinical data and performed the analysis and wrote the first draft of the paper. Amy Skiller, Julie Considine and Patricia Nicholson reviewed the analysis and critically reviewed and revised the manuscript. All authors read and approved the final manuscript.

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## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

## PEER REVIEW

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## DATA AVAILABILITY STATEMENT

Research data are not shared.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - QUALITATIVE**

# Midwives' perspectives of intravenous fluid management and fluid balance documentation in labour: A qualitative reflexive thematic analysis study

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## Abstract

**Aim:** To describe current practice, examine the influences and explore barriers and facilitators to accurate documentation, for the administration of intravenous fluids during labour.

**Design:** A descriptive qualitative study was performed.

**Methods:** Qualitative semi-structured interviews were conducted with Registered Midwives working across Australia. Midwives were recruited via email and social media advertisements. A maximum variation sampling strategy was used to identify potential participants. Interview questions explored four main areas: (i) understanding of indications for IV fluids in labour; (ii) identification of current practice; (iii) barriers to documentation and (iv) benefits and complications of IV fluid administration. Reflexive thematic analysis of recorded-transcribed interviews was conducted.

**Results:** Eleven midwives were interviewed. Clinical practice variation across Australia was recognized. Midwives reported a potential risk of harm for women and babies and a current lack of evidence, education and clinical guidance contributing to uncertainty around the use of IV fluids in labour. Overall, eight major themes were identified: (i) A variable clinical practice; (ii) Triggers and habits; (iii) Workplace and professional culture; (iv) Foundational knowledge; (v) Perception of risk; (vi) Professional standards and regulations; (vii) The importance of monitoring maternal fluid balance and (viii) barriers and facilitators to fluid balance documentation.

**Conclusion:** There was widespread clinical variation identified and midwives reported a potential risk of harm. The major themes identified will inform future quantitative research examining the impact of IV fluids in labour.

**Impact:** The implications of this research are important and potentially far-reaching. The administration of IV fluids to women in labour is a common clinical intervention. However, there is limited evidence available to guide practice. This study highlights

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the need for greater education and evidence examining maternal and neonatal outcomes to provide improved clinical guidance.

**KEYWORDS**

clinical variation, fluid balance, intrapartum, intravenous fluids, labour, labour interventions, midwifery, midwives, nurses, nursing

## 1 | INTRODUCTION

The administration of intravenous (IV) fluids in labour is a commonly used medical intervention recognized to have clinical variation (Bruce et al., 2021; Lindstrom et al., 2018). Clinical variation can present a problem for women and their babies accessing maternity care. Whilst a degree of variation is expected to meet people's different healthcare needs and choices, unwarranted clinical variation exists outside this scope (Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare, 2021). Such variation is a concern as it can signal a clinical practice that is not underpinned by robust evidence and raises uncertainty about the practice's suitability as part of care (Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare, 2021; Coates et al., 2021; McCulloch et al., 2013; Nippita et al., 2017). Unwarranted variation can contribute to an increased risk of harm through exposing a person to an intervention that they do not need or missing out of care that they do (Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare, 2021; Coates et al., 2021; Duggan et al., 2016; Nippita et al., 2017). Furthermore, it can contribute to an additional cost burden for the health care system (Liva et al., 2012).

## 2 | BACKGROUND

Intravenous fluids are administered to women during labour and birth for a variety of reasons. These include the administration of synthetic oxytocin for induction/augmentation of labour, signs of fetal distress and as a preload prior to regional anaesthesia (Lindstrom et al., 2018; Ruchala et al., 2002; Simpson & James, 2005; Walton & Peaceman, 2012). Clinical variation has been recognized within Australia (Bruce et al., 2021; Lindstrom et al., 2018). However, there is currently insufficient evidence to determine whether the clinical variation is warranted or unwarranted. Incomplete clinical documentation relating to the use of IV fluids during labour is a major barrier in determining both current practice and how far the clinical variation extends (Bruce et al., 2021).

In Australia, Registered Midwives providing care within the hospital setting work in collaboration with Medical Officers to administer, monitor and manage IV fluids in labour. A medically prescribed order is required, with two accredited health professionals needed to sign the order as checked and administered. An exception

to this would be what is known as a "standing order." Where these exist, a Registered Midwife may administer IV fluids without a prior written medical order if specific criteria are met (New South Wales Government, 2022).

This paper explores the qualitative findings of a larger mixed methods study examining the administration of IV fluids to women during labour. It is informed by the findings of our previous retrospective clinical notes review and audit of midwifery documentation (Bruce et al., 2021). The study identified a wide variety in clinical practice and incomplete fluid balance documentation at a single, metropolitan tertiary referral hospital. The findings highlighted the need for future research to explore barriers and facilitators to IV fluid documentation to help us understand more about this clinical practice.

## 3 | THE STUDY

### 3.1 | Aim

The aim of the present study was to describe the current practice for administering IV fluids during labour and childbirth; examine the influences surrounding IV fluids administration during labour and childbirth; and explore barriers and facilitators to accurate documentation.

### 3.2 | Design

This study used a descriptive qualitative design. Qualitative description embodies the characteristics of qualitative research (Bradshaw et al., 2017) and was chosen as a study design as it provided a natural way to explore and describe midwifery experiences and perceptions of IV fluid management in labour for the first time (Doyle et al., 2020). Additionally, it provided suitable foundations for the reflexive approach desired by the research team, with thematic analysis commonly used with qualitative description (Bradshaw et al., 2017). Furthermore, it is a qualitative design that can work well within a larger mixed methods research design (Doyle et al., 2020) and sat well within the overarching critical realism methodology. Together qualitative description, reflexive thematic analysis and critical realism provided the framework to examine a research question that would not have one singular truth.

### 3.3 | Participants

Potential participants were registered midwives or postgraduate registered nurse student midwives with current or recent experience within a childbirth setting. Participants were primarily recruited via an email advertisement through the Australian College of Midwives (ACM). Secondary methods of recruitment included a social media advertisement (Twitter) and a direct email advertisement to Clinical Midwifery Consultants, Clinical Midwifery Educators, midwifery managers and research midwives are known to the research team primarily from the public health and university sectors. Additionally, a snowballing technique, with participants encouraged to spread the word among their midwifery colleagues was also employed. Advertisements included a link to the participant information sheet.

The Australian midwifery workforce is varied in education and experience. Currently, most of the Australian midwifery workforce are dual registered nurse midwives. However, there is a growing number of solely registered Bachelor of Midwifery graduates (Australian Government, 2021). A maximum variation sampling strategy was used to capture views from midwives in practice from a broad range of service delivery models. Additionally, we recruited to ensure a mix of geographical location, aiming to include midwives from all Australian states and territories, and from both metropolitan and regional areas.

Eligibility was screened by a survey asking for current clinical professional role, midwifery experience, areas of work (e.g., antenatal, labour and birth care, postnatal), preference for interview location and contact information. Additionally, potential participants were screened to ensure they were currently working or studying as a midwifery professional within Australia. Current undergraduate Bachelor of Midwifery students were excluded from the study as they are not allowed to administer IV fluids without the direct supervision of a registered midwife. Selected midwives were emailed an invitation to participate in the interview, the participant information sheet and consent. Verbal and written consent was obtained from all participants.

### 3.4 | Data collection

The interviews were conducted by the lead author (BB), a PhD candidate and registered nurse midwife with experience across all major midwifery areas and emergency/critical care nursing. The semi-structured interview schedule was guided by the Capability Opportunity Motivation—Behaviour (COM-B) model. This model recognizes that behaviour is dependent upon a combination of a person's capability, opportunity and motivation (Michie et al., 2011). Whilst the COM-B is commonly used to help identify what needs to change for a behaviour change intervention to be effective (Michie et al., 2011), it was used in this study to support an evidence-based exploration of behaviour; Assisting in the development of a semi-structured interview schedule to help identify currently

undocumented influencers of midwifery behaviour. This included influences internal to the individual and within their greater social and physical environment. The resulting interview schedule consisted of seven open-ended questions, with follow-up prompts and probes (Table 1). Four main areas were explored: (i) understanding of indications for IV fluids in labour; (ii) identification of current practice; (iii) barriers to documentation; and (iv) benefits and complications of IV

**TABLE 1** Semi-structured interview schedule with example probes

Interview questions	
1.	Can you tell me a little bit about yourself and your midwifery experience?
2.	To start off, when you think about IV fluids given to women in labour, what first comes to your mind? <ol style="list-style-type: none"> <li>What reasons are IV fluids given to women during labour? (i.e. indications)</li> </ol>
3.	From your experience, could you describe how IV fluids are being administered to women during labour? <ol style="list-style-type: none"> <li>What type and rate of IV fluids are used where you work?</li> <li>Can you walk me through the steps of what is needed to start IV fluids in your workplace?</li> </ol>
4.	Can you tell me about your understanding of IV fluids in labour? <ol style="list-style-type: none"> <li>Where did you learn about IV fluids for women in labour?</li> <li>Why do you think IV fluids are given for (indication)? (i.e. rationale for use)</li> <li>What are the benefits of giving women IV fluids during labour?</li> <li>Are there any potential complications you can think of?</li> </ol>
5.	Can you tell me about fluid balance charts? <ol style="list-style-type: none"> <li>How do you find using fluid balance charts?</li> <li>What is typically documented?</li> <li>Does anything make it difficult to fill them out? (i.e. barriers)</li> <li>What makes it easier for you to fill them out? (i.e. facilitators)</li> <li>Is there anywhere else where IV fluids and maternal fluid balance is documented?</li> </ol>
6.	I have previously done an audit of IV fluid ordering for this research. During the audit I found that IV fluids were often commenced without a completed written order from a doctor. Can you think of any reasons this may occur? <ol style="list-style-type: none"> <li>Do you have any clinical practice guidelines?</li> </ol>
7.	We are almost at the end of the interview. Is there anything I haven't asked about IV fluids in labour that you would like to mention?
8.	What was your motivation for signing up to participate in this research?

fluid administration during labour. Education and experience prior to midwifery was also explored.

Initially, a pilot interview was conducted to help ensure the questions would elicit appropriate responses. No changes were made at this point. Additionally, the interview schedule was iteratively adjusted throughout data collection and early data analysis period. As part of this process, an eighth open-ended question was added. All participants were asked this eighth question.

Contact was made by BB via email following the completion of the eligibility survey to invite the participant to interview. Participants were requested to identify their preference of a telephone, face to face or online video call interview. It was envisaged that the interviews would last 20–30 min. Participants were provided with a description of the project within the participant information sheet, with the lead author briefly repeating the aim at the commencement of the interviews. The interviews were audio recorded and transcribed verbatim using a confidential transcribing service. There was no video recording. Transcripts were checked for accuracy by the lead author. Motivations for the research, and researcher knowledge and experience with the subject matter, was not discussed with the participants unless they asked. This was attended at the end of the interviews. Pseudonyms were allocated to participants (Table 2).

### 3.5 | Ethical considerations

Ethics approval for this study was obtained from the university's Human Research Ethics Committee, reference number: 2019/300. There was recognition that interview participants may disclose behaviour that is out of the legal scope of practice for a Registered

Midwife (or Registered Nurse). For example, the administration of non-prescribed IV fluids being given to women in labour. As per the National statement on ethical conduct in human research (National Health and Medical Research Council, 2007), if a participant discloses participating in clinical practice outside their legal scope of practice there may be a statutory obligation to report. This may have professional consequences for the interview participant if a report to their professional registration board is required. Consultation was sort in the development of this research to clarify risk to participants and reporting requirements. To minimize risk to participants, the research team informed each participant of this risk in the written participant information sheet and in a verbal preamble prior to the commencement of the interview. Additionally, projective questioning techniques were used, alongside asking general questions.

### 3.6 | Data analysis

Data from the interviews were analysed using reflexive thematic analysis. This method of analysis was chosen as it provided a suitable structure to systematically explore and interpret the data in depth, with patterns of meaning being identified from the collected data, and not from predetermined theme generation (Braun & Clarke, 2021; Braun & Clarke, 2022). Additionally, as it was recognized the lead author's prior experience would influence both the questions asked in the interviews and how the was data interpreted, researcher reflexivity throughout the process was important. To assist with this, the lead author maintained a journal throughout the research process to assist in critical reflection for how her personal stances related to the research.

Participant Pseudonym	Midwifery registration	Foundational midwifery training	Years of midwifery experience	Work region
Tiana	RM †	Bachelor of Midwifery	0 to 1 year	Major city
Alice	RM	Bachelor of Midwifery	2 to 5 years	Major city
Eloise	RN RM ‡	Postgraduate Diploma in Midwifery/Masters	2 to 5 years	Major city
Cara	RM	Bachelor of Midwifery	2 to 5 years	Major city
Rae	RN RM	Dual Bachelor of Midwifery/Bachelor of Nursing	2 to 5 years	Regional/rural
Alannah	RM	Bachelor of Midwifery	6 to 9 years	Major city
Cynthia	RN RM	Postgraduate Diploma in Midwifery/Masters	6 to 9 years	Major city
Kiara	RN RM	Postgraduate Diploma in Midwifery/Masters	≥10 years	Major city
Jenny	RN RM	Hospital training	≥ 10 years	Regional/rural
Mary	RN RM	Hospital training	≥ 10 years	Major city
Monica	RN RM	Postgraduate Diploma in Midwifery/Masters	≥ 10 years	Major city

TABLE 2 Demographic characteristics of midwifery participants

Abbreviations: RM, Registered Midwife; RN RM, Dual Registered Nurse Midwife.

Braun and Clarke's (2021) and (2022) six-phase process for data familiarization, coding and theme formation was utilized in the following ways. Firstly, the lead author engaged in data familiarization through both listening to the audio recordings and reading the transcription of the interviews. As this study was part of the lead author's PhD research, authors BdV and JL also read a subset of three interviews to assist in becoming familiar with the dataset. With reflexive thematic analysis supportive of both individual and collaborative coding when collaborative coding is used to facilitate in-depth understanding and interpretation of the data (Braun & Clarke, 2022).

Secondly, an inductive approach was taken to systematically code each interview. Initial codes were discussed and agreed upon collaboratively following coding of the first three interviews. The lead author then performed iterative analysis of the transcripts using the agreed coding structure and the software package NVivo 12 (QSR International Pty Ltd, 2018). However, this did not limit the development of new codes as the lead author became increasingly engaged with the dataset.

Thirdly, initial theme generation was facilitated by the creation of bulleted lists in Microsoft Word. Patterns of meaning were developed through sorting codes into broad topic areas. These topic areas were then reviewed and refined in greater depth in phase four and phase five. Themes and patterns were discussed regularly with all researchers throughout the data analysis. Finally, phase six—writing up the report, permitted further engagement in the data and the greater refinement of themes.

### 3.7 | Reliability/rigour

To assist with reliability and rigour of the study, several strategies were undertaken. Firstly, the interview schedule was guided by the COM-B model, as outlined in section 3.4. Secondly, the data generated from the interviews were systematically reviewed and analysed using Braun and Clarke's six-phase process for reflexive thematic analysis as described in section 3.6 above. Thirdly, the doctoral student researcher was supervised by three post-doctoral supervisors, two with extensive experience in qualitative research. Finally, the consolidated criteria for reporting qualitative research (COREQ) were used to guide the reporting of the study and its findings (Tong et al., 2007).

## 4 | FINDINGS

Sixty-six registered midwives and three postgraduate registered nurse midwifery students expressed interest to participate in interviews when completing the survey. Twenty-four representing a diverse range of experience and locations were invited to participate. Ten did not respond; two were unable to arrange a time to be interviewed; one did not attend the scheduled interview. Eleven interviews lasting between 24 and 47 min were conducted and analysed, two as an online video call and nine via telephone. Participants included four Registered Midwives and seven Registered Nurse Midwives with varying clinical experience (Table 2). There was at

least one participant from each of the main states and territories of Australia, except for Tasmania. From the analysis, eight major themes were identified, including six themes for influencing practice and two for documentation (Figure 1).

### 4.1 | A variable clinical practice

Midwives identified the administration of IV fluids to women in labour as a common clinical practice. One senior midwife, Monica, strongly acknowledged the clinical variation that she has witnessed.

*"I think it [IV fluids] is one of the most poorly managed aspects of intrapartum care and I've always thought that. And I've always, in previous roles wanted to find good evidence and there isn't any and it's been really curious to me how, when I go from facility to facility, everyone has different practices and nobody really understands why they do it."* (Monica).

Multiple uses for IV fluids were reported and these included: oxytocin administration; side-line maintenance fluid; as a preload prior to epidural anaesthesia; fetal tachycardia; fetal bradycardia; low variability of the fetal heart rate; maternal pyrexia; and maternal hydration. Maternal hydration was most likely to be an indication when a woman was unable to tolerate drinking (e.g., vomiting), appeared a bit "dry" or was fasting for a potential operative birth. Midwives categorized IV fluids as part of routine care in medically managed labours. However, how they are administered was commonly "ad hoc" with clinical variation recognized by most participants.

*"I think they are often given fairly ad hoc. If we've got a fetal tachycardia, if we've got, the woman looks a bit dry. If she's having an induction, there's always some fluids around."* (Cynthia).

Clinical variation was particularly recognized by midwives who had recently worked in different facilities. Reported clinical variation included IV fluid type, volume and rate of administration. The variation was particularly noticeable in the description of oxytocin administration for induction and augmentation of labour. This was because of the differences in oxytocin dilution and rates of administration described. For example, preparations of oxytocin for induction included 10 international units (IU) of oxytocin in 1000ml crystalloid solution (e.g., 0.9% Normal Saline or Compound Sodium Lactate); 10 IU in 500ml; or 30IU in 500ml. A second noticeable variation in practice was preload administration prior to epidural anaesthesia. Quite a few of the midwives acknowledged this clinical variation in the interviews. Reported preload volumes ranged anywhere between no preload given to 1000ml. For the other indications, clinical practice was more difficult to define from the responses. However, fluid boluses ranging from 250ml to 1000ml of crystalloid solution were commonly reported when IV fluids were given in response to an acute fetal or maternal concern.

### 4.2 | Triggers and habits

Midwives reported that IV fluids were commenced out of habit or expectation for many indications. Several participants expressed

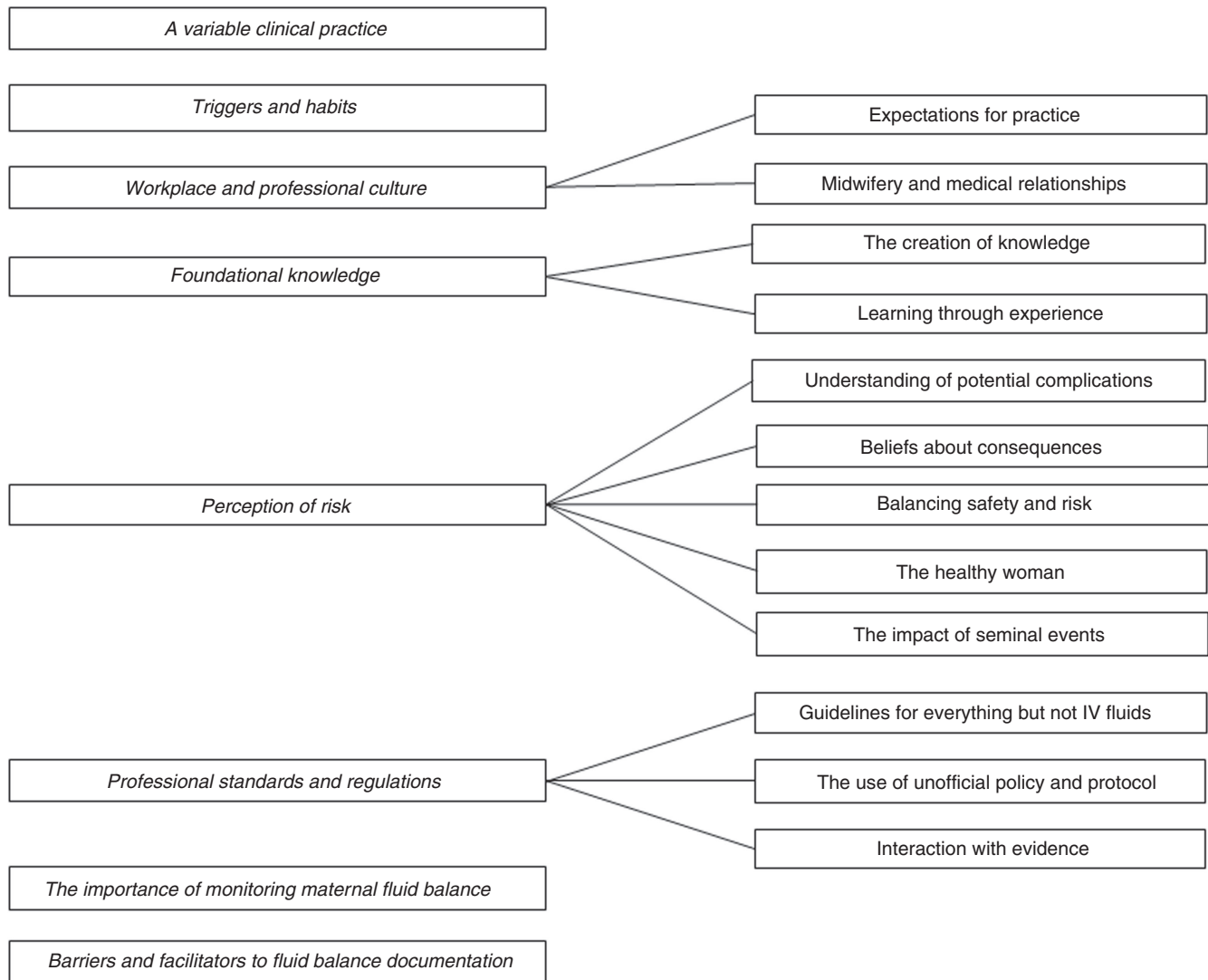


FIGURE 1 Coding tree for thematic analysis.

doubt about the suitability of IV fluids for such indications. For example, the administration of IV fluids for low variability of the fetal heart rate:

*"There's a perception that if the woman is very dehydrated that the variability is going to be reduced. Now, my understanding of variability is that it is an indication of the ability of the neuro receptors in the heart to regulate the beat-to-beat heartbeat, which is actually related to the neurological system of the fetus as opposed to anything to do with the mother's hydration levels. So, I think it's one of those practices, again, that we do, perhaps, to make ourselves feel better in a fairly powerless situation."* (Monica)

Additionally, there were conflicting views whether IV fluids should be used in women during physiologically normal labour. In their individual interviews, two of the most senior midwives (Mary and Jenny) both discussed how commencing IV fluids for women in spontaneous labour may help to keep the woman progressing along a physiologically normal pathway:

*"A labour that starts off amazingly spontaneously these days, what a miracle. But that is just taking its time, dragging along, she's nauseated,*

*she's vomiting, she's feeling really weak. Well, a bit of IV fluids can perk that woman right up, I think and get her to the end of it."* (Jenny)

However, other midwives specified that IV fluids should only be used in medically managed labours. Although, in the case of the above example of an excessively vomiting woman, Mary identified that this could be a fine line a woman who starts in spontaneous labour could cross:

*"Now it wouldn't be just because she was a little bit dry, because I know that Michel Odent said this, 'That to be ketotic in labour is not a bad thing. To be overly ketotic in labour and just vomiting persistently, is a bad thing.'" (Mary)*

### 4.3 | Workplace and professional culture

#### 4.3.1 | Expectations for practice

Midwives identified that decision-making around the intrapartum initiation and management of IV fluids rested largely on midwives.



The need for medical consultation and a prescribed medical order for IV fluids was recognized, however, there was a reported norm in some facilities for midwives to commence IV fluids without a medical order:

*"I think midwives sometimes will just do it independently as well as part of their practice, start fluids and let the doctors know later or just take that on as their role."* (Kiara).

This practice appeared to be influenced by the indication for IV fluids, workplace culture, midwifery and medical relationships and medical officer availability. For example, when IV fluids were deemed routine, midwives reported greater likelihood that IV fluids would be commenced and retrospectively prescribed by a medical officer. In contrast, midwives described the need to be more cautious when IV fluids were given for more acute reasons or concerns. However, this was still influenced by the accepted practices and available human resources of individual birth units:

*"... on labour ward, midwives can instigate IV fluid. They can actually commence it without a doctor's order. But when a woman is unwell, there is medical intervention, of course, and they will actually guide the rate and how many bags of fluid they end up having and those sorts of things... I think it's the accepted practice that if you've got a woman who's hypotensive where she's passing out, you're going to start fluids, you're not going to wait for the reg to come around and to review the situation."* (Alannah)

The expectation that IV fluids would already be in progress if calling for help was reported by several midwives. Midwives reported this to be a common expectation that came from both senior midwives and medical officers. Participant Rae, a junior midwife at rural facility, described that decision-making and setting of expectations was often led by senior midwives as they were more readily available and often more experienced than some of the medical officers:

*"I've worked in a couple of small units now, and the doctors aren't necessarily present, or even if they are, you're often talking emergency situations, so there's just not ... You're not going to delay, and you're working with, usually, the senior midwife who assumes control of the situation, and has enough clinical experience that if she's prompting the administration of fluids, you trust that that's wise clinical judgement."* (Rae)

Additionally, workplace culture influenced expectations. This was recognized by several midwives, particularly midwives who had recently changed facilities, and included expectations around fluid balance monitoring, IV fluid ordering and accepted practices. For example, several participants reported it normal practice within their units for medical officers to pre-empt the need for IV fluids, charting in advance. This allows for IV fluids to be commenced without the need for a medical review.

#### 4.3.2 | Midwifery and medical relationships

Midwives believed they should maintain good relationships with their medical colleagues. Differences in the relationship existed

between metropolitan and rural birth units, where in the latter, midwives reported lower availability of medical officers. In relation to IV fluids, this influenced the process of client review and IV fluid ordering:

*"We only have one obstetrician and that's all. And he's on call four nights a week... I'm not going to call him in the night because you know, you have to have a good relationship with them. Well, if you're calling them in the middle of the night, just to get a fluid order, you ain't going to have that good relationship..."* (Jenny)

In contrast, midwives working in bigger metropolitan units reported greater medical officer availability. Presence of medical officers on the unit facilitated the ease of consultation and prescription of IV fluid orders. However, departmental high acuity was reported by participants to decrease medical officer availability. Additionally, how this difference may affect midwifery communication behaviours was explored during the individual interviews. Mary who currently works in a tertiary centre reported that she frequently discussed the women with the medical officers. Mary described that she believes this frequent communication is respectful, and in the case of an urgent situation, can lead to less fear in the room. This contrasted with Jenny who described a greater degree of independent practice with less communication. However, it is important to note that Jenny works within a lower risk, rural facility and this likely influences the need for medical consultation.

A potential jostle of power was also brought up by Mary:

*"Initially you couldn't put IV fluids up because none of the midwives could cannulate, so you had to have a medical person come in to do that. And now everyone, well not everyone, but a lot of midwives can cannulate and if you can't as a midwife, you'll get your mate up the corridor to put the cannula in, to put fluids in. But it's who's running this show? Who's in charge here? It becomes a bit of a control thing, do they instigate these fluids or do you instigate the fluids?"* (Mary)

Whilst many midwives within the study reported that midwives commonly lead decision-making around IV fluids, it can be a difficult balance to maintain it within the required professional boundaries. This need for balance was emphasized by Rae who recognized tension around the issue of retrospective ordering:

*"It's going to be the doctor's name against that order, and if anything goes wrong, they're going to be held responsible, and I feel that it's probably not entirely fair to retrospectively say, 'hey, look, we've done this, can you sign off that you're good with that?' when they've actually not been involved in the clinical decision-making around that."* (Rae)

## 4.4 | Foundational knowledge

### 4.4.1 | The creation of knowledge

Midwives reported learning about IV fluids predominantly in the clinical environment. Midwives who could recall learning about IV fluids at university, identified that formal education was minimal, with IV fluids most likely touched on in education sessions relating to clinical deterioration and emergency situations. Other avenues



of learning included in-service education, perinatal safety short courses, journal articles and conference presentations. However, many participants had difficulty recalling if they ever had any kind of formal training relating to IV fluid administration in labour, with several concluding that they had not:

*"I can remember talking about it. Not as a set up on the lecture screen, they were going to talk about this. I can remember it being more, I can remember the lecturers talking about its ridiculous whole not allowing women to eat or drink in labour. Yes, I can remember lecturers saying, like the worst that can happen is that woman's going to regurgitate that food which happens to a lot of women anyway in the second stage. So, they'll vomit, that's not really a good enough reason to stop them from eating if they really want to. But no, I can't remember covering as a set theory topic." (Alice)*

Additionally, postgraduate trained nurse midwives reported learning more about IV fluids during their nursing studies and/or clinical experience. Some participants recognized that nurse midwives were expected to have pre-existing knowledge from their nursing education. However, participant Eloise recognized that nursing education generally does not include management of women during labour, contributing to a gap in knowledge. Nurse midwives recognized foundational knowledge was minimal but was reinforced and expanded upon within the clinical setting. This was particularly true for the most senior midwives in the study who were hospital trained. Both Mary and Jenny reported that IV fluids were not commonly used when they began midwifery, reporting that knowledge was developed later in their careers.

#### 4.4.2 | Learning through experience

Learning through clinical experience was important when it came to developing knowledge relating to IV fluids during labour:

*"Where I've really learnt about it is on the ground ... you've got the theory but actually visualising the patient and coming up with a determination as to what's appropriate for that woman at that time, given her weight and all the other clinical factors." (Alannah)*

Midwives reported how cultural norms, colleague behaviours and seminal events influenced their learning and understanding. Participants identified peer learning in the clinical environment as a possible reason for relaxed fluid balance management:

*"I'm just brainstorming here, but I don't know that we teach our student midwives about the importance of it that well? So whether or not we're just being blasé and going from generation of midwife to the next generation of midwives." (Monica)*

### 4.5 | Perception of risk

#### 4.5.1 | Understanding of potential complications

Midwives reported multiple potential complications of IV fluid administration. These included fluid overload, hyponatraemia, peripheral intravenous cannula (PIVC) issues, breast oedema and falsely

high neonatal birth weights. Additionally, a couple of participants discussed possible complications related to type of IV fluid, such as the triggering of inflammatory processes with colloid solutions. Some midwives were able to expand upon their understanding of these potential complications and could describe for example, the increased risk of fluid overload and hyponatraemia with large amounts of IV fluids administered alongside IV oxytocin:

*"So, I remember, and this has always been something, like, I've not had research, I've not had access to research about it, but it's something that's been discussed, and I've always meant to look into the research more, people talk about there being the risk of fluid overload, like water toxicity with a woman who's got oxytocin running. Yeah, but I honestly don't know more, really." (Rae)*

Furthermore, complications from PIVCs were discussed by several participants with respect to the risk of infection, particularly with women who choose to labour in the bath. Pain and restricted mobility from the PIVC were considered a complication due to the discomfort it caused women and possible negative impact on the birth process:

*"I think that we underestimate the potential complications from a cannula, particularly, in a cohort of women that are a higher risk of things like thrombosis and things like that, sepsis." (Monica)*

#### 4.5.2 | Beliefs about consequences

This subtheme covers both beliefs about consequences of administering IV fluids and not administering IV fluids. It is a subtheme identified through awareness of the theoretical domains framework (Atkins et al., 2017). Firstly, uncertainty was expressed from multiple participants relating to the administration of IV fluids during labour. The main reasons for this included potential consequences and that the practice may not always be in the best interest of women and their babies. Participants recognized that labour and birth does not occur in isolation and that there can be flow on effects from clinical interventions. Examples include unsuccessful breastfeeding initiation related to breast oedema and increased neonatal weight loss:

*"There is this strict 10% weight loss cut off whereafter we need to action a feeding plan. However, I am concerned that for babies whose mothers had fluids in labour, this figure should be greater and as a result we are stressing parents out and placing feeding plans upon babies who are actually doing fine." (Cara)*

Secondly, the main consequence reported for not administering IV fluids was delayed progression of labour related to dehydration. Multiple participants discussed how IV fluids can be beneficial for women who are excessively vomiting during labour. In this circumstance, IV fluids were recognized as a clinical intervention that could help keep a woman in "normal" physiological labour.

#### 4.5.3 | Balancing safety and risk

Midwives discussed providing proactive care to women in labour. Precautionary interventions, for example, the insertion a PIVC at the

commencement of labour care, was discouraged in some birth units, whilst seen as essential in others. Availability of additional support in emergency situations influenced decision-making:

*"We have a bit of a blanket rule, before you put prostaglandin for an induction, a cannula needs to go in. And the reason for that is, if you end up with a hyper stimulated woman in the middle of the night or something goes arse up, the trace goes off and you need to do an emergency caesar. It's one less thing you have to rush round doing in the middle of the night, right? ... We have a limited medical emergency response team at night. Staff have to travel to manned theatre, there's only two of you on the ward at night, if it's a busy night. You're going to be stuck trying to cannulate this woman, get her ready for theatre, the whole manoeuvre. So get a cannula in."* (Jenny)

In birth units where availability of emergency support is not a concern, midwives reported alternate views. Several midwives argued that interventions should only be applied when required, recognizing that interventions can carry unwanted consequences and that they have the time and resources available to intervene if required.

#### 4.5.4 | The healthy woman

Midwives reported working primarily with healthy women. This contributed to a sense of low risk and reported apathy around monitoring maternal fluid balance. Midwives reported women in their care to have "good hearts", able to compensate for the increased circulatory volume from IV fluids. However, several midwives recognized that this generalized inattention could contribute to adverse outcomes:

*"I think we generally have a healthy cohort of women that we're caring for. So it's only really when things go badly wrong that the importance of this kind of stuff is highlighted. So I think there's a little bit of apathy about keeping track of all of that."* (Monica)

#### 4.5.5 | The impact of seminal events

Several midwives reported being aware of major clinical incidents related to the IV fluids administration to women in labour. This provided specific awareness of potential complications. The most reported were maternal fluid overload and acute pulmonary oedema. Clinical incidents were recognized as triggers for clinical practice reviews and increased education following the findings. One midwife reported that a clinical incident in her training facility resulted in stricter IV fluid processes and a facility change from gravity flow IV lines to volumetric infusion pumps:

*"But I know that where I trained had had an incident where, I think, a woman received something like seven litres of fluid and I think she actually went into APO [Acute Pulmonary Oedema]... I think that's when they got a bit stricter with, okay, all fluids have to go through a pump. None of this gravity hanging 250mls max and hour, if you think you need more, we need to properly review why and go from there."* (Eloise)

However, it was unclear whether influences of seminal events impacted care and perception of risk long term.

## 4.6 | Professional standards and regulations

### 4.6.1 | Guidelines for everything, but not for IV fluids

Midwives reported a lack of clinical guidelines to inform practice. This was described as odd and unusual. In contrast to other aspects of intrapartum care, midwives identified a lack of detail. Insufficient evidence to underpin guideline creation was the most common rationale provided for this:

*"all they [the state guidelines] say with an epidural, prior to commencement ... secure intravenous access and commence intravenous fluids. That's all they say. So they don't say what rate or how long to start it or whether you need to do a pre-load. They just don't say it. They just say have access and fluids running but that's really vague. So whereas everything else, like five minute lead BP for 15 minutes. Other parts of that guideline are really specific because I don't think we have good quality evidence on it."* (Cynthia)

The need for guidelines was identified. Midwives connected this to a desire to provide evidenced-based care to their women, although there was some hesitance relating to guidelines removing an element of critical thinking and decision-making:

*"I guess I do feel that it should have a proper guideline. I hate to say policy because we're so policy driven nowadays but yes, having a clearer guideline, I think, and maybe some evidence behind it around rates and administration and the importance of accurate fluid balance."* (Eloise)

### 4.6.2 | The use of unofficial policy and protocol

It was discussed how birth units develop their own way of doing things, with common practices turning into unofficial policy. The practices becoming so ingrained, that it was not until it was questioned in greater depth, that it was revealed the policy did not exist:

Interviewer: *You mentioned you have a policy about midwives ordering, or like instigating IV fluids. Is that like a standing order, or can you tell me a bit more about what that policy says?*

Alannah: *Sorry?*

Interviewer: *The policy about midwives ordering.*

Alannah: *There's no real policy about it. I suppose it's an accepted practice.*

A second example related to the ordering of IV fluids. The use of 'as per protocol' (APP) was reported as a commonly prescribed rate for IV fluids, despite there being no protocol:

Interviewer: *Can you tell me a bit more about your orders? Are your orders still*

on paper for IV fluids?

Eloise: Yes, they are.

Interviewer: How are they often ordered? Do they have a rate on them?

Eloise: Oh there's the thing, APP, as per protocol.

Interviewer: Yes, do you have a protocol?

Eloise: Nope. Nope. No.

Midwives reported that this led to different interpretations about what to do and contributed to variations in clinical practice.

#### 4.6.3 | Interaction with evidence

Midwives demonstrated interacting with evidence at different levels. Junior midwives reported learning evidence through others and looking up clinical practice guidelines more often than senior midwives, interacting with evidence through discussion, reading guidelines and participation in educational experiences. Midwives with higher levels of academic education and seniority were more likely to provide specific examples of searches for evidence, report participation in research projects, and identify the evidence gap. However, this was not exclusive and many of the midwives reported using anecdotal evidence to guide practice irrespective of their training and experience level. Although, as identified by some of the participants, this could be reflective of the evidence gap.

Whilst it was unclear whether educational programmes influenced interaction with evidence, Cynthia did provide examples of how her nursing background influenced her midwifery care and connected this with a strong desire for evidenced-based practice:

*"As a nurse, I'm very pro normal birth and I would work very hard with a woman to – So I wouldn't put up fluids. But I'm also very keen on evidence-based practice. So I think about, do we actually need this? Is this going to benefit you and your baby? If it's not, we shouldn't do it."* (Cynthia)

Importantly, the interviews showed that the latest research does reach midwives. This was demonstrated by most of the midwives referring to research relating to IV fluid administration during labour and neonatal weight loss. However, views on this research differed. From agreement, to questioning based on previous experience:

*"Oh, look, I wouldn't know about women having too much in labour and babies being too hydrated when they come out, therefore by day three when they're weighed, they've lost too much weight. I can't say I've ever seen that in practice. I just read about it in articles."* (Jenny)

However, it is important to note that Jenny worked in a low-risk environment where reported IV fluids volumes were smaller than volumes reported in larger centres.

## 4.7 | Documentation

### 4.7.1 | The importance of monitoring maternal fluid balance

Midwives reported that accurate fluid balance documentation helped to complete the clinical picture and guide appropriate care when a woman began to show signs of clinical concern. Poor documentation of fluid balance charts was highlighted as a common issue. Midwives reported that "nine times out of ten" this would not be a problem. However, it was recognized that who it would be important for is often not recognized until it is too late, with low levels of documentation having the potential to contribute to poorer outcomes for mother and baby:

*"I had a case ... where we had a woman with undiagnosed gestational hypertension that turned into postpartum preeclampsia. And she ended up in ICU with pulmonary oedema. She was so unwell and when we looked back, we had no idea what her output had been in labour... According to the partogram and the fluid balance chart, she basically hadn't passed urine for about 12 hours and we had just – She had a block-in. So she had a really long pre-labour, so we decided that she was dehydrated and given her some fluids and she had an epidural. It was a really long labour, pumping in fluids, fluids, fluids, fluids, more fluids. And she just ended up really critically unwell and when we went back to do the review, she was clearly overloaded, dangerously overloaded."* (Monica)

### 4.7.2 | Barriers and facilitators to fluid balance documentation

Leading barriers to fluid balance documentation included workplace culture, lack of education and competing priorities. Midwives identified that workplace culture often did not encourage the completion of fluid balance documentation. For example, recognized importance was not prevalent in some workplaces, with this evaluated to contribute to low levels of documentation. Midwives reported "just forgetting" and a lack of habit to complete required documentation. A lack of education was discussed in connection with this, with junior midwives in particular identifying that more education is required regarding how to complete fluid balance charts and their importance:

*"I think it's interesting because I'm a big stickler for fluid balance charts and I've had many conversations with some of our more senior staff, consulted about these and I think there's a real lack of education around how to accurately fill out a fluid balance chart. And there's been conversations had around, "Well, how does it happen properly? And if I'm not doing it properly, what's the point?"* (Cara)

Additionally, the difficulties of documenting a complete fluid balance chart during labour care was brought up. The main reason given for this was competing priorities, with midwives describing that it's not always possible to both "be with woman" and complete all documentation. However, midwives were more likely to face this barrier whilst providing care for women with more medicalised labours. This

was despite identifying these women as higher risk of complications from IV fluids:

*"If you're looking at a highly medically managed birth, when you feel like you need 20 arms to do all of the things, probably, to be honest, the fluid balance chart would be lower on my priority list."* (Rae)

Additionally, competing priorities were not recognized to justify why fluid balance charts were frequently incomplete:

*"I don't think it's busy enough all the time to explain why they're so poorly filled out generally. ... I think busyness and acuity is one of the barriers, but I think there's also a bit of apathy towards the importance of it in midwifery."* (Monica)

In relation to facilitators, the analysis identified that workplace leaders can encourage increased monitoring and documentation of maternal fluid balance. Where participants reported workplace leaders, they identified stricter monitoring of maternal fluid balance. Workplace leaders may be either midwives or doctors (obstetrics or anaesthetics), and do not need to be from a senior level.

Finally, accessibility was discussed as a potential facilitator and/or barrier. An interesting aspect of the interviews was the transition from paper fluid balance charts to electronic medical records. For some, the electronic medical records would auto populate fluid bag commencement to a fluid balance chart. Where this occurred, midwives reported greater ease of access. However, this was not always the case with some midwives reporting preference of written fluid balance charts:

*"I just find it ... hard to access, hard to interpret, hard to enter the data, hard to remember to do it without actually being able to flick through your paper chart and see it all there, to jog your memory with what needs to happen."* (Rae)

## 5 | DISCUSSION

Our study documented accounts of widespread clinical variation for the administration of IV fluids to women in labour across Australia. The qualitative findings suggest that a lack of evidence and uncertainty around what best practice should be, are reasons for this clinical variation. However, it is difficult to truly establish this when knowledge of current practices and evidence to inform their use is lacking. Nonetheless, there is awareness of a problem and a potential risk of harm to women and their babies.

A lack of evidence to guide IV fluid administration is not limited to maternity practices (National Institute for Health and Care Excellence – NICE, 2013). Many IV fluid practices were introduced at a time where they did not undergo rigorous scrutiny with little research to progress knowledge (NICE, 2013). However, this is changing in other fields of health care, such as prehospital care where research has informed the change to infuse blood products in preference to crystalloid IV fluids for catastrophic haemorrhage (Shand et al., 2019, 2021).

This study's findings suggest that midwives could benefit from greater education relating to the administration of IV fluids in labour. Both in initial education at university and ongoing training within the

clinical setting. This may help to improve awareness of IV fluids administration in labour, the importance of monitoring maternal fluid balance (including documentation) and precautions for use. At present, cultural norms, colleague behaviours and prior personal experiences appear to have a stronger influence over practice than education. But there is a challenge in knowing what to teach, with the limited evidence available being a barrier to providing appropriate education. However, increasing education about the basics of intravenous fluid use and management, and how the risks from IV fluids may be different for mother and baby, would be advantageous. Additionally, it could be an important step for improving documentation, which is needed to improve our knowledge of current clinical practice.

However, for this to happen, it is likely that more behavioural change interventions will be needed than education and training alone. This is reflected in the recent findings of Tadaumi et al. (Tadaumi et al., 2020) who explored factors that influence midwifery decision-making in relation to eating and drinking during labour. Their findings suggested midwifery practice is more greatly influenced by social influences, such as power relationships with obstetric and senior midwifery colleagues, than knowledge, evidence or women's personal choice. Midwives within their study acknowledged institutional culture impacting upon their ability to provide evidence-based care. Similar findings were identified in this study.

A further finding of this study is that medical officers may rely on the experience and knowledge of midwives to guide decision-making for IV fluids during labour. However, the responsibility of prescribing and professional liability for that prescription remains with the medical officer. This is perhaps not unexpected when considering the lack of evidence and recognition that medical education relating to prescribing IV fluids can also be poor (Mathur et al., 2020). The finding of "APP" (as per protocol) is a potential extension of this. Allowing for a technical order to be made by a medical officer but passing forward the decision-making around rate of administration to the midwife. This may be advantageous for the midwife, allowing them to titrate IV fluids to the woman's condition. However, the issue with this ordering is the current lack of policy/protocol to refer to. No midwife in the study who reported "APP" ordering was able to identify an accompanying formal policy. This is an element of concern and opens the practice to be more freely influenced by personal and cultural practices over evidence. Such ordering also indicates the need and desire for a clinical guideline to exist. Whilst introducing a clinical guideline will not guarantee that its recommendations are followed, defining best practice and creating a clinical guideline could support both midwifery and medical decision-making. However, ongoing research examining what best practice should be is required in order for an appropriate evidenced-based guideline to be developed.

## 6 | STRENGTHS AND LIMITATIONS

This is the first known qualitative research examining the administration of IV fluids during labour. The study is limited by the relatively small number of midwives who participated in the interviews. As



part of the analytic process, further attempts were made to recruit participants in 2020, however, this was unsuccessful. A likely contributing factor was the Covid-19 pandemic making midwives less available to participate in additional research activities. Additionally, the pandemic removed the option of travelling to recruit and interview further participants face to face. However, in keeping with reflexive thematic analysis, it was judged by the researchers that sufficient information power to progress to the latter states of the analysis had been reached. The sample was diverse, with a mix of midwives from different backgrounds, geographical locations and level of experience, with the method enabling the in-depth exploration of clinical practice that will lay the foundation for future research.

## 7 | CONCLUSION

This study documented accounts of widespread clinical variation across Australia with IV fluid administration during labour identified as a clinical practice that could be improved. However, a current lack of evidence, education and formal clinical guidance contributes to clinical uncertainty around the use of IV fluids in labour. Major themes around documentation of fluid balance among women who receive IV fluids in labour were identified. These themes will inform future quantitative research around the impact of IV fluids in labour and improving documentation.

### AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE): (1) substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content.

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Research data are not shared.

### PATIENT OR PUBLIC CONSULTATION

This is a study of midwifery perspectives. No patient or public consultation was required.

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# Transition experiences of Middle Eastern midwives into Australian practice: A multiple case narrative study

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## Abstract

**Aim:** To explore transition experiences of Middle Eastern qualified midwives into practice in Australia.

**Design:** This was a qualitative study using multiple case narrative approach underpinned by structuration theory.

**Methods:** A total of 19 Middle Eastern qualified midwives from different states of Australia participated in this study. Individual semi-structured interviews were conducted between November 2020 and September 2021, digitally recorded and then transcribed. Transcriptions were analysed in three stages, with three main categories generated in the second stage and a core category that was developed in third.

**Results:** Entering the Australian workforce, Middle Eastern qualified midwives had to reframe their professional identities to fit the new system by adjusting to three aspects of the practice, including *preparation for practice*, *scope of practice* and *context of practice*. While they were prepared by medically oriented curricula, worked in systems that had limitations for midwives to practise in antenatal and postnatal and lacked regulation standards, they learned to practise autonomously in their full scope in a standardized context in Australia.

**Conclusion:** Middle Eastern qualified midwives in Australia re-evaluated their practice in their home countries, realized the gaps and adjusted to new ways of practising in Australia.

**Impact:** To effectively use the potential of Middle Eastern midwives for workforce sustainability in Australia, support should be available to enable them to develop the necessary competencies for safe practice in Australia including provision of context-specific transition programmes prior to registration and supporting mentorship after their integration into the Australian healthcare workforce.

**Patient or public contribution:** Patient or public contribution does not apply to this study as its purpose was to explore the transition experiences of Middle Eastern qualified midwives themselves.

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## KEYWORDS

Australia, immigrants, internationally qualified healthcare professionals, Middle East, midwifery, nursing, transitional experiences

## 1 | INTRODUCTION

### 1.1 | Background

Many developed countries, including Australia, rely on international healthcare workers to accommodate for a shortage of local staff and rising population healthcare demand (Aluttis et al., 2014; Safari et al., 2022). The shortage of midwives in Australia caused by an ageing workforce, insufficient recruitment and retention rates has resulted in the decline and fragmentation of childbirth and maternity health services, particularly in remote areas of the country (Hildingsson et al., 2016). With existing and anticipated critical shortages of midwifery workforce by 2030, Australia is expected to continue relying on internationally qualified midwives to mitigate workforce sustainability issues (Department of Health, 2019).

Australia is a country with a diverse and growing migrant population from 190 countries, with 29.8% of the Australian population born abroad (Australian Bureau of Statistics, 2021; Booth & Tickle, 2003). Women who experience difficulty with the host country language or culture are prone to problems accessing services and are at risk of mental health problems (Heslehurst et al., 2018). Australian health system faces a significant challenge in providing accessible and high-quality care for migrant women (Mander & Miller, 2016). Inclusion of culturally diversified personnel in healthcare was found to be a life-saving strategy for providing culturally and ethnically diverse care (Sherwood & Shaffer, 2014).

Migrating to Australia to work as an internationally qualified midwife can be challenging as one must go through rigorous assessment processes to meet strict qualification standards, English language proficiency and professional competence to determine whether they have the necessary knowledge, skills and professional attributes needed to practise in Australia (Nursing and Midwifery Board of Australia, 2020). Australia's registration regulations for internationally qualified midwives seeking professional registration in Australia have evolved significantly over the past two decades, and standards introduced for internationally qualified midwives from non-English speaking backgrounds have become progressively more complex (Nursing and Midwifery Board of Australia, 2011, 2014, 2020). Internationally qualified healthcare professionals from non-English speaking backgrounds in developed countries have been found to be more vulnerable and experience more challenges even after registration than their counterparts from English-speaking backgrounds in the host countries (Charlesworth & Isherwood, 2021; Safari et al., 2022).

It has been evidenced that migration of healthcare professionals from non-English speaking countries, has reportedly grown recently to address shortages of local personnel and rising population healthcare demand in developed countries (Safari et al., 2022). Middle

Eastern countries are among those from which refugee and skilled migration to Australia, the United States and Canada has surged significantly in the last decade, particularly due to political and socio-economic instability in the region (Hatton, 2020; Safari et al., 2022).

Midwifery in Middle Eastern countries has developed dramatically in the recent years and progress is being made towards achieving International Confederation of Midwives (ICM) standards of practice, education and regulation (Safari et al., 2021). Over the past two decades, midwifery education in Middle Eastern countries has progressively moved into institutions of higher learning, and baccalaureate degrees in countries like Iran, Jordan, Palestine and Lebanon are being adopted for entry into practice. Iran, Iraq, Israel, Jordan, Lebanon, Morocco, Saudi Arabia, Tunisia and UAE are among countries that have membership with ICM (Safari et al., 2021). The majority of Middle East countries have legislation that recognizes midwifery as an autonomous profession, excluding Djibouti, Oman, Somalia and Yemen, and registration with regulatory authorities is mandatory for practice (Safari et al., 2021).

While published literature focuses primarily on the transition experiences of internationally qualified nurses and physicians, a few have examined the transition experiences of other disciplines, with only one study on midwives out of 48 studies included in the narrative scoping review conducted by Safari et al. (2022). Additionally, the literature appears to have frequently included midwives in the context of nurse migration (Javanmard et al., 2017). The only study conducted on internationally qualified midwives in Australia was a qualitative descriptive study performed by Javanmard et al. (2020) to investigate the transition experience of midwives primarily from English-speaking countries with a similar midwifery context to that of Australia, such as the United Kingdom and South Africa. In addition, the influence of overseas experience of international midwives on their transition to the Australian midwifery system was not investigated in this study (Javanmard et al., 2020). However, midwifery practice in Middle Eastern countries has been found to be significantly different from that in developed countries, which would affect the transition experience of midwives in host countries (Batinelli et al., 2022; Safari et al., 2022).

With existing and anticipated critical shortages of midwifery workforce, Australia will continue relying on internationally qualified midwives to mitigate workforce sustainability issues. Successful integration of midwives from Middle Eastern countries into the Australian health system has the potential to make a substantial contribution, not only to the sustainability of the midwifery workforce in Australia but also to expansion of diversity in the system and promotion of culturally competent maternity care. However, little is known about challenges experienced by midwives from these countries, and more generally non-English speaking backgrounds, in Australia and other developed countries relying on internationally

qualified midwives. Thus, this study aimed to examine the transition experiences of internationally qualified Middle Eastern midwives into practice in Australia informed by the following research questions:

- What are the transition experiences of the Middle Eastern qualified midwives in Australia?
- How their overseas midwifery experiences impacted their transition into practice in Australia?

## 1.2 | Design

A multiple case narrative approach was used to capture Middle Eastern qualified midwives' dialogue to understand their transition experiences and the meanings they made of their experiences, by enabling them to construct and articulate their stories (Shkedi, 2005). Multiple case narrative, developed by Shkedi (2005), is a constructivist–narrative approach that borrows some elements from grounded theory (Shkedi, 2005). It collects information on a wide range of cases narratives, treats them as clusters of categories and promotes broad cross-case analysis for generalization purposes using an associational approach (Shkedi, 2005).

While evidence suggests that integrating immigrant health-care professionals into the professions is influenced by socially constructed characteristics, research on the social structures determining workforce integration is limited (Xiao et al., 2014). As defined by Giddens, social structure refers to the rules and resources that are either formal (policies) or informal (tactical and cultural norms). Social structures and human behaviours (or agency) do not exist in isolation as a 'dualism', but as a 'duality', inextricably linked and affected by one another (Giddens, 1984, p. 25). All systems are reconstituted by structures: sets of ideas and principles that govern the practices of individual agents. Structures are virtual in nature, existing as memory traces that inform the practices of knowledgeable agents. An agent acting in a system will learn how to go on in accordance with the appropriate structures (McGarry, 2016).

The multiple case narrative approach developed by Shkedi (2005) underpinned by Giddens' structuration theory (Giddens, 1984), provided a practical technique for examining transition experiences of Middle Eastern midwives to midwifery practice in Australia.

## 1.3 | Participants

Internationally qualified midwives were included in the study if they: (1) migrated to Australia; (2) were Middle Eastern educated midwives; and (3) had professional experience in Middle Eastern countries. A Middle Eastern qualified midwife was defined as a midwife who received their first qualification to practise as a midwife in a Middle Eastern country.

## 1.4 | Data collection

Participants were recruited nationally from Australia between November 2020 and September 2021, mainly through advertising via the Australian College of Midwives (ACM) and snowball sampling. In addition, local Arabic and Muslim groups in Australia were approached and provided with details for the study and asked to disseminate invitation emails to their memberships and place a short recruitment notice on their social media platforms. When Middle Eastern qualified midwives with an interest in the study contacted the researcher, they were sent an email and asked to review the participant information form provided to ensure that they were well informed about the study and eligibility requirements for participation. If they met the eligibility criteria and agreed to participate, a convenient time for telephone or zoom interview was arranged with them. Although, completing and returning the consent form by participants was taken as indication of their agreement to participate in this study, they were asked to verbally confirm that they were still willing to participate in the study prior to the interview commencing.

Semi-structured interviews were conducted in English with 19 participants by the primary researcher (six telephone and 13 online interviews via zoom). Semi-structured interviews were chosen as they offer continuity of questioning informed by the literature, while remaining open to new topics which can be introduced by participants (Wahyuni, 2012). To confirm the scope and relevancy of the content of the preliminary guide, establish the potential need to reformulate questions and evaluate its execution, the interview guide was pilot tested using an internal testing technique (Kallio et al., 2016). Internal testing referred to the collaborative review of the preliminary interview guide by the research team's investigators (Barriball & While, 1993). This approach could provide essential information about the interview guide in particular, including the elimination of ambiguities and improper leading questions and the identification of any potential bias (Chenail, 2011). In this study, the primary investigator adopted the role of the participant and was interviewed by another researcher. Gaining insight into how it felt to be interviewed encouraged the ethical and responsible manner in which sensitive patients were addressed (Kallio et al., 2016).

Interviews lasted an average of 1 h and ranged between 40 and 150 min. The interview guide focused on the professional integration experiences of participating Middle Eastern qualified midwives, following the sequential migration process from their pre-arrival experiences through the challenges they encountered with registration and practice after arriving in Australia. The interview questions were mostly drawn from a previous scoping review conducted to inform the broader study (Safari et al., 2022). Each interview dialogue began with one broad, open-ended question to initiate storied responses, such as 'What have you been doing since you arrived in Australia?' As each interview unfolded, follow-up questions were asked, encouraging continuous narratives, and further investigating emerging themes. The participants' overseas practice and education experiences were also explored during the interviews, as it was found to be relevant to their transition experiences in Australia (Safari

et al., 2022). These questions were developed in accordance with the International Confederation of Midwives competency standards for practice, education and regulation (Butler et al., 2018; Thompson et al., 2011). Table 1 contains examples of interview questions used for exploring the transition experiences of Middle Eastern qualified midwives into practice in Australia.

Data collection was completed after 19 interviews, when thematic saturation was deemed to have been achieved (Guest et al., 2006; Shkedi, 2005).

## 1.5 | Ethical considerations

The research received ethics approval from the La Trobe University Human Ethics Committee (Approval Number: HEC20403). Confidentiality, informed consent, freedom to refuse to participate

TABLE 1 Interview questions

1. What are the requirements for studying in a midwifery programme in your home country?
2. What are the available degrees for midwives to study in your home country?
3. What midwifery qualification is required for entry into practice in your home country?
4. How was the midwifery curriculum in your country? Did your midwifery programme include both clinical and theoretical components?
5. What were the requirements for graduation?
6. What was the qualification of midwifery teachers in your home country?
7. How would you compare midwifery education in your home country to Australia?
8. Did you apply for professional registration in Australia?
9. What were the requirements for your registration?
10. Are you currently practising midwifery in Australia?
11. Did you have orientation into practice in Australia?
12. In which clinical area have you been practising midwifery in Australia? How did you find it to be different from your home country?
13. Do you have the autonomy to practice midwifery in the full scope in Australia? How did you find it to be different from your home country?
14. Do you practice updated midwifery practice standards in Australia? How did you find it to be different from your home country?
15. Do you find midwifery practice in Australia to be legally oriented? How did you find it to be different from your home country?
16. How was your experience with documentation in Australia? How did you find it to be different from your home country?
17. How would you compare midwifery practice in your home country to Australia?
18. What are your main challenges with midwifery practice in Australia?

or withdraw from the study, and refusal to discuss specific issues were addressed at all stages of the research project. The data were deidentified and securely stored in accordance with the National Statement on Ethical Conduct in Human Research, Australia (National Health and Medical Research Council, 2015).

## 1.6 | Data analysis

Interview transcriptions were uploaded to NVivo 12 and analysed in three stages as recommended in the multiple case narrative approach (Shkedi, 2005). At initial stage, the data were segmented, allowing for the identification of categories without requiring consistency or a connection between categories to be apparent in NVivo 12, which facilitates the management of the vast amount of information that the researcher must deal with. The process of grouping together components of data that pertain to the same phenomenon is referred to by Shkedi as categorization (Shkedi, 2005). This starts with a few broad categories to establish a general overview and then finding ways for progressively refining the data. In the mapping stage, families of categories were beginning to emerge as cross-case analysis of emergent categories and their prevalence was explored, which resulted in finding relationship between pattern of main categories in different groups of participants.

Focused categorization occurs when the researcher centralizes data into a cohesive account around the core categories and starts to formulate a better picture of study findings (Shkedi, 2005). Focused analysis continued until the writing up of the findings, where core categories were created. In the process of producing core categories, the researcher sought out the category that had the ability to generate a coherent narrative, what appeared to be the key focus or issue of the participants, was frequently present in the data, and was easily related to other categories.

Three research team members conducted analysis by contributing to the development of primary categories in the second stage and core category in the third stage. Throughout the analysis process, the team reviewed interview experiences and discussed findings in weekly meetings. The emergent themes were reviewed several times until consensus was reached. The involvement of the research team's reflections and constant comparative method enabled generation of credible conclusions. Structuration theory used in this study informed analysis of the impacts that Australian practice standards and regulations had on the way in which Middle Eastern qualified midwives practised their profession in Australia, as well as strategies they employed to adapt to challenges they encountered during this process.

## 1.7 | Rigour

The first author conducted preliminary data analysis, communicated findings to the team for cross-checking and led regular team meetings to discuss findings. To address dependability, an

audit trail was created storing all codes and coded data in a matrix in NVivo 12 (Shkedi, 2005). This allowed for reviewing, verifying and auditing of the coding schema and associated data by the co-authors prior to finalizing the analysis. Trustworthiness and rigour were further addressed through methods of reflexivity (Shkedi, 2005). The primary researcher, who is an internationally qualified midwife, undertook the analysis in a reflexive manner, in which personal beliefs, assumptions and roles were continually discussed in the team during analysis to prevent premature interpretations of the data and recognize any assumptions and bias (Malterud, 2001).

Respondent validation, the process of researchers discussing interpretations of data with study participants, who may verify, alter and offer feedback as to whether they are recognizable and compatible with their experience also contributed to the elimination of bias in this study (Roberts & Priest, 2006). Thus, whenever the validity of the researcher's interpretation was doubted, participants were contacted and requested to check their transcribed and interpreted data and reject or amend any components with which they disagreed. Reporting in this manuscript is in accordance with COREQ guidelines (Tong et al., 2007).

## 2 | FINDINGS

### 2.1 | General characteristics of the participants

Nineteen Middle Eastern qualified midwives participated in this study; general characteristics are presented in Table 2. Their average age was 44 years, 17 participants (90%) were Iranian and spoke Farsi as their first language, while the remaining 10% ( $n = 2$ ) were Lebanese who reported Arabic as their first language and French as their second. The majority (43%) resided in the state of New South Wales, while others were living in other states/territories including Victoria, Queensland and the Australian Capital Territory. Most participants had migrated to Australia via student (37%), dependent skilled worker (26.5%) and partner visas (26.5%). All participants held a bachelor's degree in midwifery from Iran or Lebanon; seven also had a master's degree from Iran; and six studied PhD degrees in Australia. Average work experience among participants was 7 years overseas and 8 years in Australia. The majority of participants working clinically, were working in postnatal area in Australia, having no previous postnatal experience overseas. A significant proportion worked in the fields of research and education, both overseas (36.5%) and in Australia (30%).

### 2.2 | Second stage of analysis

In accordance with the multiple case narrative approach, following analysis of individual cases in the first stage, cross-case analysis was performed on all narratives in the second stage, and the professional transition experiences of Middle Eastern qualified midwives were

TABLE 2 General characteristics of the participants ( $n = 19$ )

Participants' characteristics	Frequency
Age (years)	
Average	44 ± 8
Range	28–60
Nationality	
Iran	17 (90%)
Lebanon	2 (10%)
First speaking language	
Farsi	17 (90%)
Arabic	2 (10%)
Residential state/territory in Australia	
New South Wales	8 (43%)
Victoria	6 (32%)
Queensland	3 (15%)
Australian Capital Territory	2 (10%)
Immigration visa type	
Student visa	7 (37%)
Dependent skilled worker visa	5 (26.5%)
Partner visa	5 (26.5%)
Refugee	1 (5%)
Work and holiday visa	1 (5%)
Overseas Education	
Bachelor's degree in Midwifery (Iran, Lebanon)	12 (65%)
Master's degree in Midwifery (Iran)	7 (35%)
Australian education	
PhD	6 (32%)
Masters degree in midwifery	2 (10%)
No degree	11 (58%)
Overseas working experience (years)	
Average	7 ± 6
Range	1–21
Sector of working overseas	
Labour and birth	7 (35%)
Antenatal	5 (26.5%)
Education and research	7 (36.5%)
Working experience in Australia (years)	
Average	8 ± 6
Range	2–20
Sector of working in Australia	
Postpartum	7 (35%)
Labour and birth	2 (10%)
Education and research	6 (30%)
Assistant midwife <sup>a</sup>	1 (5%)
Pathology collector	1 (5%)
Disability worker	1 (5%)
Not working	1 (5%)

<sup>a</sup>Working under direction of the registered midwife to deliver limited care to women.

classified into three categories, including *preparation for practice*, *scope of practice* and *context of practice*.

### 2.2.1 | Preparation for practice

Participants described characteristics of midwifery education programmes in Middle Eastern countries including admission requirements, programme duration, available midwifery degrees and clinical and theoretical components that prepared midwives for practice. Education system characteristics in Iran and Lebanon were generally similar. Entry requirements for midwifery programmes included 12 years of schooling and successfully passing the national entrance exam in both Iran and Lebanon (P3, P4, P6, P15, P17 and P18).

A bachelor's degree in midwifery was required for practice in these countries, which was obtained through 4 years of university education via direct entry (P6, P16 and P10). Postgraduate degrees including master's degree and doctorate (PhD) programmes were available to study for midwives in Iran, but not in Lebanon (P2, P18, P3, P9). The midwifery curriculum consisted of both clinical and theoretical components in Iran and Lebanon. According to Lebanese midwives, theoretical participants were totally taught by obstetricians in that country (P4, P6). Iranian participants also stated that obstetricians lectured into midwifery participants in this country and that they used obstetrics textbooks, rather than midwifery sources to study (P2, P3, P5, P8, P9, P16, P18 and P14).

Clinical components of courses were described as focusing on instruction of foundational midwifery skills in the first year, becoming more specific and increasing in length towards the last year (P6, P19). Clinical placements for midwifery students were carried out in a variety of settings, including prenatal, labour and delivery and family planning settings in these countries (P8, P18, P4, P2, P11 and P15).

Graduation criteria for the midwifery students in Iran included conducting 80 births and 40 episiotomy suturing.

...I remember I needed to have at least 80 deliveries, 40 of those births needed to be primi mothers to suture their episiotomy... I needed to be the main midwife managing the birth, but of course supervised by my teacher.

(P2)

The requirements for graduation in Lebanon were performing 55 deliveries and suturing 10 episiotomies.

In order to be graduated, you should do at least 55 deliveries. And 10 of them were with episiotomy. You should do suturing...

(P4)

A majority of participants in this study also experienced the midwifery education system in Australia by working in academia (P2, P3, P8, P9, P11, P15 and P18) or studying midwifery programmes as they were required to upgrade their overseas qualifications for registration (P5,

P7, P12, P17 and P19). Therefore, they often compared the midwifery education programmes in their home countries with those in Australia. Some appreciated the broader curriculum employed in Middle Eastern nations, while others argued that the midwifery education in their home country was medicalized and featured more irrelevant participants compared with the midwifery-focused curriculum offered in Australia (P3, P12 and P17).

In Iran, we study midwifery for four years, learning many aspects, not only midwifery like irrelevant subjects, like family planning, or treatment of vaginitis, all those things that midwife can't deal with. But in Australia, you learn to focus more in helping women to have baby and supporting them throughout the normal pregnancy.

(P17)

They verbalized being impressed by the subject of midwife-led continuity of care incorporated in midwifery curricula in Australia, in which the midwife as a principal care provider follows a woman throughout pregnancy, birth and postpartum periods (P17, P5).

Another great thing that I learned here is continuity of care, which we didn't have in Iran, so in here, like during my study at university, I had 10 women, I followed them up all by myself throughout pregnancy, during all that antenatal care, and I was there during birth...so, it was new thing for me.

(P17)

### 2.2.2 | Scope of practice

Participants perceived the midwifery scope of practice in Middle Eastern countries to be very different from that in Australia. Iranian graduate midwives identified that the scope of midwifery practice in Australia was more limited than in Iran, where their role was similar to that of obstetricians and gynaecologists (P7, P8, P9, P10, P12, P13, P14 and P18). They indicated that midwives in Iran were authorized to practice in their own private clinics in that country. They were also eligible to independently provide family planning methods and administer certain medications and diagnostic tests for common vaginal infections and pregnancy (P2, P8, P11 and P18).

...I remember in Iran; midwives can do more than the Australian midwives. For example, when I was working in Iran in my clinic, I could do family planning; inserting IUD [intrauterine device], prescribing oral contraceptive pills or other types of contraception methods, but in here I think the maternity child health nurses, they can do that, but not the midwife. ...I can say we were probably similar to maybe obstetrician or gynecologist in Iran, with limited practice.

(P13)



Some had opposing views and argued that midwives in Iran undertook responsibilities that were not for them, whereas Australian midwives largely focused on skills that fell in their scope (P3, P17),

Midwifery in Iran is a mixture of everything, women health, midwifery, nursing, and family planning, it is not a midwifery job. Even I don't think that midwives can take pap smear here; nurses can take it, but midwives cannot. But they are very strong in labour and delivery care. (P3)

They mentioned that antenatal care was predominantly delivered by obstetricians in their home countries as women preferred them over midwives (P3, P4, P6 and P16).

Antenatal care is not provided by midwives in Lebanon. A pregnant woman likes to go to a specialist, to obstetrician... (P4)

Both Iranian and Lebanese midwives highlighted that they had never worked in postpartum wards in their home countries because, in Iran, this care was routinely provided by nurses and, in Lebanon, women were discharged from the hospital shortly after giving birth in Lebanon, so there was no time for postpartum care. This experience made it challenging for them to be expected to provide postpartum care in Australia. (P1, P10 and P15)

It's a whole different system in Lebanon. Like, we didn't have postnatal care in Lebanon. The woman would have her baby, then go home... after couple of hours and there's no follow-up because the woman goes home so early. Here, no, they stay, and we take care of them... it is a bit challenging ... (P6)

Mothers' personal care and breastfeeding education following delivery were routinely provided by family members in Lebanon, and women relied more on their relatives than midwives. Thus, delivery of these forms of care in Australia were perceived as unfamiliar and an additional burden for Lebanese midwives.

In Lebanon, it's the aunty and the mother support mother. They can give advice about how to breast-feed and attach and all these things and if it doesn't work, they go to formula. They rely more on family than the midwives. Here, it does put more pressure on the midwife to help more and support - bathing and feeding and dressing of mother, all these little things that the family would have helped. (P6)

Similar experiences were reported by Iranian midwives. They highlighted that, unlike Australia where midwives are expected to assist women with personal care in postpartum wards, cleaners, enrolled

nurses or family members of the women routinely undertook these roles in Iran.

In Iran we wouldn't do lots of thing as a midwife. Cleaner would have done it, the enrolled nurse or husband or mum or sister would have done it. In here, we have to do everything, which I agree with that. Like, for example, if patient going to have - in postnatal- have a shower, lots of Iranian midwife were offended if you tell them, "You need to get patient up and take her - help her with having shower", but here, midwives should do everything.

(P15)

Providing labour pain management, particularly using epidural anaesthesia, was another new aspect of midwifery in Australia for participants as it was not practised in their home country, so they reported lacking the relevant skills (P1, P2, P10, P12 and P18).

... in Lebanon there's no, back then there was no focus on pain relief. We weren't taught much about pain relief, so the women would just stay in bed the whole time. ... So, when I came here, one of the tests for registration I had to do was about pain relief, and I failed that test ..., lots of women using epidural here... looking after them needs different training. (P6)

Practising midwifery model of continuity of care in Australia, which was not part of midwives' roles in Middle Eastern countries, was described by participants as 'wonderful' (P17), 'absolutely excellent care' (P13) and 'interesting care' (P19) that 'makes a lot of difference by building trusting relationship with women' (P5).

Moving to a new model of midwifery care in Australia that places women at the centre of care and involves them in decision-making was reported as a new and satisfying experience for participants. They referenced their overseas practice, where midwives made the majority of decisions and women were not consulted for their consent about the care they received (P2, P4, P6, P7, P9, P11, P12, P15, P17 and P18).

... here they really appreciate the women, and their body and their choice, which in Iran they don't appreciate the women choice at all. The way they treat patients in Iran is terrible and here they just respect women and what they decide and what they do. Well, you can't do anything without their permission, in Iran midwives force women to do what they wanna do, so here is a lot different in ways that respect women better.

(P19)

However, providing women-centered care was found demanding by some participants (P1, P6) as accommodating all the labouring

woman's needs was challenging and they believed that mothers' decisions were often not medically appropriate. One pointed to her experience working overseas, where she provided intrapartum care for a couple of women, which she found more manageable than delivering one-on-one care in Australia.

In Lebanon we had to take care of more than 10 patients in labour, but, still it was easy... here, it is one-to-one care, one midwife for one patient. It was difficult for me, as mothers have many choices, sometimes she is in pain and she does not want to use epidural, and she just want gas, so you give her gas, and she will use the gas for some time, and again she thinks the gas is not helping her with her pain, so she asks for epidural...you know it is a lot of work for me in the labour room...sometimes you think you should give a care to the patient, as you think it is right for her based on your knowledge, but she does not want that, and she deny your care, so you don't know what to do. (P6)

According to participants, midwifery practice in Iran and Lebanon was interventional and not evidence-based. They stated that women in these countries were not given sufficient support during labour and that their labours were commonly expedited by any form of intervention, including induction of labour and routine episiotomy (P3, P6, P7, P9, P18, P15 and P17).

We do not allow patient to have normal delivery process, we're doing something like injections, anything as long as we make the delivery process shorter...we normally do episiotomies for all the primi [primigravidas]... But in Australia no, we just support the patient to have a normal birth. (P6)

### 2.2.3 | Context of practice

When comparing the systems, participants from Lebanon frequently mentioned that they had limited autonomy and independence over their practice in Iran and Lebanon (P3, P6, P10, P9, P16, P17, P18 and P19). Midwives' professional status was also seen to be more valued in Australia, where they worked autonomously as part of a multidisciplinary team and were enabled to practice in their scope (P3, P9, P16 and P19).

I just feel sorry for the midwives back home. Here, they [healthcare team members] really appreciate what the midwives do, like we work along with the obstetrician and pediatricians, and no-one interfere with others, and they work in a multi-disciplinary team.

(P19)

Lebanese midwives indicated that all the legal responsibilities of maternal care was with obstetricians, and that obstetricians were penalized for midwifery misconduct in Lebanon (P4, P6). Participants from both countries discussed their new experiences in Australia that necessitated legally conscious midwifery practice.

In Lebanon, obstetricians are responsible for whatever we do... in Australia, if you give the patient a Panadol tablet wrong, the patient can take her right directly. But you should be very very careful about each task you are given. (P4)

Following strict documentation rules and responsibilities for midwifery practice in Australia was discovered to be a significant difference between Australia and participants' home countries. While documentation was not practised or was quite restricted in Middle Eastern countries, it was an essential component of midwifery practice in Australia, and midwives were expected to record details of care provided (P5, P6, P11, P12 and P15).

I always was told that you've got to be very careful, make sure you always document, because one day, there will be one day when you're going to be called to court to be a witness. I see that they have written "I gave her a bottle of water" or "I turned the light off" or "I draw the curtain" or like similar, very simple things like this, they document everything. When I was in Lebanon, there was no - we hardly ever documented. There was no documentation. (P6)

Australia's midwifery practice was differentiated from that of Middle Eastern countries by its strict adherence to clinical guidelines and clear and precise job descriptions (P1, P2, P4, P5, P12, P17 and P19).

There were not clear protocols in Iran. Here, we have our own protocols which came from the head organisation. And we are definitely needed to be practising based on those protocols. (P2)

While participants realized that adhering to regulation standards and strict documentation in Australia contributed to increasing the safety of midwifery practice, they were frustrated as they were not familiar with this model of practice in their own country. They also indicated that because a major portion of their time was spent on documentation in Australia, they were unable to deliver midwifery care that they used to do in their home country. According to participants, abiding to Australia's stringent regulations decreased their confidence to the point where they reported deciding not to practice some skills to avoid legal repercussions (P5, P, P11 and P15).

I think some of roles in Australia are good, some of them are too much. It exhausts you; you know it just puts lots of stress on you, but in a sense that they think about every detail, it's good for staff safety...

Since I came, I haven't done stitching because of the paperwork and extra work I already have to deal with in my shift, ...I just call doctor to come and do it. (P5)

They found it unusual and restricting to be required to obtain further training and certificates to practice some skills in Australia that they had regularly undertaken after graduation in their home countries (P6, P12, P13, P15 and P19).

For us was very funny to have to go and do a course to be able to take blood, because it was part of everybody's job in Iran. But in here, everything, you should have a certification - you should go through a course and be certified to be able to do that.

(P15)

They found the Continuing Professional Development (CPD) programme and its rules in Australia to be well organized and effective for updating their skills, in contrast to the situation in Lebanon or Iran, unlike in their home countries, where it was either unavailable (Lebanon) or very limited (Iran) (P1, P4, P8, P9, P11, P15 and P17).

Here, every year you have to have at least 20 CPD points...for those who work, they have to do - every year they have to do training modules on all aspects of labour and birth, like the dystocia, postpartum haemorrhage and ... So, you have to do 20 hours, so it could be in any of these. So, it's really good system.

(P11)

### 2.3 | Third stage of analysis

The third stage of analysis was devoted to methodically combining the generated categories into a core category of *reframing professional identity*. According to the case narratives in different categories of *preparation for practice*, *scope of practice* and *context of practice* collectively, Middle Eastern qualified midwives modified their practice to fit Australian standards, and in so doing modified their professional identities. They re-evaluated the practice of their home countries, adjusted to new ways of practising in Australia and acquired new sets of responsibilities and professional relationships as part of the process of restructuring professional identity.

When the characteristics of midwifery education in Middle Eastern countries were reconsidered, participants discovered inadequate preparation to practice according to Australian standards, as their curriculum lacked a midwifery focus by inclusion of obstetricians as main educators and that did not support midwifery concepts. Additionally, while the Australian Health Practitioner Regulation Agency (AHPRA) maintains strict partnerships with universities and precisely defines the criteria expected from midwifery graduates, citation of inadequate collaboration

between regulatory organizations and education providers about requirements for midwifery students demonstrated lack of education standards in home countries and accreditation of education programmes in these countries.

... here the AHPRA is very connected to universities, they say if you don't do this and this, we don't approve your graduates, you know, they need the approval of AHPRA. They say if your students don't get this amount of practice or these assignments, we don't give them qualifications. But in Lebanon, there is no link and universities are independent. (P6)

The scope of practice, and the authority that they held in the workplace in Australia, were all a novel experience for them. Participants reported having to upskill and develop new competencies to be able to practice in full scope of Australian midwifery practice as they lacked overseas working experience in prenatal and postnatal care.

Participants described stripping themselves of their previous professional identities and transition to Australia from Middle Eastern countries where midwives' autonomy was restricted due to interprofessional power struggles among physicians and midwives. Practising autonomously in well-defined job boundaries in Australia, they did not have to work beyond their scope of practice, while there were unclear boundaries between their own and obstetricians' roles in Middle Eastern countries, where midwives undertook responsibilities that were for obstetricians (P4, P9, P10, P17, P18 and P19).

It's much easier here, much easier, not so much work... in Lebanon, you should do everything, we are alone in labour, and do whatever doctors do ... here, they have well-defined job description. They only work within their scope, if there is something they don't know, they refer it to the obstetrician. (P4)

Middle Eastern midwives, who were not legally accountable in their home countries, adopted new professional identities that conformed to documentation norms and evidence-based guidelines in transition to the litigation-conscious midwifery practice prominent in Australia. Previously, they had followed obstetricians' instructions as there were no clinical protocols accessible and obstetricians determined clinical rules as the dominating profession in these countries (P1, P2, P5, P12, P17 and P19).

Back home is mostly what the obstetrician decides to do, it is not what the guideline says. Actually, there were not clear protocols in Iran, it is what the obstetrician wants to do.... midwives have to do obstetrician's order... I just felt that in Australia everything is based on guideline, and the midwives really stick to them ...

(P19)

### 3 | DISCUSSION

Middle Eastern qualified midwives came to Australia with already well-formed professional identities reflecting their overseas context of practice; thus, entering the Australian work system they had to adjust their imported identities as professionals by reevaluating the familiar patterns of skills, re-learning the role of their professional cadre in the workplace and adapting to the way their profession was practised in Australia. To the author's knowledge, this is the first time that the transition experiences of non-English speaking background midwives from countries with midwifery education, practice and regulation that differ significantly from that of their host country is reported. The limited literature on internationally qualified midwives has been primarily focused on midwives who are coming from a similar system that was as developed as their host countries (Javanmard et al., 2020). Thus, the issues reported by participants in this study were found to be significantly different, with more focus on how considering the remarkable gaps in their overseas practice, Middle Eastern midwives adjusted to the new way of practising that required them to adhere to high professional standards.

Middle Eastern midwives participated in this study had been in practice for several years prior to migrating to Australia and had gained entry into Australia, demonstrating that their qualifications and skills met Australian standards. Thus, modifying their professional identities to fulfil Australian standards of practice required them to strike a balance between presenting themselves as qualified to practice in Australia and determining how they needed to adapt their professional presentation to fit in. A similar observation was found in a Canadian study, where the process of professional adjustment was more profound for international health professionals from non-western healthcare systems, than for their counterparts from countries with comparable systems to Canada such as the United States, United Kingdom, Australia and France (Neiterman & Bourgeault, 2015).

When comparing the characteristics of their previous training and education to Australian standards, Middle Eastern midwives discovered important gaps in the way they were prepared for practice as their midwifery curriculum was not standardized, medically oriented and primarily lectured by obstetricians. Coming from medicalized systems was also evident in the terminology they used in interviews: 'patient' instead of 'woman' and 'delivery' rather than 'birth'. In Australia, regulatory authorities implement accreditation standards for developing midwifery curriculum that are guided by ICM standards for midwifery education (ICM, 2014), which emphasize the philosophy that introduces and prepares midwives as advocates for non-intervention childbirth and are primarily educated by qualified midwifery lecturers (Hainsworth et al., 2021). Middle Eastern qualified midwives must be properly assessed against the education standards expected from graduate midwives in Australia before registration, and opportunities to upgrade their qualifications should be made available to compensate for gaps in their overseas education (ANMAC, 2014).

Another aspect of midwifery care lacking in midwifery education and practice of Middle Eastern midwives and required significant

professional adjustment was midwifery-led continuity of care, which is included as a mandated clinical practice-based learning component in midwifery programmes leading to registration in Australia from 2009 (Tierney et al., 2018). Midwife-led models of care are viewed as an essential strategy for strengthening women's choice and a fundamental component of woman-centred care in Australia (McLachlan et al., 2022), which was another feature of care that Middle Eastern midwives who participated in this study had not been exposed to prior to moving to Australia. Their transition to the Australian healthcare system, therefore, was not simply a process of adaptation to a new workplace; it was often acquiring new competence to provide new approaches to midwifery care. Thus, specific instruction should be provided for overseas midwives prior to registering in Australia to prevent them from encountering further issues. The transition of internationally qualified healthcare professionals has been described as comprised of interconnected stages, and unresolved issues in the registration stage can result in emergence of serious issues in the workplace (Safari et al., 2022).

The process of restructuring professional identity for Middle Eastern midwives required them to modify their practice and develop insights into how the status of their profession in Australia differed from what they were accustomed to. In contrast to UK midwives, who reported restricted authority for practice in Australia (Javanmard et al., 2020), Middle Eastern midwives in this study experienced greater autonomy in Australia, in contrast to their home country experiences where midwives were subordinate to obstetricians who held a predominant role in the hierarchical structures of the healthcare system. Rank and status of the profession establish roles in the workplace (Neiterman & Bourgeault, 2015), hence Middle Eastern midwives may struggle to adjust their professional identities without informing of them about their role as independent primary care providers in Australia and the responsibility that came with this status.

To adapt to the local model of practice in Australia, midwives from the Middle East learnt the new professional landscape of the host country that involved independent care of women across all stages of childbearing. This was in contrast to their overseas experience, where they did not practice prenatal and postpartum care because obstetricians were the primary antenatal care providers, and postpartum care was either not offered or provided by nurses. Additionally, they were required to support mothers with early postpartum self-care, which was usually delegated to family members accompanying patients in their home countries. This was consistent with results of a scoping review that examined midwifery practice, education and regulation in Middle Eastern and North African countries in the context of ICM standards (Safari et al., 2021). Given that the majority of Middle Eastern midwives in this study worked in postpartum in Australia, indicating that they are more likely to be interested in or find employment in this area despite lacking overseas experience, the question of how well they are prepared for this practice in Australia arises. Prior to registering Middle Eastern midwives, a context-specific and evidence-based upskilling programme, followed by mentorship customized to their needs in the workplace, is crucial to consider to maximize their proficiency and ensure safe practice and public safety in Australia.

Generally, learning which responsibilities are undertaken by midwives in the host country and which are delegated to other members of the healthcare team is considered a necessary first step towards professional integration (Neiterman & Bourgeault, 2015). Clear role description for midwives in Australia facilitated this transitional phase for Middle Eastern midwives and made practising in Australia easier for them, as they were overburdened by taking on obstetrics tasks because of the ambiguous division of responsibilities in their home countries.

Middle Eastern midwives, who were not legally accountable in their home countries, made significant adjustment to maintain legal practice by strictly following guidelines and documentation rules; however, for some it negatively influenced their confidence and discouraged them from practising skills that made them prone to litigation. Moreover, using additional time and attention to fulfil the increasing requirements of documentation towards regulatory standards interfered with practising other skills, such as episiotomy suturing, that they had normally practised in their home countries. Similarly, Australian midwives complained about having difficulty tailoring care to each woman due to the increasing amount of data that they were required to document (Verrall et al., 2015). Documentation requires specific skills for which Australian midwives are educated and prepared (Gray et al., 2019); it is important to recognize that Middle Eastern midwives may need more time to acquire it due to lack of overseas experience. Future studies may shed more insight on how delays caused by establishing new skills in the host country can impact international midwives' efficiency in performing other competencies that they were proficient in.

## 4 | LIMITATIONS

Some limitations in relation to this study are acknowledged. Despite extensive recruitment strategies being employed, the participants do not represent the diversity of all Middle Eastern countries as they were predominantly from Iran. As evidence indicates, this could be related to the fact that the only degree available to midwives in some Middle Eastern countries is an associate degree, which is not eligible for registration in Australia (NMBA, 2020; Safari et al., 2021). Additionally, only Middle Eastern qualified midwives who felt confident in their experiences or language ability may have chosen to participate. Although the multiple case narrative research approach employed in this study has the potential for sample to population generalization, the sample size was insufficiently large and heterogenous for this purpose, yet, there are valuable insights from this work that may inform other health professions and policy contexts (Shkedi, 2005).

## 5 | CONCLUSION

This study provides an opportunity to discuss views and experiences relating to the professional transition of Middle Eastern qualified midwives in the Australian context, an area that has been significantly under-researched. Seeking professional integration in Australia,

Middle Eastern midwives had to significantly modify their professional identities and learn new skills, roles and responsibilities to reflect a new practice context. The preparation, scope and context of midwifery practice in Middle Eastern nations were found to differ from those in Australia by lacking midwifery-oriented curricula, autonomy to practice in full scope, clear job descriptions, evidence-based guidelines and documentation rules. A significant gap in midwifery practice in Middle Eastern countries suggests that strategies should be developed to ensure their safe and women-centred practice in Australia, including provision of context-specific transition or upgrade programmes before registration, and supporting mentorship after integration into the Australian healthcare workforce. While healthcare systems of Australia, similar to the majority of the developed world will likely continue to rely on internationally qualified midwives, various stakeholders must acknowledge the level of support that Middle Eastern midwives require to practice competently and in accordance with Australian standards to maintain patient safety.

## AUTHOR CONTRIBUTIONS

Kolsoom Safari: Conceptualization, methodology, investigation, data curation and formal analysis, Writing: Original draft. Jenny Davis: Conceptualization, methodology, formal analysis, visualization, supervision, writing—review and editing and validation. Lisa McKenna: Conceptualization, methodology, formal analysis, visualization, supervision, writing—review and editing and validation.

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## CONFLICT OF INTEREST

The authors declare no potential conflict of interest with respect to the research, authorship and/or publication of this article.

## PEER REVIEW

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## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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# Symptom management needs of patients with irritable bowel syndrome and concurrent anxiety and/or depression: A qualitative study

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## Abstract

**Aims:** To understand the experiences and needs of symptom management among individuals with irritable bowel syndrome and concurrent symptoms of anxiety and/or depression.

**Design:** This study used a qualitative descriptive research design.

**Methods:** Individuals with a diagnosis of irritable bowel syndrome and concurrent symptoms of anxiety and/or depression participated were recruited through an on-line ResearchMatch and a listserv. Semi-structured interviews focused on symptoms and experiences with symptom management interventions conducted from June to August 2020. Interviews were transcribed and data were analysed based on thematic analysis.

**Results:** Twelve individuals participated in this study; all reported current irritable bowel syndrome and anxiety/depression symptoms. The data analysis cumulated with three themes related to symptom management: (a) irritable bowel syndrome negatively impacts physical and mental well-being; (b) a trial and error approach to symptom management; and (c) challenges with healthcare professionals supporting symptom management including negative interactions with healthcare professionals and lack of nutritional expertise and support.

**Conclusion:** There is a need for individualized approaches which consider patients' current symptoms of anxiety and depression, previous experiences with the trial-and-error process and consideration for intervention delivery methods.

**Impact:** There is a limited qualitative research focusing on the experiences of individuals with irritable bowel syndrome and concurrent symptoms of anxiety and/or depression. This research highlights the need for individualized approaches to enhance symptom management that acknowledges patients' psychological state and past negative experiences with providers and prior dietary regimens.

## KEYWORDS

anxiety, depression, diet intervention, irritable bowel syndrome, nurses, nutritionists, symptom management

## 1 | INTRODUCTION

Irritable bowel syndrome (IBS) is a disorder of gut–brain interaction in which diagnostic criteria include experiencing abdominal pain and changes in bowel patterns (Vasant et al., 2021). The impact of IBS includes poorer quality of life and disability, as well as missed work and school absenteeism and presenteeism (Buono et al., 2017). IBS commonly co-occurs with anxiety and depression, with up to 50% of patients with IBS reporting anxiety or depression (Grinsvall et al., 2018; Hu et al., 2021; Turkiewicz et al., 2021). The gut–brain axis refers to the close connection that occurs between the brain and the gut, commonly through neurotransmitters such as serotonin, metabolites of bacteria and through the afferent sensory fibres of the vagus nerve (Lee et al., 2017). Additionally, the brain communicates with the gut through the central and autonomic nervous systems, using efferent pathways targeting the intestinal wall, as well as signalling via the hypothalamic–pituitary–adrenal (HPA) axis (Carabotti et al., 2015). As such, previous research may have overlooked the unique needs of those with concurrent anxiety and/or depression and bowel symptoms. Nurses are the most common healthcare providers worldwide and have the potential to address the experiences and needs of individuals with IBS and concurrent anxiety and/or depression. Therefore, it is important to understand the subjective experiences and symptom management strategies used by patients with IBS who also experience symptoms of anxiety and/or depression to inform ways to enhance self-management of symptoms.

## 2 | BACKGROUND

Adults with IBS have greater levels of anxiety and depression than the general population (Arasteh et al., 2018; Lee et al., 2017; Mykletun et al., 2010). Individuals who have IBS and symptoms of anxiety and/or depression experience additional burden of disease as they have greater IBS symptom severity, reduced quality of life and greater healthcare utilization compared with individuals with IBS alone (Cho et al., 2011; Goodoory et al., 2021; Kopczynska et al., 2018; Midenfjord et al., 2019). Effective symptom management interventions are needed to consider the overlap of anxiety, depression and chronic gastrointestinal symptoms in this population.

A variety of effective interventions have been designed to reduce symptoms for individuals with IBS (Black & Ford, 2021; Chen, Zhang, et al., 2022; Cong et al., 2018; Vasant et al., 2021). The two most widely used interventions are the low fermentable oligosaccharides, disaccharides, monosaccharides and polyols (FODMAP) diet and cognitive behavioural therapy (CBT), yet little is known regarding experiences using these symptom management interventions among individuals with IBS and concurrent symptoms of anxiety and/or depression. Current evidence supports the low FODMAP diet as superior to medication (e.g. spasmolytics) in reducing IBS symptoms (Carbone et al., 2022; Liu et al., 2020). Some research

indicates that although the low FODMAP diet is effective in reducing gastrointestinal symptoms, it may be less effective in reducing symptoms of anxiety and depression (Chan et al., 2022; Kortlever et al., 2019). CBT targets cognitions and behaviours associated with IBS symptoms, and can include relaxation strategies and psychoeducation (Sugaya et al., 2021). However, a recent meta-analysis indicated that patients with comorbid anxiety or depression were less likely to benefit from CBT (Sarter et al., 2021) and few, if any, studies have focused on the unique symptom management experiences and needs of patients with IBS who have concurrent symptoms of anxiety and/or depression.

One approach to understanding the symptom management needs of patients with IBS and concurrent symptoms of anxiety and/or depression is to conduct a qualitative study of their perspectives. Previous qualitative studies of the lived experiences and needs of those with IBS (Molinder et al., 2015; Parlar Kılıc et al., 2020; Skrastins & Fletcher, 2018) and a recently published systematic review of qualitative studies identified four themes of living with IBS: (1) physical, psychological and social consequences (which included anxiety and depression); (2) impact of IBS on working adults; (3) dealing with IBS and (4) sources of support and support needs (Shorey et al., 2021). However, it is not clear from the review or the studies themselves how many participants had concurrent symptoms of anxiety and/or depression as this information was not reported (Shorey et al., 2021). Thus, this study sought to address this gap by specifically focusing on experiences of symptom management among individuals with IBS and concurrent symptoms of anxiety and/or depression. Furthermore, since the current leading interventions may be insufficient for those with symptoms of anxiety and/or depression, it is important to understand the experiences and needs for symptom management among individuals with IBS, anxiety and depression.

## 3 | THE STUDY

### 3.1 | Aims

The aim of this study was to understand the experiences and needs of symptom management among individuals with IBS who also experience symptoms of anxiety and/or depression. Understanding this lived experience and needs can inform the development and/or personalization of symptom management interventions.

### 3.2 | Design

We used a qualitative descriptive research design to collect data on the patients' perspective of their symptoms, symptom management experiences and needs (Sandelowski, 2000, 2010; Vaismoradi et al., 2013). A qualitative descriptive design enabled a comprehensive summary using everyday language and the ability to stay closer to the data (Sandelowski, 2000, 2010). An inductive

thematic analysis approach was selected to enable interpretation of the patient's experiences and needs related to symptom management.

### 3.3 | Sample/participants

Participants were recruited online through ResearchMatch, a national health volunteer registry support by the US National Institutes of Health and through the University of Washington Institute of Translational Health Sciences website. Potential participants completed online screening; data on the screening process has already been published (Kamp et al., 2021). Purposive sampling was used to obtain a diversity of age, gender and race. The inclusion criteria were ages 18–70, met Rome-IV IBS criteria, have a diagnosis of IBS from a healthcare provider, report at least moderate anxiety and/or depression (Generalized Anxiety Disorder-7 > 10; GAD-7 [Spitzer et al., 2006]; Patient Health Questionnaire-9 > 10; PHQ-9 [Kroenke et al., 2001]), and able to read and write in English. The exclusion criteria were: having a first degree relative with colorectal cancer before the age of 60 or multiple 'Red Flag' symptoms (i.e. loss of 10 pounds without trying, blood in stool and anaemia) as these may indicate organic causes of gastrointestinal symptoms.

### 3.4 | Data collection

Data were obtained through semi-structured interviews conducted between June and August 2020. A semi-structured interview guide was developed by the research team which included backgrounds in nursing, social work, human-centred design and usability. The interview guide included questions about gastrointestinal and psychological symptoms and experiences with previous symptom management approaches. Participants completed the virtual interview from a location that was comfortable and convenient to them with a female nurse scientist who has experience conducting interviews and focus groups (KK). Data collection continued until there was sufficient data for understanding the experiences and needs of symptom management, which occurred after 12 participant interviews. Interviews lasted between 32 min and 1 h and 11 min (mean 47 min) and participants received a \$50 gift card. To describe participants and consider the impact of IBS, participants also completed demographic and clinical questionnaires. Demographic questions included age and gender. Clinical questionnaires included the IBS quality of life and Sheehan Disability Scale. The IBS quality of life questionnaire includes nine subscales emotional, mental health, sleep, energy, physical functioning, diet, social role, physical role and sexual relations (Hahn et al., 1997). The Sheehan Disability Scale evaluates functioning in work/school, social life/leisure activities and family life/home responsibilities as well as absenteeism and presenteeism (Leon et al., 1997; Sheehan et al., 1996).

### 3.5 | Ethical considerations

Ethics approval was obtained from the University of Washington Institutional Review Board prior to recruitment. Verbal informed consent was obtained prior to conducting the interview. Participants were informed about the purpose of the interview and that they could stop participating at any time. If participants became uncomfortable or anxious, a list of resources was available, although this was not needed in this study.

### 3.6 | Data analysis

Audio recordings were transcribed. The data were analysed using thematic analysis based on Braun and Clarke (2006, 2019). The authors began the process of immersion by reading all the transcripts multiple times without notating or tracking codes. After the authors were fully immersed in the content, they went through each transcript to generate initial codes, and met to discuss codes. The codes were then sorted and grouped into themes. The codes and themes were presented to the entire authorship team who provided feedback and discussed any necessary changes. The Consolidated Criteria for Reporting Qualitative (COREQ) studies checklist guided this manuscript (Tong et al., 2007).

### 3.7 | Rigour

The Standards for Reporting Qualitative Research (SRQR) guided our approach. To enhance rigour, we used Lincoln and Guba's evaluative criteria of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility was enhanced by peer debriefing to compare codes and themes and examining the personal values and preconceptions of the researchers. The researchers spanned a multidisciplinary background of nursing, social work and human-centred design. The data analysis was conducted by three authors (KK, HM and LY) who are each registered nurses and also conduct research. KK and LY conduct research in gastrointestinal disorders and HM conducts research in eating disorders. Throughout the process of data analysis, we met regularly to discuss the findings as well as our assumptions which could influence the findings. Transferability, the extent to which findings are applicable in other contexts, was enhanced by providing participant demographics as well as clear study descriptions and research findings. Confirmability and dependability were established through an audit trail.

## 4 | FINDINGS

The group consisted of 12 individuals. For IBS subtypes, five had IBS-diarrhoea, five had IBS-mixed and two had IBS-constipation. Nine participants were female and 3 were male. Table 1 presents data on quality of life and disability to further describe the impact of

TABLE 1 Participants demographics

Characteristics	Mean (SD)
Age	36.8 (12.2)
Anxiety score	14.1 (5.7)
Depression score	15.0 (6.7)
<b>Quality of life</b>	
Emotional	29.7 (32.0)
Mental	65.8 (22.0)
Sleep	72.2 (30.0)
Energy	44.8 (26.9)
Physical	61.8 (29.2)
Food	47.2 (23.5)
Social	53.7 (31.4)
Physical role	33.3 (34.3)
Sex	45.8 (24.0)
<b>Sheehan disability scale</b>	
Work/school	6.9 (3.2)
Social life/leisure	6.8 (3.3)
Family life/home	7.0 (2.7)
Missing school, work or being unable to carry out Normal daily activities (days)	2.1 (1.9)
Reduced productivity due to symptoms (days)	3.3 (2.2)

Note: Key: Anxiety range: 0 to 21 (higher indicates greater anxiety); Depression range: 0 to 27 (higher indicates greater depression); Quality of Life range: 0 to 100 (higher indicates greater quality of life); Sheehan Disability Scale range: 0 to 10 (higher indicates greater symptom disruption).

disease, with the majority of participants reporting low quality of life and moderate disability.

The data analysis cumulated in three themes, with sub-themes, which outline the experiences and needs of managing IBS and concurrent symptoms of anxiety and/or depression: (a) IBS negatively impacts physical and mental well-being; (b) a trial and error approach to symptom management; and (c) challenges with healthcare professionals supporting symptom management. Table 2 provides an overview of the themes and sub-themes.

#### 4.1 | IBS negatively impacts physical and mental well-being

Participants in this study provided salient insight to their individual experiences with IBS, including the symptoms (both psychological and physical) that they endure. In the unique population studied (individuals who had both IBS and symptoms of anxiety and/or depression), the impact of the mental and physical symptoms was often described as cyclical in nature and fed into one another. Sub-themes related to the impact of IBS on the participants' holistic well-being involved recurring distressing physical symptoms, the impact of those symptoms both internally and externally, and how those symptoms disrupt their daily lives.

TABLE 2 Overview of themes and sub-themes

Themes	Sub-themes
IBS negatively impacts physical and mental well-being	Shared experiences with distressing physical symptoms
	Relationship between IBS symptoms and anxiety/depression
	IBS symptoms impact normal activities of daily living
Trial and error approach to symptom management	Interpersonal relationships and symptom perception
	Identifying strategies for managing symptoms
	Impractical and ineffective interventions
Challenges with healthcare professionals supporting symptom management	'What haven't I tried?' - Trying multiple interventions
	Negative interactions with healthcare professionals
	Lack of nutritional expertise and support

Abbreviation: IBS, Irritable bowel syndrome.

##### 4.1.1 | Shared experiences with distressing physical symptoms

Significant physical symptoms related to IBS were an almost ubiquitous experience among those interviewed. Many of these symptoms had negative impacts on the individual's physical well-being, with the most frequently reported symptoms being abdominal pain, faecal urgency, diarrhoea, constipation and bloating. These symptoms not only caused physical distress but often resulted in psychological stress as well, with some describing a sense of 'losing control' over their bowel habits.

I get really bad diarrhea and I get bloated... It's not uncommon for me to have six or seven bowel movements a day...The urgency is the one that I think is the worst. (Participant 2, female, mild anxiety, moderately severe depression)

Stomach cramps are really the most stressful part of actually having IBS for me, because it's constant and it's not something that can really be controlled. (Participant 8, male, severe anxiety, moderately severe depression)

It became horrible, just excruciating pain all the time, uncontrollable changes in bowel frequency, consistency, anything I ate was uncomfortable. (Participant 1, female, severe anxiety, severe depression)

Another physical symptom brought up by several participants was fatigue. Participants stated that sleep issues, both in falling asleep and staying asleep, were troublesome and a source of discomfort. However,

symptoms of fatigue and poor sleep were not always in the context of a participant discussing their IBS symptoms, but instead their anxiety or depressive symptoms. For those whose fatigue was tied to their IBS symptoms, gastrointestinal discomfort or pain were the primary reasons for inadequate sleep. And while not explicitly defined as fatigue, Participant 11 discussed situations in which their stomach pain would leave them 'wiped out,' colloquially referring to fatigue or exhaustion. Additionally, for these participants, frequent or severe gastrointestinal symptoms can result in physical symptoms of fatigue, even when not directly related to sleep disturbances.

I would say the hardest thing is definitely the stomach pain. Even though I don't experience it as often as I used to, it wipes me out. It wasn't really an issue when I was in high school, but I think it was two summers ago. I was on vacation in just a little cabin with my family. And for the entire vacation, after every time I would eat, I would just not be able to do anything. I would just sit on the couch in pain, just watching TV. And it was the most miserable time.

(Participant 11, female, moderate anxiety, mild depression)

#### 4.1.2 | Relationship between IBS symptoms and anxiety/depression

Many participants expressed that their mental health was negatively affected by their experiences with IBS and vice versa, in that a worsening of one would often result in the worsening of the other. Participants noted the negative physical impact of IBS on their bodies as a source of depressive and anxiety symptoms, often due to disruptions in their normal social or work routines.

Mostly the depression, just because if I don't feel good, I don't want to go out, and a lot of times, my energy level or willingness to do something active really, really correlates to how I feel physically, and most of that correlates with my stomach."

(Participant 1, female, severe anxiety, severe depression)

Conversely, participants described circumstantial stressors (e.g. life changes, financial concerns and housing instability) preceding discomforting GI symptoms, which in turn added more stress to the participants' subjective experiences.

I think it was a combination of a lot of stuff that was going on in my life. I was going through some things that were not ... There was a lot of uncertainty about where I was going to live and work and all that stuff. But also, managing that and going out and talking to people, I would be like, "Okay, I really want to go and

talk to my husband about this situation," and I noticed that it was always coinciding with a really bad attack, a bad stomachache. So, it came together. So, maybe I was stressed out about things outside, but then it made my stomach hurt, which made it more difficult for me to deal with the situation, which made me hurt more.

(Participant 9, female, mild anxiety, moderately severe depression)

I can kind of trace it back to enormous amounts of circumstantial stress, but then the stress on my stomach and my digestion got so bad that it felt like that was the real stress and it was so distracting from the other conditional things that I've been dealing with. It was sort of like a chicken or the egg situation.

(Participant 10, female, severe anxiety, severe depression)

#### 4.1.3 | IBS symptoms impact normal activities of daily living

Participants discussed how their IBS and other GI symptoms disrupted their normal schedules, work activities and personal relationships. This included having to structure their schedules and outings around bathroom accessibility. Without access to bathrooms, participants noted a significant uptick in their anxiety.

I mean, a really hard time, I mean, having to rush to get to the bathroom. I mean, I've had to have many times, but I've never not made it to the bathroom. But I got to go, and I got to get there, and I've got to get to where I'm going or find a place to stop. That's the most irritating of all.

(Participant 5, male, moderate anxiety, mild depression)

In many ways, these lifestyle disruptions were perceived as more frustrating than the physical symptoms of IBS itself due to the many potential consequences it could have on their long-term personal and professional relationships, academics and careers.

Oh, the leakage ... I do a lot of functions work-wise and you'd be out and after maybe a couple of drinks you think you would want to pass winds and the next thing you have a leak and that's the hardest of that. That's the one that gets you down, you know?

(Participant 3, male, severe anxiety, moderately severe depression)

I don't have a lot of flexibility in my schedule. And so, if I'm not feeling well, either I have to sacrifice like my health and be in a lot of discomfort throughout the



day, or I have to cancel on a client, which is also very frustrating.

(Participant 7, female, severe anxiety, mild depression)

Overall, participants described distressing physical symptoms, which resulted in situations that made conducting their daily routines difficult, as a primary concern.

#### 4.1.4 | Interpersonal relationships and symptom perception

Participants' perceptions of how others viewed them was impacted by their IBS symptoms. Many experienced heightening feelings of self-consciousness. For instance, participants commonly experienced feelings of embarrassment, anxiety and self-doubt, especially in social situations where the individual felt their symptoms—or steps they take to manage those symptoms—caused others to view them negatively:

The uncertainty, the uncertainty of when it's actually going to hit me, fear of me being out, maybe at the office or even in public, running errands or something, and it hits me, that's a huge fear of mine, because it has happened and it's really embarrassing.

(Participant 8, male, severe anxiety, moderately severe depression)

So, being around people eating is excruciating. I hate it. I absolutely hate being around people eating, (...) Because they look at me and then they think that I have an eating problem when it's really, I'm avoiding things that will make me feel bad.

(Participant 1, female, severe anxiety, severe depression)

Participants also brought up intimate personal relationships, including long-term partners or spouses, as an important part of their experiences. One participant noted their symptoms were severe and pervasive enough to cause sexual dysfunction and embarrassment regarding intercourse in their marriage.

I think pain and the looseness of the stools can just create this exhaustion. And that pain also bleeds into my marriage life, and that I noticed on the hand-outs that you gave, it's like the sexual symptoms are pretty... they're becoming more and more significant, I feel like as I get older.

(Participant 12, female, severe anxiety, moderate depression)

However, these relationships could also be sources of social support that positively affected an individual's resilience.

I think it's really important that my husband's really supportive and he doesn't judge or overthink it...the really important thing is sort of having that support.

(Participant 9, female, mild anxiety, moderately severe depression)

## 4.2 | A trial-and-error approach to symptom management

Participants with IBS and symptoms of anxiety and/or depression identified a variety of bothersome symptoms which interfered with their daily life, as indicated above. This led to a trial-and-error approach to symptom management comprised of three sub-themes: identifying strategies used for managing symptoms, impractical and ineffective interventions and 'What haven't I tried?'—trying multiple interventions.

### 4.2.1 | Identifying strategies for managing symptoms

Identifying strategies to manage symptoms was a priority for participants. The most commonly identified strategy was the management of symptoms through dietary approaches, primarily by identifying trigger foods and maintaining the low FODMAP diet. Over half of the participants discussed trying the low FODMAP diet. Common trigger foods (i.e. foods associated with increased IBS symptoms) included dairy, raw leafy greens and spicy foods. Identifying trigger foods was viewed as a method to avoid or reduce symptom severity.

Watching things that I eat, it's a huge help to avoid the symptoms being as severe.

(Participant 8, male, severe anxiety)

Participants also discussed a variety of complementary strategies to manage symptoms, including stress management, relaxation, mindfulness, acupuncture and journaling. Medications were used to address bowel symptoms as well as symptoms of anxiety and depression. Some participants also used supplements, herbs and probiotics.

### 4.2.2 | Impractical and ineffective interventions

Many of the strategies that participants tried did not consider their unique backgrounds and were considered impractical techniques. Several participants discussed how commonly used strategies required focusing on and evaluating their symptoms. For some, this practice of tracking symptoms led to unhealthy rumination on the symptom experience. Likewise, participants noted similar challenges in interventions containing mindfulness, yoga and relaxation.

Mindfulness does not help. I'll think about it walking outside. My mind will just ... it's a record player, just go over, and over, and over again, so I have to be very distracted. Thinking about it makes it worse. So, I tried the mindfulness or the deep breathing, but then I think about everything that hurts in the body when I do that.

(Participant 1, female, severe anxiety and depression)

All participants who had tried the low FODMAP diet discussed it being an ineffective diet for them. Despite identifying the low FODMAP diet as ineffective, some found the low FODMAP diet allowed them to identify trigger foods, such as garlic and onion, or found that continuing the gluten-free bread and lactose-free milk were beneficial. Overall, participants expressed disappointment in the low FODMAP diet's ineffective treatment of their symptoms, discussing its burdensome and complex restrictive nature as significant barriers to adherence.

I've done the low FODMAP diet and the only thing I've stuck to since on the Low FODMAP diet is the gluten-free bread and the lactose-free milk because I just felt they assaulted me, you know? ... And when I did the reversal, it didn't make any difference either, you know? I was no better and I was no worse by doing it. I just wanted to because actually, I thought that was going to be the solution.

(Participant 3, male, severe anxiety, moderately severe depression)

Another challenge was interventions that did not seem to be designed for participants' routines, preferences and constraints. Interventions and strategies that required tracking in the moment were difficult for those who did not have phones or paper nearby throughout the day. One participant discussed how doing breathing exercises every hour was challenging while working in a retail environment.

"Well, at the time I was working retail and it'd be like, every hour stop and do this...And then throughout the day it had different things to do throughout the day and it just wasn't realistic for my life at that time. It just wouldn't have worked. And then it said stretch or walk around every hour or something. I'm like, I couldn't do that."

(Participant 2, female, mild anxiety, moderately severe depression)

#### 4.2.3 | 'What haven't I tried?'—Trying multiple interventions

Impractical and/or ineffective interventions coupled with continued symptoms led participants to try multiple interventions. Thus, there

was no one-size-fits-all approach to management for participants with IBS and symptoms of anxiety and/or depression since no strategy was effective for all people. Almost all participants reported trying and failing multiple interventions to find something efficacious for them. Many participants independently identified strategies by seeking out information on the Internet without medical oversight.

Just Google and all those blogs that tell you one thing and the other. I just fumbled around in the dark for a long time. I think I did have one of those, "Is this FODMAP safe?" apps and things. I don't know. It's just a really slippery slope. You can just open your phone or Instagram or the internet and there are a million people with a million different stories and suggestions. I just followed their advice instead of trained professionals.

(Participant 10, female, severe anxiety and depression)

Some participants felt alone in the trial-and-error process and became frustrated when things were not working. In response to being asked about what other strategies a participant had used to manage symptoms, participant 10 stated: 'It's like "what haven't I tried?"' Several participants discussed feeling there was no solution to successfully managing their IBS symptoms. For some, this indicated a sense of acceptance of their disorder, whereas for others, it was a sense of resignation.

I just crossed my fingers most of the time, to be honest with you. I never really know.

(Participant 6, female, mild anxiety, moderate depression)

Through the process of trying multiple interventions, participants did identify a few interventions such as monitoring trigger food and physical therapy that were described as effective in managing symptoms. Participants were able to integrate these strategies into their life by creating rules for which foods they could eat or integrating exercises during periods of higher pain. In other words, participants developed individualized approaches to integrating strategies into their daily lives.

#### 4.3 | Challenges with healthcare professionals supporting symptom management

Many participants had challenges in receiving a diagnosis, guidance and treatment to address their IBS. Rather than receiving support from healthcare professionals, participants mentioned being confused and receiving blanket advice that was not tailored to their life (e.g. a yoga teacher being advised to get more exercise to manage their IBS). Despite healthcare professionals providing food-related education (i.e. trigger foods, low FODMAP diet), participants sought effective and accommodating food-related interventions supervised

by a dietitian. Especially for individuals with a current or history of disordered eating attitudes and behaviours, restrictive diets as well as food tracking, without the supervision of a dietician, resulted in exacerbation of disordered eating symptoms. Findings related to disordered eating attitudes and behaviours were emergent from the data as some participants disclosed a history of eating disorders. We developed two sub-themes regarding negative interactions with healthcare professionals and a lack of nutritional expertise and support.

#### 4.3.1 | Negative interactions with healthcare professionals

Participants report incidences in which healthcare providers did not take their IBS symptoms seriously. Furthermore, some healthcare providers would inaccurately attribute their symptoms to other health conditions, particularly mental health conditions. Participants felt dismissed and treated as though they were a 'hypochondriac' in the eyes of healthcare providers.

Not having people believe me because it's subjective and any type of objective test they try to take will not prove my symptoms. So, people not believing me or blaming mental health for the cause of it.

(Participant 1, female, severe anxiety and depression)

Many participants recall having their IBS symptoms begin during their mid-teens and young adult years. During their journey to diagnosis, many felt their health concerns were invalidated despite the participants stating that this was not their baseline. At times, there was conflict between the participant's concerns regarding their IBS symptoms and their perceived wellness by healthcare professionals. For instance, subjective symptom reports by participants did not hold weight against objective medical findings when interacting with healthcare professionals. One participant was told by a healthcare professional that their IBS symptoms were 'normal', as a young female.

I told my nurse practitioner about it probably... I see her as my main doctor just because it's so much harder to get in to see my doctor, and she knows all of my things. And so, she's the one I regularly see. But I'd mentioned it to her probably at the beginning of my treatment, or maybe a little earlier. And she... it was kind of invalidating because she was like, "Well a lot of young women have these symptoms. It's just normal." And I was like, "Are you sure? Okay. I guess this is fine."

(Participant 11, female, moderate anxiety, mild depression)

For several participants, the message that was given by healthcare professionals lacked empathy and failed to support patients in finding

a diagnosis and managing their symptoms. When discussing the messages given by healthcare professionals, participants described providers using phrases such as, 'It'll clear up eventually', 'I don't know' and 'It's all in your head'. One participant relayed frustration at healthcare professionals seemingly giving up on identifying the root of the problem, having been told that there was no clear diagnosis, and they should learn to accept their condition as-is.

Then I just got so sick of everyone saying, "We don't really know what's wrong. We can't point this out on a test, so you're just going to have to live with it."

(Participant 10, female, severe anxiety and depression)

The inadequacies of healthcare professionals could be a contributor to participants reporting a long delay, even years, before obtaining a diagnosis. Additionally, it can take multiple attempts and overcoming many hurdles to receive healthcare treatment for IBS. A delay in diagnosis for IBS could be due to requiring multiple tests before diagnosis, such as CT scans, upper endoscopies and allergy testing. Not only are these procedures time-intensive and expensive, but they also do not always come back as 'abnormal' for persons with IBS.

And so, there was a lot of testing that I had. Oh gosh, they did an upper endoscopy. They did a bunch of tests basically to try to rule out other things. And so finally they said that it was IBS. And so, I've gotten some scans and things like that.

(Participant 7, female, severe anxiety, mild depression)

#### 4.3.2 | Lack of nutritional expertise and support

Many participants reported modifying their diet to manage their IBS symptoms. However, even after their diagnosis with IBS, several participants had difficulty accessing a dietitian and finding dietary guidance to alleviate their symptoms.

I haven't worked with a dietitian. My university has like a dietician at our health center. They're super booked. So, I haven't been able to get in to see a dietitian.

(Participant 7, female, severe anxiety, mild depression)

Without a dietitian, some participants relied on the nutritional information they received from healthcare providers who did not provide specialized or tailored nutritional education. Much of this information was left to the individuals to interpret and apply in their daily lives. Two participants navigated the dietary information from physicians on their own, and one participant's symptoms worsened when attempting to follow the guidance from multiple physicians on

fiber intake, whereas another discussed receiving a handout on the low FODMAP diet.

So, in the beginning when I would go to doctors, they'd be like, "Okay, eat more fiber." And I believe them. I recognize that eating more fiber's a good thing, but without knowing how much of fiber was in my diet or having any kind of understanding of that, what I ended up doing was overeating fiber, and it became a trigger.

(Participant 9, female, mild anxiety, moderately severe depression)

The dairy limitation was kind of a mixture of the doctor recommending it, but that hasn't been guided in any way. Like she gave me like a, here's a sheet on what FODMAPs are kind of thing. So, I was on me to like look up those things. Like fiber, again, there was like a, I don't know, a handout of like, fiber's good or whatever, but it wasn't very helpful or instructional. So other than that, it's just been me looking up things.

(Participant 7, female, severe anxiety, mild depression)

Participants discussed diet broadly and it was often not clear if the diet was being used to identify trigger foods or for ongoing management after identifying triggers.

Not only is restricting certain foods difficult for individuals on a low FODMAP diet, but also the constant tracking of consumed foods further added to the burden of this diet for individuals with IBS and symptoms of anxiety and/or depression. The need to continuously monitor their food intake resulted in participants being overwhelmed with thoughts of food. An underlying thought process predicated on what foods not to eat and obsessing about food, for some, became all-consuming and translated into negative actions, such as food restriction and avoidance.

Interviewer: What made it [the Low FODMAP diet] difficult? Participant: It's the constant tracking. For me personally, being like, "Okay, I'm going to eat ... Okay, this dish is going to need how many of each of the different types of ..." What are they? I forget now. Whatever. But is this going to be for me, or is this too much? (Participant 9, female, mild anxiety, moderately severe depression)

Participants had a strong desire to obtain dietary supervision from a dietician but were often unable to find a dietician or obtain an appointment due to their demand. Participants who were able to work with a dietician discussed the benefits of receiving expertise to ensure they were receiving adequate caloric intake and nutrients, as well as worked to create a lifestyle diet that was both feasible and reasonable.

Additionally, dieticians were able to provide tailored and individualized support such as holistic guidance on food tracking.

It wasn't until I entered treatment for my anorexia that I was actually supervised by a proper dietician. She was just like, "This is crazy, what you're doing. You have to actually eat food. Enough of it and a variety of it. If you don't, you'll never feel better in any way." Yeah. I feel like she was the first doctor who actually suggested that ... Who suggested a more reasonable approach to eating that took all of my symptoms into consideration instead of looking at me through a tiny microscope.

(Participant 10, female, severe anxiety and depression)

Several participants disclosed having a history of an eating disorder. The negative impacts of restrictive self-dieting without supervision from a dietitian were exacerbated for participants who had a history of disordered eating behaviours and attitudes. For these participants, navigating diets proposed by providers resulted in a slippery slope to further food restriction and even a relapse of disordered eating behaviours. In the context of disordered eating behaviours and attitudes, the complexities of the low FODMAP diet coupled with a lack of supervision from healthcare providers may have led to a hyper-restrictive version of the low FODMAP diet. This is primarily a risk when patients do not understand the temporary nature of the low FODMAP diet and continue it past its intended use.

It was just a passing recommendation from a ... I think it was a GI doctor. It could have just been my GP, but it didn't help me at all. I didn't really get the memo that that's a diagnostic diet. That's not a lifestyle diet. I just went on and on and on and on, basically eating nothing. It put me in really, really bad shape.

(Participant 10, female, severe anxiety and depression)

Participants with disordered eating behaviours and attitudes also discussed the complex relationship between IBS, anxiety/depression and disordered eating. IBS symptoms are related to the ways participants view their own body and eating in general. For one participant, their body image was the most frustrating part of IBS as bloating changed the way their body looks.

I would say the effect that it has on my body image, which is actually a really interesting thing ... it was really difficult because it was like well, I'm trying to feed my body and give it what it needs. But it's like it doesn't even want me to... it's also bloating if I get stomach pain, too. It not only makes it difficult to dance, but it also affects the way your body looks obviously.

(Participant 11, female, moderate anxiety, mild depression)

## 5 | DISCUSSION

The purpose of this qualitative study was to understand the experiences and needs of symptom management among individuals with IBS and concurrent symptoms of anxiety and/or depression. Overall, participants discussed how IBS negatively impacted their physical and mental well-being, with a bidirectional relationship between physical symptoms and mental health. Symptom management required a trial-and-error approach, with several barriers impeding effective clinical management including negative interactions with healthcare providers and lack of nutritional expertise. Throughout each of the themes, participants highlighted the necessity of an individualized approach to symptom management.

This study specifically focused on the needs of participants who have IBS and concurrent symptoms of anxiety and/or depression. Most participants discussed a bidirectional relationship between physical symptoms and anxiety/depression and how gastrointestinal and psychological symptoms impacted activities of daily living. A recent report focusing on the relationship between IBS and perceptions of physical and mental health found that among individuals with IBS, mental health but not physical health, interfered with daily activities (Kutschke et al., 2022). Among individuals with IBS, psychosocial and somatic symptoms may have a greater impact on quality of life than IBS symptoms (Addante et al., 2019; Kutschke et al., 2022). Although participants in this study identified that both physical and mental health as well as their combination influence activities of daily living. This supports the need for healthcare providers to not only provide clinical guidance for the management of gastrointestinal symptoms, but to also counsel on the interpersonal and mental health-related impacts through shared decision-making processes.

Management of IBS concurrently with mental health conditions is difficult to do without clear guidance and oversight from healthcare professionals. Despite this, many participants interviewed relayed feeling a lack of support for the management of their IBS symptoms after diagnosis, resorting to independently curating information from the Internet to aid their ability to self-manage their symptoms. The importance of support in the context of symptom management aligns with the social cure perspective which highlights that social groups can promote health but only if people feel a sense of belonging with the group (Wakefield et al., 2022). Although there is no cure for IBS currently, many studies aim at improving quality of life, symptom severity and self-efficacy in managing IBS through interventions designed to support self-management behaviours (Cong et al., 2018). While a plethora of self-management interventions have been developed to address this population (including Internet-based strategies, self-training booklets, individual and groups therapies, cognitive behavioural therapy and exercise-based therapy), it is not clear the level of individualization provided by these interventions (Chen, Kamp, et al., 2022; Cong et al., 2018). Additionally, the process of introducing patients to self-management tools, such as the importance of supportive interactions of providers and nurses in particular including empathy and validating patient experiences, remains relatively unexplored in the literature.

Multiple attempts at various interventions were also reported by participants. These repeated trial-and-error approaches were commonly met with feelings of frustration, confusion and at times hopelessness at the expense of the participant. Refractory IBS, or treatment-resistant IBS, can be a common reason for trying multiple approaches for symptom management and may result in additional emotional burden on the patient throughout this process (Sibelli et al., 2017, 2018). CBT has been identified as an effective method of mitigating the negative psychosocial and somatic impacts of IBS symptoms (Lackner et al., 2018). However, these therapeutic strategies are rarely used in clinical applications despite growing evidence of their utility (Lackner et al., 2018). Various tools or services could be designed to support patients as they navigate the trial-and-error process of symptom management, with a consideration for providing emotional support throughout the process.

Diet is a key element in IBS treatment and symptom management (Chey et al., 2022). The low FODMAP diet is effective at reducing IBS symptoms and improving quality of life and is included as a best practice advice in the American Gastroenterology Association Clinical Practice Guidelines for IBS (Chey et al., 2022; van Lanen et al., 2021). Over half of the participants in this study attempted to identify trigger foods and/or change their diets to mitigate symptoms. However, participants were unable to find a dietitian or obtain appointments. This aligns with previous research where over 50% of individuals with IBS were prescribed a specific diet by a healthcare professional, but only about 5% received a referral to a registered dietitian nutritionist (RDN) (Adams & Broughton, 2019).

Participants identified that the low FODMAP diet was ineffective in managing their long-term symptoms. Yet, participants were able to identify trigger foods through trying the low FODMAP diet. In research studies examining the low FODMAP diet, participants receive access to guidance from nutritionists including personalized and tailored nutrition plans (van Lanen et al., 2021). Whereas, implementation of the low FODMAP diet in clinical practice often involves general information from primary care practitioners and gastroenterologists which is perceived by patients as simplistic with little personalization (Trott et al., 2019). For participants in our study, it is not clear if the failure of the low FODMAP diet was due to the diet itself, misunderstanding of the diet or diet phases, anxiety and/or depression leading to hyper-focusing on dietary attributes or to the lack of nutritional support to implement the diet. In particular, some participants were not clear that the low FODMAP diet had several phases—elimination, reintroduction and personalization—which each can present unique challenges for patients and should be individualized by a dietitian (Whelan et al., 2018).

The complexity of the low FODMAP diet can be further exacerbated if individual characteristics are not considered. For instance, adherence to the low FODMAP diet has been associated with a higher education level (Gearry et al., 2009). Thus, when recommending diets for IBS, such as the low FODMAP diet, healthcare providers should consider how the health literacy of the patient as well as food insecurity might limit access to the types of foods available to patients. Practitioners must also consider, prior to prescribing

specific regimented diets to IBS patients, such as the low FODMAP, the appropriateness of the patient to be placed on a strict nutritional diet. For instance, it has been suggested that aspects of the low-FODMAP diet lend themselves to increased risk of eating disorder exacerbation, including rumination over food choices, strict tracking of food for identification of triggers, heightened awareness of one's body (may impact body dysmorphia) and restriction of food options (Burton Murray et al., 2022). Concerningly, while several participants reported a history of eating disorders, none were referred to a nutritional specialist, such as an RDN, on being told to follow a FODMAP diet. One participant stated that it was not until she was seen by a dietitian for her eating disorder that she actually received proper nutritional guidance in addressing her IBS symptoms. While not all individuals who have disordered eating behaviours (e.g. rumination over food choices) develop an eating disorder meeting DSM-V criteria, it is imperative that appropriate individualized treatment plans are developed based on the patient's health history and, where appropriate, consultations with other providers (e.g. psychologists, RDNs, eating disorder specialists) are included in a patient's treatment course for their safety (Scarлата et al., 2020).

## 5.1 | Limitations

Despite the important findings regarding symptom management of individuals with IBS and symptoms of anxiety and/or depression, there are several limitations that should be addressed. Participants were recruited and interviewed during the COVID-19 pandemic which might influence their perceptions and experiences with symptom management. Additionally, online recruitment was used which might have led to a sample that is not reflective of the general population. It could be that individuals who achieved more effective management of their disease were less likely to participate in this study. All the participants in this study were able to read and write English; thus, their experiences might not include the unique challenges related to language barriers and communication. Lastly, our sample was mostly female (75%) and had IBS for greater than 10 years which might influence the lived experiences with IBS (van Kessel et al., 2021).

## 6 | CONCLUSION

This article highlights the trial-and-error approach that patients with IBS and symptoms of anxiety and/or depression experienced to manage their symptoms. Our findings have several important implications for nurses and other healthcare professionals caring for patients with IBS and symptoms of anxiety and/or depression. First, nurses and other healthcare professionals should begin with a comprehensive assessment to evaluate patients' previous experiences with symptom management interventions as well as important past medical history including symptoms of anxiety and/or depression and current or history of disordered eating attitudes

and behaviours. The development of a therapeutic relationship is particularly important as many participants felt overlooked by the healthcare system. As the most common healthcare professional worldwide, nurses are in a unique position to promote therapeutic relationships with patients. Second, when providing information regarding symptom management interventions, particularly dietary interventions, provide participant referrals to a registered dietitian nutrition (RDN) or mental health professionals. If providing hand-outs regarding interventions, use evidence-based teaching methods such as the teach-back method to assess for participant comprehension. Finally, consider each interaction an opportunity to implement a personalized healthcare approach to IBS management, considering the intersectionality of patient identities which may influence their engagement with the healthcare system and symptom management.

## AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and met at least one of the following criteria (recommended by the ICMJE\*):

1. substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
2. drafting the article or revising it critically for important intellectual content.

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The authors have no conflicts of interest to disclose.

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## PATIENT OR PUBLIC CONTRIBUTION

No patient or public involvement.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - QUALITATIVE**

# How nurses use National Early Warning Score and Individual Early Warning Score to support their patient risk assessment practice: A fieldwork study

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## Abstract

**Aim:** To explore and describe how the National Early Warning Score (NEWS) and Individual Early Warning Score (I-EWS) are used and how they support nurses' patient risk assessment practice.

**Design:** A qualitative observational fieldwork study drawing on ethnographical principles was performed in six hospitals in two regions of Denmark in 2019.

**Methods:** Data were generated from participant observations and informal interviews with 32 nurses across 15 different wards in the hospitals. A total of 180 h of participant observation was performed. The observations lasted between 1.5 and 8 h and were conducted during day or evening shifts.

**Results:** NEWS and I-EWS supported nurses' observations of patients, providing useful knowledge for planning patient care, and prompting critical thinking. However, the risk assessment task was sometimes delegated to less experienced staff members, such as nursing students and healthcare assistants. The Early Warning Score (EWS) systems were often adapted by nurses according to contextual aspects, such as the culture of the speciality in which the nurses worked and their levels of competency. In

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some situations, I-EWS had the effect of enhancing nurse autonomy and responsibility for decision-making in relation to patient care.

**Conclusions:** EWS systems support nurses' patient risk assessment practice, providing useful information. I-EWS makes it easier to factor the heterogeneity of patients and the clinical situation into the risk assessments. The delegation of risk assessment to other, less experienced staff members pose a risk to patient safety, which needs to be addressed in the ongoing debate regarding the shortage of nurses.

**Impact:** The findings of this study can help ward nurses, hospital managers and policy-makers to develop and improve strategies for improved person-centred nursing care.

#### KEYWORDS

decision-making, early warning score, ethnography, nursing, observation practice, participant observation, qualitative research, risk assessment, track and trigger system

## 1 | INTRODUCTION

The National Early Warning Score (NEWS) is a track-and-trigger system where patients' vital signs are measured a minimum of twice a day and an aggregated score from 0 to 20 is calculated. Depending on the value of the aggregated score (for which a high score indicates patient deterioration), an escalation protocol dictates the patient monitoring interval, as well as actions to be taken for preventing patient deterioration (Royal College of Physicians, 2017). The NEWS provides a score for risk of deterioration for use in the patient risk assessment. Early Warning Score (EWS) systems are part of nurses' patient risk assessment practice, which includes risk assessment tasks and the nurses' clinical judgement. EWS systems can contribute useful knowledge about the patients' physiological condition and risk of deterioration. Thus, the detection of deterioration is complex, and nurses' clinical judgement is an essential part of the risk assessment of patients. However, Langkjaer et al. (2021) found that neither nurses' clinical judgement nor EWS systems are by themselves sufficient for identifying deteriorating patients.

## 2 | BACKGROUND

Since 2012, the NEWS has formed part of nurses' patient risk assessment practice in the eastern part of Denmark. Before the implementation of the NEWS, a study estimated the incidence, staff awareness and subsequent mortality of patients with abnormal vital signs on general wards and found that one out of five patients developed abnormal vital signs during hospitalization and that these patients had a threefold-increased 30-day mortality. However, for half of the patients, the nurses were not aware of the presence of abnormal vital signs (Fuhrmann et al., 2008).

The NEWS was implemented to standardize clinical monitoring and to serve as an aid to nurses' clinical assessment as well as decision-making (Royal College of Physicians, 2017). Several studies have investigated nurses' perceptions of and reactions to the

implementation of EWS systems. One study revealed tensions between using a standardized system and relying on clinical judgement, as well as tensions related to rules and compliance (Jensen et al., 2019a). Furthermore, clinical relevance and meaningfulness were identified as being crucial to the implementation process and high compliance with the system (Bunkenborg et al., 2016). While EWS systems have been widely adopted in healthcare systems all over the world, issues involved in the timely recognition of and response to patient deterioration remain complex (Jensen et al., 2018). Patient safety relies to some extent on nurses having the appropriate knowledge and skills for early recognition, reporting and response to patient deterioration, and adverse events may be avoided if these competencies are present. NEWS provides nurses with quantitative knowledge of the patients' clinical condition, but several studies have found a risk of nurses' and physicians' over-reliance on NEWS and an underestimation of nurses' clinical assessment and intuition (Grant, 2019; Jensen et al., 2018). The underestimation of nurses' clinical assessment and intuition may impact nurses' patient risk assessment practice and be one of the reasons why poor compliance with the NEWS has been found (Credland et al., 2018).

A standardized system like NEWS does not differentiate between different types of diseases or the patient's individual physiological response, which is why it has been referred to as a "one-size-fits-all"-system (Grant, 2018). Therefore, the Individual Early Warning Score (I-EWS) system was designed in 2018 as an attempt to develop a standardized assessment system that included a clinical assessment. Studies have found that a structured clinical assessment can provide important information in the recognition and reporting of and response to patient deterioration (Hasselbalch et al., 2019; Iversen et al., 2019). I-EWS is based on NEWS, which means that nurses record patients' vital signs systematically and follow the NEWS escalation protocol for rescoring. The patients are still assigned an aggregated score from 0 to 20, but with I-EWS, nurses can adjust the score based on their clinical assessment of the individual patient. The score can be modified in the electronic health record with a maximum of -4 or + 6 points. The nurses can continue



with the initial score and simply make a modification of 0 (Nielsen et al., 2022). The criteria and rules of such modifications differed between the wards depending on what the ward management had decided. Prior to the implementation of I-EWS, local research staff, representing all participating wards, attended teaching sessions.

A cluster-randomized, multicentre study including 90,964 patients has investigated if I-EWS performs as well as NEWS regarding clinical outcomes and the use of resources (Nielsen et al., 2022). The study found that I-EWS performed as well as NEWS in terms of all-cause mortality at 30 days. However, the study also revealed increased 30-day mortality in surgical patients. Furthermore, a minimal reduction in routine measurements was found with the I-EWS, which, in the long term, could lead to a reduction of resources spent (Nielsen et al., 2022). Nurses' experiences and perceptions of using I-EWS and NEWS are important reasons why a focus group study has explored this topic (Langkjaer et al., 2021). This study found that EWS systems are meaningful to nurses, but the detection of deterioration is complex. Nurses' clinical judgement is an essential part of their patient risk assessment practice. However, Langkjaer et al. (2021) argue that neither nurses' clinical judgement nor EWS systems are by themselves sufficient for identifying deteriorating patients; it is the interaction between the two that supports the identification of patient deterioration. Despite the results from these studies, there is still a need to clarify how NEWS and I-EWS influence and support nurses' patient risk assessment practice. It is therefore important to explore how nurses use the NEWS and I-EWS and how these systems support their patient risk assessment practice.

### 3 | THE STUDY

#### 3.1 | Aim

The present study aims to explore how nurses use EWS systems with and without the opportunity to adjust the score based on clinical assessment, and how these systems support nurses' patient risk assessment practice.

#### 3.2 | Design

A qualitative fieldwork study using participant observation was conducted. Participant observation allowed an investigation of nurses' clinical practices while using I-EWS and NEWS. Furthermore, this research design enabled an exploration of nurses' knowledge and behaviour in a cultural context (Spradley, 1980).

#### 3.3 | Sample, participants and settings

Purposeful sampling was used to conduct broad and in-depth observations, and 32 nurses were recruited (Malterud et al., 2016). The nurses were recruited from 15 different wards in six regional and

TABLE 1 Participant characteristics (N = 32)

	N (%)
Age (years)	
20–29	20 (62.5)
30–39	7 (21.9)
40–49	1 (3.1)
50–59	4 (12.5)
Gender	
Female	30 (93.7)
Male	2 (6.3)
Experience (years)	
<1	1 (3.12)
1–4	20 (62.5)
5–10	4 (12.5)
11–20	4 (12.5)
>20	3 (9.38)
Departments	
Medical	17 (53.1)
Surgical	9 (28.1)
Emergency	6 (18.8)

university hospitals in the Capital Region of Denmark and Region Zealand, Denmark. The nurses were recruited through local research staff, and to ensure an adequate sample size, the recruitment was carried out based on 'information power' (Malterud et al., 2016). Information power is related to the following: whether the aim of the study is broad or narrow; the specificity of the participants' experiences and knowledge; the established theory used; the quality of dialogue; and the analysis strategy (Malterud et al., 2016). The participant characteristics are shown in Table 1.

#### 3.4 | Data collection

A total of 180 h of participant observation were conducted from February to August 2019. During participant observation, the researcher engaged with the research setting and the nurses were aware that they were observed (Spradley, 1980). The observations were conducted by the first author, and each nurse was observed one time. The observations lasted between 1.5 and 8 h, during day or evening shifts. Inspired by Spradley (1980), three different forms of observation were used. For the first form, the focus of the observations was descriptive and open to what was seen, heard and observed when the nurses did the NEWS/I-EWS scoring. For the second, the observations were more structured and focused on aspects and steps related to NEWS/I-EWS scoring. Finally, for the third form, the observations were selective and focused on the contrasting aspects of NEWS/I-EWS scoring (Spradley, 1980). The three forms of observation were often used in a dynamic interaction during the same observation. Examples of the focus of observations are illustrated in Table 2. During the observations, informal interviews



were conducted with follow-up questions to help ensure an understanding of what was observed. Field notes were made during the observations and further expansions, as well as transcription, were completed immediately after each observation. The field notes were written as verbatim and concretely as possible (Spradley, 1980).

### 3.5 | Ethical considerations

Informed consent was obtained from all participants before inclusion. The study was presented to the Regional Ethics Committee, and according to Danish law, no formal approval was needed (J. no. H-18053090). All data were anonymized and carefully stored in a secure place approved by the Danish Data Protection Agency (J. no. HGH-2017-116, I-suite no. 06030) and in accordance with the General Data Protection Regulation (GDPR).

### 3.6 | Data analysis

An ethnographic analysis was performed based on Hammersley and Atkinson (2007). The analysis started with a thorough reading of the field notes and an initial coding. Based on the initial coding, patterns, concepts and categories were identified. Patterns, concepts and categories were then organized and processed until new categories emerged. The analysis was inductive, which allowed findings to emerge from central and substantial themes in the raw data. To secure trustworthiness in the empirical data, descriptions and quotations from the observations are presented in the findings. The analysis was a back-and-forth process between the various steps of analysis, and thus not a linear process. Furthermore, there was a dialectic interaction between the gathering of empirical data and the data analysis of this data, that is, analysis began when the first author identified the area of research, before intensifying during participant observations and then progressing to in-depth analysis after the fieldwork had been completed (Hammersley & Atkinson, 2007). Researcher triangulation was carried out when performing the analysis. The first two authors made the initial analysis, which was then discussed with the third and last authors until an agreement was reached.

### 3.7 | Rigour

All phases, from designing the study to analysis and conclusion, were conducted through collaboration and discussion within the research

group. Researcher triangulation contributed to the credibility, confirmability and validation of the data collection and analysis because of the different credentials in the author group. All of the authors are either nurses or physicians and have insider knowledge about the field. This can make it easier to gain access to the field, but it can also mean that some elements are taken for granted and so not observed in-depth (Wadel et al., 2020). The first author, who conducted the observations, is a registered nurse with a master's degree and is currently a PhD student. She was unfamiliar with the wards and different practices where the data collection took place, which allowed the researcher to be open-minded and reflexive during observations. To prevent behavioural changes among the observed nurses it was emphasized that the first author was a novice researcher interested in learning about the patient risk assessment practice. Field notes were written as verbatim and concretely as possible to maintain transparency in the observations. Furthermore, the researcher's own reflections were challenged by writing down thoughts and discussing them within the research group.

## 4 | FINDINGS

The aim of this study was to explore how nurses use the NEWS and I-EWS and how these systems support their patient risk assessment practice. Three categories emerged during analysis: (1) Effects on nursing practices, (2) NEWS requires local adaptations and (3) I-EWS affects nurses' professionalism.

### 4.1 | Effects on nursing practices

It was observed that nurses started their shift by collecting information from the electronic health record to gain an overview of the patients he/she was appointed. The nurses collected different information about the patient, including the current NEWS score, former scores and time points for the next risk assessment, as dictated by the escalation protocol. All this information was noted on a piece of paper, which the nurse kept in his/her pocket:

The nurse starts her shift by getting an overview of her patients via the electronic health record. She looks at blood samples, medications, diagnoses and the current NEWS score, former scores, and when the next risk assessment is scheduled. She writes this down on a piece of paper, which she keeps in her

TABLE 2 Focus of observation and types of questions

Kinds of observations	Descriptive observation	Focused observation	Selective observation
Type of questions	Descriptive	Structural	Contrast
Focus	Open	Ethnographic	Narrow
Kind of questions	Where are vital signs measured?	What are the steps in an EWS measurement?	How are the measurements different from each other?

pocket. (Fieldnote no. 8, Department of Pulmonary Diseases)

Information about the NEWS score, former scores and when the next risk assessment was scheduled seemed to guide the nurses in planning nursing care for the individual patient. As an example, based on the electronic health record, a nurse noted that she had to test the patient's need for oxygen supply to determine if the patient was ready for discharge. However, the nurse expressed that even though this overview provided information on the patient's status, it had to be validated by seeing the patient:

The nurse says that the electronic health record does not really say anything. I have to go out and see my patient to form a real impression of how they are. (Nurse no. 3, Department of Emergency Medicine)

This validation would often happen when the nurse measured the vital signs, since it created an opportunity to gain knowledge, not only about the physiological condition but also about other relevant aspects. As the following observation emphasized, while measuring the blood pressure, information on how the patient was feeling, how he had slept and his level of pain were explored:

While the blood pressure is being measured, the nurse asks how the patient is doing after his surgery. The patient says that he has slept badly and is in pain. The nurse, therefore, offers the patient extra painkillers. (Fieldnote no. 6, Department of Orthopaedic Surgery)

A nurse expressed that the NEWS was beneficial because the system and the escalation protocol created a framework that guided the risk assessment of the patients. However, a delegation of the risk assessment to less experienced staff members, such as nursing students or healthcare assistants, was observed when the nurses were busy. In some wards, it also seemed to be an integrated part of the culture that nursing students or healthcare assistants were appointed to this task:

A nursing student is at work, and there is a note on which the nurses can write assignments for the nursing student. The nurse writes the next risk assessment of one of his patients on the note, and then the nursing student is going to measure the vital signs instead of the nurse. (Fieldnote no. 2, Department of Emergency Medicine)

During the observations, it became clear that using NEWS was generally perceived by the nurses as being of benefit; the system contributed useful knowledge about the patients' overall physiological condition and risk of deterioration, which the nurses used to plan their nursing care. However, when the risk assessment was delegated to

nursing students or healthcare assistants, essential information about the patient's condition might be overlooked which could affect the detection of deterioration.

## 4.2 | NEWS requires local adaptations

The way in which NEWS was used for structured observation and scoring of patients' vital signs seemed to be affected by culture, context and the nurses' competencies. In some wards, nurses followed the escalation protocol punctually, while in other wards, nurses had specific hours during which they measured the vital signs. Different cultures of using the EWS systems seemed to be reflected in nurses' clinical practices. Some nurses attached higher values to some of the vital signs than others. However, this valuing of specific vital signs was professionally justified and based on the nurses' knowledge of the patients. For example, for patients with haematology diseases, prevention of infections is especially crucial, and therefore extra attention was paid to the score for fever.

The nurse measures a patient's vital signs and asks if he feels like having a fever. The nurse says that they are very aware of fever in this ward in relation to preventing infections. (Fieldnote no. 33, Department of Hematology)

Different strategies were observed for how the nurses customized the NEWS and the escalation protocol according to the context in which they were using them. The nurses tended to measure vital signs when they found them relevant based on their knowledge of the individual patient and his/her situation, and often the nurses measured the vital signs more than the minimum number of scorings dictated by the escalation protocol. This was observed as being used in the morning to gain a status of the patient's condition, and if something about a patient worried the nurse. It was also observed how nurses prioritized other nursing tasks, such as helping patients' toileting, above measuring vital signs. Prioritizing other nursing tasks was based on the nurses' assessments and reflections on the situation since following the escalation protocol punctually did not always make sense:

The nurse uses the scoring system as a working tool, and she is fully aware that she does not always follow the escalation protocol and says that it just does not always make sense to follow it. (Fieldnote no. 3, Department of Emergency Medicine)

The nurses' competencies to act on patient deterioration were seen to depend on which ward they worked in, the culture and the patient group. It was also seen to depend on the individual nurse. If the nurses were used to handling acute patients and situations, they seemed not to fear patients having a high score. This influenced their use of the EWS system in relation to whether they acted on the high score by themselves or if they involved the physician:

Several of the hospitalized patients on the ward have high NEWS scores. When asked, the nurse said that

they are used to dealing with acute conditions or situations, and they are not nervous about patient deterioration. (Fieldnote no. 11, Department of Neurology)

Cultural influences, the current context and the nurses' competencies were observed to affect the observation practice. NEWS requires structured observation and does not take these elements into account. These elements play an essential role in the risk assessment of patients, and therefore the nurses needed to customize NEWS to their context.

### 4.3 | I-EWS affects nurses' professionalism

The opportunity to modify the score when using the I-EWS was observed to have an impact on nurses' patient risk assessment practice and the frequency with which they conducted patient assessments. The nurses expressed that NEWS and the escalation protocol could be rigid and deprive them of their independence. According to the nurses, I-EWS impacted their patient risk assessment practice, both regarding their sense of autonomy and regarding having an increased responsibility for preventing patient deterioration. The nurses seemed willing to take on the responsibility of adjusting the score based on their extensive knowledge of the patients, regardless of their level of experience:

The nurse has experienced that I-EWS gives freedom and increased responsibility. It is a responsibility that she wants to take, as she is the one being with the patients all the time compared to the physicians. (Nurse no. 3, Department of Emergency Medicine)

I-EWS seemed to trigger critical thinking among nurses, due to the simple fact that it was possible to adjust the score. This critical thinking meant that the nurses paid attention to the single parameters and not only the aggregated score. Hence, the opportunity to adjust gave the nurses an easy and safe way to signal their concerns to both nursing colleagues and to the physician:

The nurse adjusts the score upwards and states that it is an easy and simple way to signal to colleagues and to the physician that she is worried about the patient and that they need to be extra attentive. (Nurse no. 24, Department of Surgery)

During the observation of nurses using I-EWS, it became clear that there still was a close collaboration between nurses and physicians in relation to the patient's condition. However, it seemed like the nurses' reflections and the opportunity to adjust the score had strengthened their decision-making and how often they involved the physician. They did not always follow what the escalation protocol dictated, but based their decisions on their clinical assessment of the patient and the situation:

According to the escalation protocol, the nurse should contact the physician, but the nurse chooses to lower the score by -2 due to the patient's chronic illness. The nurse has experienced that I-EWS has reduced unnecessary calls to the physician. She is very pleased about this, as many of the calls were a waste of resources, and the nurse was frustrated that she had to call, even though she had assessed something else. (Fieldnote no. 18, Department of Gastromedical)

On some wards, no adjustments in scores were made, and I-EWS did not seem to influence the nurses' patient risk assessment practice at all. The nurses expressed that their decisions not to adjust scores were made based on worries of overlooking warning signs if they downgraded the score and not wanting to accept such a responsibility:

The nurse does not want to accept such a responsibility, as he is worried that he overlooks something. The nurse fears that if he adjusts the score and the patient has to be scored later than what the escalation protocol dictates and the patient's condition have worsened, then the nurse would be responsible. (Nurse no. 5, Department of Orthopaedic Surgery)

Some nurses expressed that NEWS and structured observations could support their risk assessment of the patients, albeit most of the nurses stated that the opportunity to adjust the score with I-EWS made it possible to include their clinical assessment. This opportunity seemed to strengthen their professionalism and make it easier for them to factor the heterogeneity of patients and the clinical situation into their risk assessments.

## 5 | DISCUSSION

One main finding of this qualitative observational fieldwork study is that the EWS systems NEWS and I-EWS support nurses' patient risk assessment practice. The introduction of NEWS means that the nurse or another colleague sees the patients at fixed time intervals, which was not necessarily the case before. Nurses gain knowledge about the physiological condition and risk of deterioration, but they also get an opportunity to assess and identify other relevant aspects of the patient's condition while measuring vital signs. This provides a base of knowledge on which they can plan and initiate individualized nursing care. This is in line with other studies reporting that NEWS is perceived as being beneficial and that routine measurements of vital signs create an opportunity for nurses to do an in-depth assessment of the patient (Langkjaer et al., 2021; Mølgaard et al., 2022). Furthermore, focusing on signs and symptoms other than vital signs is valuable because nurses' sense of worry and pattern recognition have been found important in providing information in detecting patient deterioration in early stages (Douw et al., 2016; Romero-Brufau et al., 2019). Therefore, essential information about

the patient's condition, that aids nurses in detecting patient deterioration, risks being lost when delegating the risk assessment to nursing students or healthcare assistants. Several studies have raised concerns regarding delegating the task of risk assessment to less experienced staff members without assurance that they have the competencies needed to identify patient deterioration (Grant, 2019; James et al., 2010). Nursing students and healthcare assistants can take on the role of recognizer and recorder; however, the challenge is that less experienced staff members are often unable to interpret the results. They may not have the training or qualifications to understand the physiology and pathophysiology of the measured vital signs, which can result in the undetected deterioration of patients (Beaumont et al., 2008). Thus, the role of the responder will always be the nurses' responsibility.

The nurses perceive NEWS as beneficial; however, they find it problematic that the EWS system is standardized because the standardization means that culture, context and the individual nurse's competencies are not considered important parts of NEWS. Furthermore, the NEWS is a "one-size-fits-all" system that does not consider the heterogeneity of patients (Grant, 2018). When using the NEWS according to the guidelines, nurses considered it to be rigid. Since the NEWS was first implemented, both nurses and physicians in the study settings have been repeatedly taught to pay attention to high NEWS scores. The value of other data and supplementary knowledge about the patient from nurses' clinical assessments have been less emphasized, resulting in a risk that important signs and symptoms are omitted. The result of this emphasis on NEWS could be an overly task-oriented culture (Grant, 2019). A task-oriented culture potentially influences nurses' patient risk assessment practice and may contribute to nurses feeling limited in practising person-centred care. This is consistent with other studies suggesting that nurses feel responsible for something beyond merely following protocols and reporting their actions and that NEWS should be used alongside the nurses' clinical assessment (Alam et al., 2014; Jensen et al., 2019b).

Using NEWS to risk assess hospitalized patients is a complex process and nurses are faced with a paradox: on one hand, there is this task-oriented, depersonalized and mechanistic approach pushed forward by control-of-care standards, for which practical skill dominates; on the other, however, there is a need for understanding and involving the patient and creating a nurse-patient relationship (Kitson et al., 2014). According to the nurses in this study, I-EWS gave them autonomy and responsibility for their nursing care, and the opportunity to adjust the score called for them to include their clinical assessment when assessing the patients. This opportunity clearly strengthened their professionalism and made it possible for them to factor the heterogeneity of the patients into their risk assessments. This was in line with a study that found that nurses assessed their patients' conditions more accurately when they incorporated their professionalism, competencies and clinical assessment with NEWS (Jensen et al., 2019a). This study argues that the I-EWS can bridge the two sides of the paradox and make it possible for nurses to practice person-centred care while using an EWS system.

This study clearly demonstrates that nurses' use of EWS systems like NEWS and I-EWS supports their patient risk assessment practice. Furthermore, the study clarifies the importance of nurses actively integrating their clinical assessment of the individual patient with the standardized EWS system when identifying and managing patient deterioration. Furthermore, this study highlighted the risk to patient safety of delegating scoring and clinical assessment to students or less skilled staff; a risk that needs to be addressed in the ongoing debate regarding the nursing shortage.

Altogether, the findings of this study can help not only ward nurses but also hospital managers and policymakers to develop and improve strategies for improved person-centred nursing care.

## 6 | LIMITATIONS

The observations were conducted during day and evening shifts, so nurses' use of NEWS and I-EWS during night shifts do not form part of this study. However, most of the risk assessments were done during day and evening shifts, and if nurses talked about an experience with the EWS systems during a night shift, this was included in the field notes (Spradley, 1980).

The nurses who were willing to participate in this study may represent nurses with specific perceptions of EWS systems. To achieve diversity among the participants, we used purposeful sampling when recruiting the nurses (Malterud et al., 2016). The recruitment focused on varying levels of experience, age and gender. Furthermore, 32 nurses from 15 different wards in six different hospitals participated, which helped to ensure a broad variance in beliefs, practices and experiences.

No Patient and Public Involvement (PPI) was carried out for this work because the participant observations were done with nurses. In future research, it would be interesting to involve the patient perspective on being risk assessed with I-EWS and, furthermore, to engage in PPI (e.g., to identify topics and choose the right research question).

## 7 | CONCLUSIONS

EWS systems support nurses' patient risk assessment practice, providing useful knowledge about patients' overall physiological condition, risk of deterioration and other relevant aspects when planning nursing care. The opportunity to adjust the score with I-EWS strengthens the professionalism and makes it easier to factor in the heterogeneity of patients and the clinical situation into the risk assessments. However, risk assessments were sometimes delegated to less experienced staff members, which poses a risk to patient safety and needs to be addressed in the ongoing debate regarding nursing shortages.

## AUTHOR CONTRIBUTIONS

CSL, KB, GB, PBN, KKI, MHB, DGB: Made substantial contributions to conception and design, or acquisition of data, or analysis

and interpretation of data. CSL; KB, GB, PBN, KKI, MHB, DGB: Involved in drafting the manuscript or revising it critically for important intellectual content. CSL; KB, GB, PBN, KKI, MHB, DGB: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. CSL; KB, GB, PBN, KKI, MHB, DGB: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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## CONFLICT OF INTEREST

No conflicts of interest have been declared by the authors.

## PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15547>.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request. All data are in Danish.

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# Women's power in hospital-based nursing: A critical qualitative study

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## Abstract

**Aim:** To understand the factors that affect power in hospital-based nursing and reveal how the female gender affects an individual's ability to feel empowered.

**Design:** Critical qualitative research design.

**Method:** Semi-structured interviews were conducted with nurses working in inpatient hospital settings in Utah and New Mexico. Data were collected from February to March 2022. Interviews were analysed using thematic analysis.

**Results:** Sixteen participants were interviewed. Six themes were identified from the data, four of which related to nurses' power at work, and two of which specifically related to how gender affects a nurse's ability to use power and feel empowered. These themes include supportive leaders, positive unit culture, successful advocacy, personal factors, societal gender roles and sexism.

**Conclusion:** Empowered nurses can revolutionize health care. The themes developed in this study will help nurse leaders and nurses alike increase nurses' ability to use their power and feel empowered in the workplace.

**Impact:** Nurse leaders should strive to be supportive of their nurses and build a positive work environment while also providing consistent consequences for sexist actions of staff. Nurses should take opportunities to advocate for their patients, be autonomous and build their knowledge base to improve empowerment. As nurse leaders and nurses alike work together to improve health care, nurse experience, patient and clinical outcomes will be improved.

**Patient or Public Contribution:** The nurses interviewed for this study contributed their experiences and insights during data collection. Some also contributed rigour to the data analysis process by participating in member checking.

## KEYWORDS

empowerment, nursing management, power, women, work environment

## 1 | INTRODUCTION

Nurses are essential to health, both locally and globally. Nurses provide direct care in peoples' homes and communities, schools, workplaces, hospitals, long-term care facilities, rehabilitation centres, primary care, over the telephone and online. However, increased levels of stress and burnout related to the COVID pandemic and nursing shortage threaten nurses' ability to provide high-quality care (Labrague et al., 2022). Nurse empowerment may provide one effective strategy for leaders seeking to retain and strengthen their staff. Empowering nurses benefits the nursing workforce, improves patient care and enhances organizational outcomes (Fackler et al., 2015; Molina-Mula & Gallo-Estrada, 2020; Woodward, 2020). However, evidence suggests nurses are not sufficiently empowered to actualize their potential to contribute to healthcare systems (McMillan & Perron, 2020). The current literature also fails to adequately explore the systems and structures that can be disempowering to nurses and the role of gender in nurse empowerment. As a result, nurses, nurse leaders and other healthcare professionals do not have the evidence-based guidance necessary to fully empower the nursing workforce. This study sought to understand the factors that affect power in hospital-based nursing and reveal how the female gender affects an individual's ability to feel empowered. We hope that additional work in this area will ultimately emancipate and empower nurses to create more egalitarian healthcare systems that improve health for everyone.

### 1.1 | Background

The word 'power' is a noun, commonly understood as the ability to act, while the word 'empowered' is an adjective describing the quality of having power. Empowered nurses are vital to creating and sustaining a healthy nursing workforce. Empowered nurses have increased job satisfaction (Wählin, 2016) and enhanced critical reflection and communication skills (Van Bogaert et al., 2015). Nurses with power also experience decreased levels of distress and psychological strain, increased perceptions of control at work and enhanced professional development and growth (Wählin, 2016). In contrast, disempowered nurses are less satisfied with their jobs, more susceptible to burnout (Leiter & Laschinger, 2006) and depersonalization (Manojlovich, 2007), and experience increased turnover (Valizadeh et al., 2016).

Nurses who are empowered can provide high-quality patient care. Nurses use their power to advocate for patients, improve patient care and create relationships with team members and clients alike (Fackler et al., 2015; Molina-Mula & Gallo-Estrada, 2020), which have been shown to reduce the length of hospital stays and improve quality of care (Molina-Mula & Gallo-Estrada, 2020). Empowered nurses may be more willing to give feedback about quality improvement ideas and engage in organizational changes, which may improve patient outcomes (Kuokkanen & Leino-Kilpi, 2001). Empowered nurses also improve overall patient safety culture (Amiri et al., 2018), which contributes to improved patient outcomes and quality of care.

Nurses who have power can improve organizational outcomes. Empowered nurses may use their power to implement organizational improvements (Lyman et al., 2022). For example, a nurse who recognizes increased catheter-associated urinary tract infection rates in their hospital unit may use their power to advocate for and implement an evidence-based procedure for catheter insertion. After identifying a research-supported intervention, the nurse may sponsor an in-house training on proper catheter insertion. As team members engage in deliberate learning and practice sterile techniques, the learning may lead to increased nurse confidence, decreased infection rates and overall improved quality of care. The empowered nurse is able to take steps to improve the organization. In contrast, a nurse who lacks power may notice increased infection rates and know a useful improvement effort but choose to remain silent for fear of punishment or criticism, resulting in a missed opportunity for organizational improvement. Thus, empowered nurses are essential as they are more likely to take deliberate actions that improve organizational, team and individual outcomes.

As women comprise a strong majority of the nursing workforce, realizing the benefits of empowered nurses is only possible when empowerment transcends gender. However, evidence suggests women working in health care are not adequately empowered (McMillan & Perron, 2020). Lack of empowerment, in part, stems from hierarchical nurse-physician relationships, which tend to shift the balance of power towards physicians (Fewster-Thuente & Velsor-Friedrich, 2008). Moreover, societal gender biases and norms are perpetuated in the hierarchical structure of healthcare systems (Hay et al., 2019), making it difficult for female nurses to have power in the workplace. These gender biases and societal norms contribute to females experiencing gender-based inequities in the workplace including females receiving more negative feedback and evaluations than men (Galvin et al., 2015), increased levels of sexual harassment (Kahsay et al., 2020) and significant wage gaps (Muench et al., 2015). These inequities further prevent female nurses from using their power in the workplace. Nurse leaders need to address these inequities to fully empower the nurses on their teams.

While researchers have sought to understand the level of nurse empowerment, much remains to be learned about factors that affect nurse empowerment. Previous research includes surveys and questionnaires designed to measure levels of nurse empowerment (Irvine et al., 1999; Leslie et al., 1998; Spence-Laschinger et al., 2001). However, they do not offer insight into the specific factors that promote and prevent female nurse empowerment. They do not illustrate, question or challenge systems and structures that negatively impact women's ability to use their power in the nursing workplace. They also do not assess how structural barriers such as sexism (Chrisler et al., 2016), racism (Elias & Paradies, 2021) and religious biases (Tackett et al., 2018) in health care impact nurse empowerment.

Systemic barriers to women's power must be addressed to improve staff, clinical and organizational outcomes. However, persistent, pernicious power inequities in nursing and across health professions (Browne et al., 2016) indicate that current empowerment interventions such as transformational leadership behaviours (Khan

et al., 2018) and fostering an appropriate organizational culture and climate in the workplace (Trus et al., 2018) do not fully address these systemic barriers that are detrimental to nursing power. Adequately addressing power inequities in nursing provides better insights into the factors, systems and structures that influence nursing power.

## 1.2 | Conceptual foundation

Power is a commonly used concept with a wide range of definitions (Manojlovich, 2007). For the purpose of this study, we conceptualize nurses' power as the ability to mobilize resources, produce intended effects and actively take steps to empower patients. This study combines definitions of power from Birchenall and Birchenall (1998), Kanter (1993) and Benner (2001). Birchenall and Birchenall (1998) define power as being able to produce intended effects, while Kanter (1993) describes power as the ability to complete tasks, mobilize resources and use those resources to meet goals. Benner (2001) specifically focuses her definition around the scope of nursing and describes power as the specific caring practices nurses use to help empower patients. Combining these three definitions provides a holistic, conceptual understanding of power.

## 2 | THE STUDY

### 2.1 | Aims

The aim of this study was to understand the factors that influence nurse empowerment and reveal systems and structural barriers that prevent women from having power in the nursing workforce. We anticipate the insights gained through this study will guide organizations' efforts to mitigate such barriers and empower all nurses.

### 2.2 | Design

This study used a critical qualitative research design (Denzin et al., 2017), which involves a qualitatively focused exploration of societal systems and structures that perpetuate power imbalances and oppression. The purpose of critical research is to reveal oppressive systems and structures, so they can ultimately be transformed.

### 2.3 | Participants

Participants were nurses whose primary responsibility was providing direct patient care in inpatient hospital settings. This population was selected because they have first-hand, in-depth experience with barriers that prevent female nurses from using their own power and advocating for themselves. Excluded were individuals who were not registered nurses, as well as registered nurses primarily functioning in administrative and/or auxiliary roles. Gender was not used as an

exclusion criterion because the researchers felt all nurses, regardless of gender, witness hospital power dynamics and may have important insights into women's power. Participants were recruited in Utah and New Mexico because their contact information was accessible to the authors. Contact information for these nurses was purchased through Utah's Division of Public Licensure (DOPL) and the New Mexico Board of Nursing (NMBON), both of which permitted obtaining and using this data for research purposes. Ethics approval from the authors' Institutional Review Board was also obtained for this study (Approval #: IRB2022-031).

A contact list was generated by both DOPL and NMBON. The contact list generated by DOPL included 40,145 registered nurses actively licensed in the state of Utah. Email addresses were missing for 174 people on this list. The contact list generated by the NMBON included 30,125 registered nurses actively licensed in the state of New Mexico, with emails available for all nurses. The DOPL and NMBON contact lists were merged and 1600 registered nurses were randomly selected from the merged list. Recruitment emails were sent via Qualtrics to those 1600 registered nurses. To ensure participants met the inclusion criteria, the recruitment email contained a link to a Qualtrics survey in which the first question asked whether the patient is a registered nurse primarily responsible for providing direct patient care in an inpatient setting. Those answering 'Yes' were then able to view the next page of the survey, which included a link to complete a consent and audio release form. Once consent for the study and audio release was obtained, the authors corresponded with consenting individuals via email—responding to any questions or concerns voiced and to schedule an interview.

### 2.4 | Data collection

Data were collected by the authors from February to March 2022. The authors conducted semi-structured interviews (Table 1) over the telephone to gather information about nurses' experiences with power in hospital-based nursing. This approach provided a foundation for systematic exploration of each participant's personal experience with a nurse's power. It also permitted the flexibility to discuss other relevant insights alluded to by participants during the interviews. Interviews were guided by researcher-generated questions. For this reason, questions were specifically generated for this study to understand the specific barriers to female nurses obtaining power in the workforce. To develop the questions, the authors drew on their understanding of the literature, their experiences providing direct patient care (either as nurses or in close collaboration with nurses) and their previous experience with qualitative research. The questions were not piloted prior to data collection, although potential changes to the questions were considered at several points during the data collection process. Ultimately, no changes were deemed necessary. Interviews provided the authors an opportunity to listen to participants' experiences with power distribution in the nursing workforce. Interviews lasted up to 30 min and participants were given \$25 Amazon gift cards as compensation. The interviews were

TABLE 1 Semi-structured interview questions

Demographics
<ul style="list-style-type: none"> <li>• Is your primary role in the inpatient setting with direct patient care?</li> <li>• What gender do you identify with?</li> <li>• How long have you been a nurse?</li> <li>• How long have you been working with your current employer?</li> <li>• How long have you been working on your current unit?</li> </ul>
Research questions
<ul style="list-style-type: none"> <li>• How would you define having power in the nursing workforce?</li> <li>• Can you tell me about a time where you felt you had power in the hospital setting?</li> <li>○ What is it about that experience that made you feel powerful?</li> <li>• Can you tell me about a time where you felt you did not have power in the workplace?</li> <li>○ What is it about that experience that made you feel powerless?</li> <li>• What types of things help you feel powerful in the workplace?</li> <li>• What types of things make you feel powerless in the workplace?</li> <li>• What would help you feel more powerful in the workplace?</li> <li>• How does your gender affect your ability to feel powerful or powerless at work?</li> <li>• How do you think gender, in general, affects one's ability to feel powerful or powerless in the workplace?</li> <li>• How often do you feel powerful or powerless?</li> <li>• Have you ever had a time where you did not feel safe speaking up? Why?</li> <li>• What else about the work environment helped support empowerment?</li> </ul>

audio-recorded and transcribed verbatim. Data collection ended when data saturation (Saunders et al., 2018) was reached. None of the interviewers were previously known to any of the participants.

## 2.5 | Ethical considerations

Ethics approval for this study was obtained through the authors' Institutional Review Board. Informed consent via a web-based survey was obtained from all participants. Participants were informed they were welcome to refrain from answering any questions that caused discomfort and could choose to stop their participation at any time. Any participants needing additional psychological assistance would have been referred to their individual employee assistance or employee health office. In this article, pseudonyms are used to ensure participant confidentiality.

## 2.6 | Data analysis

Sixteen participants were interviewed for this study. Interviews were analysed using Nowell et al.'s (2017) 6-step thematic analysis process. The authors familiarized themselves with the data by listening to audio recordings and reviewing transcripts. Interviewers independently identified initial codes and phrases to describe those codes. The authors then met to discuss and refine codes. Themes were constructed based on relationships seen among codes. The

authors conducted member checking with four participants to ensure confirmability of codes. Names and definitions of codes were generated and prepared for dissemination. Findings were prepared for dissemination using the consolidated criteria for reporting qualitative research (Tong et al., 2007). No data analysis software was used for the analysis.

## 2.7 | Rigour

The second author has doctoral preparation in qualitative research methods and has since conducted and published from several qualitative studies. The first author also has experience conducting and publishing from qualitative research. The third and fourth authors were mentored and supervised by the first and second authors throughout the data collection and analysis processes.

Yin (2018) and Morse (2015) outline specific research design elements to improve rigour and validity in qualitative research. As construct validity is strengthened when the influence of the researcher's personal biases are mitigated (Yin, 2018), we triangulated multiple interviews from multiple participants to inform our perspective about power structures (Morse, 2015). Member checking also served to ground our interpretations in the participants' intended meanings (Morse, 2015). Likewise, to strengthen internal validity, we conducted a thorough review of the literature to generate and test alternative explanations for our findings (Yin, 2018). We also developed a coding system to ensure the meaning of the analysis remained the same between the coders, which further enhanced the study's validity (Morse, 2015).

To improve reliability, the authors followed Gibbert and Ruigrok (2010) and Yin's (2018) suggestions for rigour in qualitative research. Gibbert and Ruigrok (2010) suggest external reliability is strengthened when findings can be generalized beyond this study. Thus, the authors studied multiple units across various hospital systems in hopes of revealing patterns potentially generalizable to other settings. Reliability is also strengthened when a study can be repeated in the same way and yield the same results (Yin, 2018). To this end, the authors followed a detailed research protocol, maintained a database of all evidence generated through the study and created chains of evidence to show the linkage between our findings, data and research questions.

An important step in critical research is for the researchers to acknowledge and voice their assumptions about social values and structures. We believe that, despite women comprising much of the nursing workforce, societal systems and structures that disempower women are present and perpetuated in the hospital setting. We also believe that, as healthcare organizations empower employees (including women), the lives of women, their families and their communities will improve (Brownie et al., 2018), as will patient outcomes (Hay et al., 2019). We anticipate studying power structures in nursing and how they relate to diversity in gender will ultimately emancipate and empower nurses to create more egalitarian healthcare systems that improve health for everyone.

### 3 | FINDINGS

A total of 48 individuals started taking the study recruitment survey and 44 completed it, resulting in a 92% completion rate. All 44 individuals who consented to participate and completed the survey were contacted to schedule an interview, 28 of whom did not respond to subsequent contact from the researchers. Interviews were scheduled and conducted interviews with the remaining 16 participants, including 13 who self-identified as female and three who identified as male. No participants identified with a gender other than female or male. Participants were practicing in Utah and New Mexico in a variety of clinical units including the emergency department, labour and delivery, postpartum, operating room, behavioural health, medical surgical and oncology. Their experience working as registered nurses ranged from 1 to 38 years, with a mean experience of 11.28 years.

Six themes were identified from the data, four of which related to nurses' power at work, and two which specifically related to how gender affects a nurse's ability to use power and feel empowered. The empowerment themes were: supportive leaders, positive unit culture, successful advocacy and personal factors while the gendered intersection themes were: societal gender roles and sexism.

#### 3.1 | Empowerment factors

Participants expressed that supportive leaders, positive unit culture, successful advocacy and personal factors impacted their empowerment.

##### 3.1.1 | Supportive leaders

Participants expressed that supportive leaders improved their ability to feel empowered and use their power at work. Specifically, participants felt empowered when leaders (i.e. nurse leaders and managers) provided intentional learning opportunities, showed appreciation and respect and supplied adequate resources.

###### *Intentional learning opportunities*

Several participants expressed feeling empowered when leaders supported their growth through intentional learning experiences, such as orientations and mentorship opportunities. Describing his initial experiences after being hired on a new unit, Anthony said the unit leaders provided a 'really good orientation experience where I was oriented not just to my role, but to all of the supporting, [interdisciplinary] roles. And I found that to be really empowering'. Anthony further explained how nurse leaders who orient nurses to the unit's structures, goals and resources increased empowerment by ensuring the unit nurses are aware of all resources that can be used to help them achieve personal and organizational goals. Likewise, Camille shared how intentional learning experiences, specifically mentoring, at the beginning of her career helped her feel empowered in her role.

Camille explained that her nurse leaders provided an 'excellent mentoring program ... [where she] wasn't just learning patient care, [but] was learning how to be an effective nurse on behalf of the patients'. Through mentoring opportunities, leaders empower their nurses by helping nurses learn their exact roles and responsibilities. Camille expressed that knowing her responsibility as a nurse empowered her to be her patient's advocate and achieve good patient outcomes. Leader-provided learning opportunities empower nurses by orienting them to resources available on the unit, educating them about their unique role as nurses, and improving the knowledge needed to confidently and competently provide exemplary patient care.

###### *Appreciation and respect*

Participants also reported feeling empowered when they received appreciation and respect from nurse leaders. Danielle reported she felt empowered when 'upper management sees the work that I'm putting in, and what I'm doing to make a difference in changing and following policy. You know appreciation, just some kind of recognition, some kind of "whoa hoo!" Likewise, Mary described how when nurse leaders '[send a] kind of "Thank You", it's just really, like, validating. I can see that [the nurse leader] is wanting to support me to keep our patient healthy. So it's a very small gesture, but I really appreciate it'. Leaders who show appreciation for their staff motivate nurses to continue providing high-quality patient care and achieve unit goals.

###### *Feeling heard*

In addition, participants reported feeling appreciated when their input was heard and respected by their nurse leaders. Many participants stated they felt respected when leaders intentionally listened to and acted on their nurses' concerns, ideas and opinions. Monica stated, 'If I see there's a problem here and am able to make a suggestion, I think the important thing is being heard and being respected enough that you can make those changes'. Likewise, Danielle shared, 'I like when they ask for my opinion on things that will directly affect my job, that kind of empowers you when there's a change that needs to go on or they see a change and they ask for your opinion on how things should change'. Participants felt respected and valued when leaders included them in decision-making. Being an active participant in decision-making enabled the nurses to speak up and share their ideas for quality improvement, which empowered them to make positive changes in their unit.

###### *Providing adequate resources*

Participants also expressed that the availability of resources affects their empowerment. Several nurses shared that, due to the lasting implications of COVID-19, understaffing and lack of medical supplies regularly impede empowerment. Although the availability of resources is a multifaceted problem, the responsibility to ensure work continues on hospital units primarily dwells on nurse leaders. According to Brittany, one of the most difficult aspects of a shortage of healthcare workers is spending less time with patients. Brittany described this disempowerment by stating, 'I feel that I would love

to care for my patients more and get to know them more, ... and have a good conversation with them, but [instead] it's more of like you go into a room, you do what you got to do, you assess them, make sure they're still alive, they're breathing, and then you're like, "Okay, next one". Having less interaction consequently made nurses feel powerless because that aspect of their patient care was out of their control. Thus, the lack of resources and face-to-face interaction prevented nurses from developing relationships with their patients, which ultimately disempowered the nurses and negatively impacted their ability to provide high-quality, holistic care.

Sufficient resources are fundamental to nurses' empowerment. Participants shared that having adequate resources helped them feel supported by nurse leaders and better able to provide the best possible care. In situations where nurse leaders attempted to use temporary or float staff (without the proper training) to provide sufficient staffing, nurses also felt disempowered. John, a nurse on an inpatient behavioural health unit, shared this disempowerment stemmed from the float staffs' unfamiliarity with the unit, stating, 'Sometimes we do get people floated over from another part of the medical campus that just have no idea what they're doing. If there's a crisis, I don't want to have to walk somebody through it while trying to keep the patient from killing themselves'. Having to find medical supplies and explain to float staff about how things are done in the unit may be time-consuming and lead to poorer quality of patient care. The less time the nurse has to provide care, the less care the patient will receive. A lack of consistent, competent staffing prevents nurse empowerment by reducing nurse-to-patient interaction, which does not allow them to provide the highest quality care possible.

### 3.1.2 | Positive unit culture

Participants reported that a positive unit culture, including good teamwork and strong communication, and helped them feel empowered. Specifically, nurses shared that teamwork and communication with nurse leaders and physicians are empowering because they increased the nurses' ability to achieve positive patient outcomes.

#### *Teamwork*

Several participants expressed working in supportive teams helped them feel empowered. Teamwork refers to the collective effort to achieve a common goal. John, a nurse in an inpatient psychiatric unit, shared that when patients get combative on the unit, it was empowering when 'we have somebody who's working on getting medications available, taking care of the other patients, while we have staff that is working to de-escalate the patient'. Similarly, for Mary, teamwork was empowering because it allowed her to feel more competent in her work. She explained, 'having a supportive team where, if you call out for help and somebody responds immediately or just comes in and asks what you need, is so helpful and helps you feel more competent'. This collaboration enabled nurses to complete all their tasks, feel competent and have time to better support their patients.

In contrast, a lack of teamwork disempowers nurses. For example, Cristina explained that power comes from unity and working together towards a shared goal. However, when teams lacked this unity, nurses felt overwhelmed, frustrated and powerless. Cristina expressed how a lack of teamwork prevented change in the unit when she stated, 'I just feel like nobody looks out for nobody. That's why things don't change, because nobody's together'. Cristina further explained that she feels powerless to make improvements and advocate for patients when she lacks team support. Thus, the lack of team support prevented nurses from having the power to make positive changes in their workplaces.

#### *Good communication with leaders*

Participants shared that good communication with leaders increased their power in hospital-based nursing. Danielle reported she felt empowered when there was good communication with nurse leaders. She shared that when nurse leaders 'communicate on a regular basis to everybody in a way that doesn't put people out ... and keeps everybody on the same page, this empowers employees in a huge way'. By communicating effectively and respectfully, nurses and leaders can collaborate, discuss pertinent topics and prevent misunderstandings and disagreements. This enables them to take positive steps towards making change. In addition, Anthony shared that 'communication with management can give predictability and transparency with assignments, policy changes, and expectations'. Good communication allowed nurses to understand unit expectations and changes, helping them feel involved and considered in the decision-making process. Good communication can also prevent misunderstandings and can clarify the goals of the patient, nurse and leaders. Effective communication serves as a channel for both nurses and leaders to increase nurse empowerment and achieve their desired outcomes.

#### *Good communication with physicians*

Participants also shared that good communication with physicians was empowering. Several participants felt respected and powerful when physicians asked for their opinions. For example, Danielle shared, 'when the doctor respects our advice, or our opinion, you know, when we give them a call, we say, "This is what we need to do ... and I suggest we might try this", and when they respect that and let you do that with their blessing that is still empowering'. Similarly, Annie described how she feels 'appreciated when [physicians] want the nurses to be in on rounding. I feel like I have power in that situation because they're taking recommendations from me. And they're listening to what I have to say in my concerns and then taking that into their management of the patient'. Physicians who included nurses in decision-making and care plans empowered nurses by showing that nurses' voices and knowledge were valued and respected. Effective communication also allowed nurses to have an active role in providing patient care and promoting positive outcomes.

In contrast, poor communication with doctors disempowered nurses. Poor communication is exhibited through condescending communication, lack of respect and ignoring nurses' concerns.



Anthony shared, 'there have been some surgeons that don't really take input or that will try to micromanage patient care, and things like that kind of demean the nursing role'. When condescending communication occurs in the unit, nurses do not feel safe proposing ideas or care plans that might be beneficial for the patient's health. Katherine shared she feels most powerless when she does not have an effective way to communicate with other nurses and physicians. When describing this lack of power she stated, 'I just feel like, no control, no respect, and I just feel powerless because that communication and respect is gone'. When communication and respect between co-workers are absent, nurses are disempowered because they are unable to effectively communicate on behalf of their patients.

### 3.1.3 | Successful advocacy

The participants expressed that successfully advocating for their patients increased their feelings of power at work. When they spoke up for their patients, they felt they were successfully fulfilling their obligations as a nurse while also promoting positive patient outcomes. Camille explained that her power as a nurse stemmed from 'the development of the fundamental core belief that you are the patient's advocate, period. There's nothing else, that's all'. Several other participants agreed, stating that advocating for their patients helped them feel as though they were fulfilling their role by improving patient outcomes and satisfaction. Brittany explained the empowering nature of advocacy when she stated, '[as a nurse], you are advocating for your patients, you are taking their words, communicating to the doctors, making them heard. There's so much power in that ... we're also the voice to advocate for our patients, to the doctors, to even family, [when] sometimes the patient isn't getting heard'. Thus, the participants described a virtuous cycle between advocacy and power—when they successfully advocate for their patients, they feel empowered to continue doing so.

### 3.1.4 | Personal factors

Participants reported feeling empowered when they were autonomous and had adequate knowledge. These personal factors increased nurses' abilities to provide high-quality patient outcomes.

#### *Autonomy*

The participants felt powerful when they were autonomous, as they were allowed to make decisions to improve their patient's outcomes. Autonomy can be defined as the ability to act based on one's own judgement. Justin explicitly defined having power in the nursing workforce as 'being able to make decisions and have [the] managers and physicians that I work with understand my reasoning [for] clinical decisions'. Justin further explained that he felt empowered 'having the autonomy that we know what we're doing, we understand our jobs and the clinical decisions that we're making and how they're going to impact us and the patient'. The participants shared

that autonomy gave them the power to make decisions for their patients and provide better patient care.

#### *Education*

Participants also shared that education was empowering. Education helped the nurses feel more competent and confident in their ability to make decisions and act according to patient's needs. Annie shared that having the knowledge to 'fix problems [makes] me feel powerful at work because I feel very competent within my role'. Similarly, Mary shared, 'education and seeking to keep learning has been an empowering aspect for me because I feel like I have more tools in my tool belt [to help my patients] when I am learning more'. Thus, a strong foundation of knowledge empowered nurses by increasing their confidence and competence in providing patient care and by providing the knowledge to make decisions that will improve patient outcomes. Education positively impacts nurses by providing knowledge and experience that will ultimately empower them.

## 3.2 | Intersection of gender and power

As participants shared their experiences, many participants expressed that societal gender roles and the presence of sexism in the workplace affected their ability to feel empowered. While some participants did not feel their gender affected their empowerment, it is important to highlight the possible intersection between gender and empowerment.

### 3.2.1 | Societal gender roles

Societal gender roles may influence how different genders experience power. Several participants described how female nurses often had increased difficulty gaining leadership positions or accessing power since society tends to pressure women to conform to gender roles. John explained that 'there's definitely societal pressure. I don't think a managerial position is flexible for families. And it's still very much expected for mom to be the primary caretaker of kids, whereas men are supposed to be the primary breadwinners'. Similarly, Kennedy expressed how she grew up being told to 'appreciate your elders and listen to the man' which has led her to treat male healthcare workers with the utmost deference even when she disagrees with their opinions. Societal norms and expectations may influence female nurses' abilities to access power through decision-making, advocacy, and leadership roles. Moreover, several participants described how society tends to show a greater degree of respect towards men than women. Danielle attributed this respect differential to men being 'more commanding in their presence, where women are a little more shy in their speaking'. Camille carried this idea further, explaining women are 'more likely to acquiesce—to go along to get along because they don't have a lot of support systems that will shore them up if something happens to their jobs'.

Thus, power may be more accessible to male healthcare workers, simply because of their gender, while female nurses may experience powerlessness.

### 3.2.2 | Sexism

The presence of sexism in the healthcare industry may also affect how nurses experience power. Sexism can be defined as prejudice, stereotyping or discrimination, typically against women, on the basis of sex (Masequesmay, 2021). Sexism is illustrated in nursing when physicians or nurse leaders show a preference for male healthcare workers and when men are disproportionately represented in leadership positions. Anthony mentioned that 'there are some fairly sexist power dynamics. Like there are some surgeons that will treat male nurses better than female nurses'. Similarly, Kennedy added to this idea and mentioned she felt male nurses are listened to and valued more than female nurses. This explicit preferential treatment of male nurses highlights how sexism may infiltrate the healthcare system and affect how different genders experience power. In addition, John, Danielle and Kallie all recognized that more men are in leadership positions than females, despite the majority of nurses being female. Kallie specifically mentioned that 'the male managers get further along than the female ones', highlighting how societal preferences may tend to favour the male nurse over their female counterparts. Several participants attributed this preferential treatment to, what they described as, innate male characteristics, such as being more dominant, respectable and valued. The presence of sexism in health care diminishes women's ability to have power at work.

## 4 | DISCUSSION

Empowering nurses benefits the nursing workforce, improves patient care and enhances organizational outcomes (Fackler et al., 2015; Molina-Mula & Gallo-Estrada, 2020; Woodward, 2020). Therefore, it is essential to understand factors that empower nurses. This study provides important insights into how nurses perceive and experience power. The findings suggest nurses are empowered by supportive nurse leaders, a positive unit culture, successful advocacy efforts and personal factors. Likewise, we also found that societal gender roles, as well as sexism, can impact nurse empowerment. These findings validate previous research and provide unique contributions to the literature on power in the nursing workforce.

### 4.1 | Nurses' perception of power

Through their responses, nurses provided interesting insights into their perceptions of power. Their perceptions generally aligned with our initial conceptualization of power, which was the ability to mobilize resources, produce intended effects and actively take steps to empower patients (Benner, 2001; Birchenall & Birchenall, 1998; Kanter, 1993).

For example, participants described power as their ability to mobilize resources, including their time and clinical equipment. Alternately, nurses felt disempowered when they had insufficient time to build relationships with their patients. The participants produced their intended effects by communicating information with other members of the healthcare team, successful patient advocacy and using teamwork to keep patients safe. Successful patient advocacy was also the primary strategy the nurses used to empower their patients. Nurses empowered patients by advocating for them, voicing their concerns and helping them receive clear answers to their questions.

The nurses identified their clinical knowledge and perspectives as sources of power that helped them better care for their patients. This perspective aligns with the Foucauldian position that power exists when sources of power (e.g. access to knowledge and resources) are used to influence the choices made by other individuals who are acting of their own volition (Foucault, 1982). For example, receiving specialized education influenced the nurses' clinical decision-making. Similarly, a nurse sharing an insightful clinical perspective may influence how other healthcare providers choose to treat a patient. The nurses recognized that the context in which they practiced (e.g. unit culture) shaped their ability to influence the clinical care provided by the healthcare team.

An aspect of the context in which the nurses practiced was their sense of being 'lower' in the hospital hierarchy than physicians and people in formal leadership roles (Aspinall et al., 2021). Participants expressed this perception through descriptions of physicians and managers as the default source of decisions about patient care, hospital unit operations and resource allocation—with the nurses feeling privileged simply to have been included in the decision-making process. Notably, participants were empowered when hospital unit culture, team dynamics and communication reflected a flattening of the hierarchy.

The nurses' perceptions of power also reflected the influence of managerialism on their care (Cope et al., 2016). Managerialism in health care refers to supplanting traditional nursing values such as compassion and altruism with market-based values such as productivity and efficiency (Molina-Mula, 2018). For example, the nurses valued human connection, therapeutic relationships with patients, holistic care, and advocacy. Yet, when facing a scarcity of time, staff or supplies, their focus necessarily narrowed to simply keeping their patients alive. Unfortunately, nurses are often compelled to choose between practicing according to their values and achieving metrics related to operational efficiency.

### 4.2 | Supportive leaders

Our findings indicate nurses experience increased levels of empowerment when they feel nurse leaders are supportive. Several participants explained that nurse leaders' efforts to provide a supportive work environment through mentoring and continuing education opportunities increased nurse competence, confidence and ability to use their power at work. Similarly, prior research highlights leaders' foundational role in creating a supportive work environment that

empowers nurses (Kowalski et al., 2020; Wei et al., 2020). Our participants felt they had more power when nurse leaders took an active role on the unit, which is consistent with other research suggesting leaders empower front-line nurses when they show organizational support and commitment (Al-Bsheish et al., 2019). Additionally, our findings validate Rega et al. (2017) whose findings suggest leaders empower nurses by showing appreciation and respect. Our research also indicates that including nurses in decision-making and providing continuous education opportunities further empowers nurses.

### 4.3 | Positive unit culture

This study suggests a positive unit culture improves nurse empowerment. Specifically, our findings imply teamwork and good communication between nurse leaders and physicians can improve unit nurses' ability to feel powerful. While previous studies have shown that teamwork and empowerment both positively correlate with organizational commitment (Hanaysha, 2016), the relationship among these three factors remains unclear. However, this study provides additional insight into the relationship between these three factors—specifically, that teamwork contributes to empowerment, which subsequently increases organizational commitment. Our participants also described how they feel powerful when nurse leaders listen to their concerns and physicians ask for and implement the nurse's recommendations. Similarly, other research highlights how assertive communication skills in teams and between teams may help nurses become more empowered (Darawad et al., 2020). Our research further suggests good communication with leaders can provide a sense of support, understanding and trust in the workplace that enables nurses to use their power.

### 4.4 | Successful advocacy efforts

Nurses in this study report feeling empowered when they successfully advocate for their patients. The nurses cited successfully advocating as empowering because they have the power to make the patient heard and are active agents in making positive change in the units. While previous studies highlight how advocacy can improve patient empowerment (Nsiah et al., 2019), our study builds on this idea by highlighting how successful attempts at advocacy can also improve nurse empowerment. Moreover, Nsiah et al. (2019) suggests protecting patients, being the patients' voice and developing relationships with patients improves patient advocacy and empowerment. Our study builds on this idea and suggests that as nurses advocate for and empower their patients, the nurses also feel empowered.

### 4.5 | Personal characteristics

Personal factors, such as autonomy and education, were identified by nurses as empowering factors. Our participants explained that

having the freedom and autonomy to make decisions for their patients allowed them to feel powerful as they make intentional efforts to achieve high-quality outcomes and empower patients. While previous studies highlight how the feeling of empowerment may increase a nurses' willingness to exercise autonomy (Gottlieb et al., 2021), our research highlights that the reverse is also true—that autonomy can increase nurse empowerment. This finding coincides with Watkins et al. (2016), who suggest there is a significant relationship between psychological empowerment and autonomy in newly licensed registered nurses. In addition, our research validates the idea that competence, knowledge and experience can empower nurses (Tan & Conde, 2021; Tracy et al., 2019). Our research further highlights the specific ways competence and experience can be increased, namely through mentoring, effective orientations and supportive leaders.

### 4.6 | Societal gender roles and sexism

This research suggests societal gender roles and sexism may all influence an individual's ability to feel empowered. While previous research has examined how gender relates to the way people experience power in various specialties such as tourism (Boley et al., 2016) and innovation management (Abukhait et al., 2019), our research is the among the first to show how gender roles and perceived societal expectations may affect an individual's ability to feel power in hospital-based nursing. Our participants described how societal pressure to fulfil 'motherly duties' often prevents female nurses from acquiring leadership positions. Likewise, other participants described the inherent need to respect and listen to male healthcare workers even when the nurses' opinions differ. These examples illustrate how societal pressure to conform to gender norms negatively affects women's ability to use their power to obtain higher positions and advocate for themselves and their patients.

Our research validates previous studies suggesting the presence of sexism in health care (Chrisler et al., 2016; Mesquita Filho et al., 2018; Ozerdogan et al., 2017). For example, Mesquita Filho et al. (2018) found that more than half of health professionals may experience gender stereotyping, hostile sexism or benevolent sexism. Our study validates the presence of sexism in health care while also suggesting sexism negatively affects nurse empowerment. Our participants shared that sexism in health care is evident when physicians tend to respect and value male nurses over female nurses and when men are disproportionately represented in leadership positions. This preferential treatment decreases female nurses' willingness to speak up and advocate for their patients. Similarly, Ozerdogan et al. (2017) found that male professionals tend to adopt more hostile sexism to maintain the power-related advantages of being male (Ozerdogan et al., 2017). The presence of sexism at work may prevent the creation of a positive work culture, which may further contribute to decreased levels of perceived empowerment for nurses.

## 4.7 | Implications

These findings present implications for nurse leaders, individuals feeling disempowered and individuals who have power.

### 4.7.1 | Implications for nurse leaders

Nurse leaders have a vital role in creating an environment that helps empower nurses. Leaders should seek to create a shared team vision, support an inclusive culture that fosters open communication and facilitate time for leaders and teams to work together without interruptions (Linnen & Rowley, 2013). In addition, leaders should increase opportunities for continuing education and mentorship (Wei et al., 2019) to develop each nurse's competence and confidence. Leaders can also provide adequate staffing and resources to direct care to ensure they have the equipment necessary to provide the best care to their patients (Kowalski et al., 2020). In addition, nurse leaders can take time to talk to each nurse individually, hear their concerns (Markey et al., 2020) and actively include nurses in all decision-making opportunities and policy changes (Rasheed et al., 2020). Moreover, nurse leaders should seek to support all nurses alike regardless of their gender and provide consequences for those who engage in sexist behaviours that may disempower members of the team. Only when nurses are truly included in every aspect of patient care can we ensure they will be empowered.

In the process of supporting and celebrating their nurses, leaders should be cautious about propagating the 'hero' discourse, which has been used to mask the racism, sexism, inequitable power relations and hazardous work conditions nurses experience (Mohammed et al., 2021). Portraying nurses as heroes might be intended as a form of recognition, but has also been used to exploit nurses to accept inadequate pay and staffing, normalize their exposure to workplace risks (e.g. sharps, chemicals, violence, musculoskeletal injury and infectious disease) and conceal ongoing challenges in nursing work, including hospital hierarchy and managerialism. Rather, nurse leaders should acknowledge and work directly to address such issues.

### 4.7.2 | Implications for nurses and those feeling disempowered

Nurses should take every opportunity to feel empowered and express their power. Each nurse should strive to improve their confidence and competence by building a strong foundation of knowledge, participating in continuing education and asking for mentorship opportunities (Kuokkanen et al., 2016). Competence and confidence will help increase a nurse's ability to be autonomous and make decisions, which can help improve empowerment. Nurses should also remember their unique role as patient advocates and strive to communicate with nurse leaders and the interdisciplinary team to provide the best care possible for their patients. By being the patient's voice, nurses may feel an increase in power and

responsibility. Likewise, nurses should support each other as they strive to work towards a shared purpose of providing high-quality patient care. As nurses work as teams, they may feel more supported, valued and empowered to make quality improvements and improve patient care (Donovan et al., 2018). Finally, nurses who notice sexist behaviours in health care, staff should immediately report the findings to their nurse managers to ensure these tactics are not tolerated (Castner, 2019). Teams who value each person equally will probably notice an increase of power on their unit.

### 4.7.3 | Implications for those in power

Individuals who have power in the healthcare setting such as nurse leaders, physicians and hospital administrators should seek to recognize their place of power. They should seek to acknowledge how power dynamics in their facility affect their relationships with other healthcare workers. Second, individuals who are in positions of power should seek to listen and learn from all staff, specifically the nurses (Raso, 2016). These individuals should recognize that nurses provide the majority of patient care and often have very valuable insights into patient status and include the nurses' opinions and insights in their decision-making. Third, individuals who have power should ensure they are showing respect to each person. They should seek to help each individual feel like a valued, essential part of the medical team (Hughes, 2017). Finally, individuals who have power should recognize their purpose and the shared goals they have with all the healthcare workers around them. They should strive to work as a team towards positive outcomes and empower their staff to reach those goals. When those in power work to empower the powerless, healthcare may be transformed.

## 4.8 | Limitations and future research

While this study provides important insights into nurse empowerment, it does have limitations. Although the authors reached data saturation, this study included 16 participants licensed in either New Mexico or Utah, making generalizability of the data difficult. Future research could seek to gather experiences from a larger, more diverse sample. This would help determine if these findings are similar in other settings with different populations. This study used 30-min interviews with each participant, which may be considered short for qualitative research. Future studies could use longer or repeated interviews to generate richer insights. Another limitation includes the sole focus on nurses' experiences with power. Interviewing only nurses prevented the authors from understanding how other healthcare workers including nursing managers or physicians experience power in the hospital setting. Future research could focus on learning how other healthcare groups experience power to understand what structural factors may affect all healthcare worker's abilities to feel empowered. Finally, data for this study were collected during the COVID-19 pandemic. As such, some insights about workplace

power dynamics and access to resources may best reflect circumstances unique to pandemics. Additional research in other contexts is important to gain a fuller understanding of women's power in the hospital setting.

## 5 | CONCLUSION

Nurses who have power and are empowered can revolutionize healthcare. In this study, four themes were identified to help empower women. In addition, this study presented two suggestions for how gender affects one's ability to feel powerful. Moreover, nurse leaders should seek to recognize areas where their units show empowerment and areas that may be disempowering to nurses to empower nurses to reach goals and improve care for all. Likewise, nurses and those in power should all take steps to ensure each member of the healthcare team is empowered. Only when everyone has access to power can health care be transformed.

### AUTHOR CONTRIBUTIONS

Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data: Kaitlyn C. George, Bret Lyman, Andy Pilarte Alcantara and Maya Stephenson. Involved in drafting the manuscript or revising it critically for important intellectual content: Kaitlyn C. George, Bret Lyman, Andy Pilarte Alcantara and Maya Stephenson. Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content: Kaitlyn C. George, Bret Lyman, Andy Pilarte Alcantara and Maya Stephenson. Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: Kaitlyn C. George, Bret Lyman, Andy Pilarte Alcantara and Maya Stephenson.

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### CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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### PEER REVIEW

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### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - MIXED METHODS**

# Investigating the clinical decision-making of nursing students using high-fidelity simulation, observation and think aloud: A mixed methods research study

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**Abstract**

**Aims:** The aim of this study was to investigate nursing students' clinical decision-making by using high-fidelity simulation of a deteriorated patient scenario.

**Design:** A convergent parallel mixed methods research design was used consisting of quantitative and qualitative data collection.

**Methods:** Twenty-three students completed the Health Science Reasoning Test before and after the simulation between October 2015 and June 2016. They were presented with a simulated scenario and asked to 'think aloud' during and after the simulation. The students were audio-video recorded and observations were collected by the researcher.

**Results:** There was a significant moderate increase in the 'deduction' and 'analysis' sub-scale scores and overall test score, suggestive of improved analytical decision-making processes through the simulation experience. Think-aloud and observation data identified that students predominantly applied 'forward' reasoning during the simulated 'patient's' deterioration, focusing mainly on cue acquisition. 'Backward' reasoning with a focus on cue interpretation was most prominent in the debriefing data, in line with the survey outcomes. Accurate cue interpretation of critical, key cues appeared more useful than the total number of cues in solving the main clinical case problem.

**Conclusion:** Students learn different clinical decision-making skills during the simulation compared to what they learn from debriefing. Using observation and think-aloud methods have significant benefits for researchers seeking to optimize the evaluation of the clinical decision-making process.

**KEYWORDS**

clinical decision-making, dual process theory, high-fidelity simulation, nursing, nursing students, observation, think aloud, verbal protocol analysis

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## 1 | INTRODUCTION

Clinical decision-making (CDM) is integral to nursing practice and clinical competency and is a central component in nursing education and practice (Johansen & O'Brien, 2015; Nursing and Midwifery Council, 2018). It is a complex process, requiring more of the nurse than just making defined choices between limited options. Nursing staff are required to make decisions with different foci; assessment, diagnosis, communication, intervention, seeking information and evaluation (Thompson et al., 2004). CDM is dependent on how information is processed and given clinical value by the decision-makers. It involves reasoning and judging different alternatives before selecting and evaluating specific actions. It is not affected by nurses' cognitive processes alone but also by the contextual factors, system design and the complexity of tasks all of which will affect the nurses' ability to effectively recognize and respond to salient aspects of the clinical situations. Furthermore, terms referring to CDM are used interchangeably in the literature, demonstrating confusion and lack of consensus, and there has been a lack of educational interventions which are based on theories of decision-making (Thompson & Stapely, 2011). The process by which CDM is applied by students remains unclear and this paper therefore reports a study which applied Dual Process Theory (DPT) and utilized multiple data collection methods to evaluate the CDM in a group of students working with a clinical scenario using high-fidelity simulation.

### 1.1 | Background

In the last three decades, concerns have been expressed regarding patients' safety and the raised incidences of sub-optimal standards of care that were linked to worse patients' outcome (National Confidential Enquiry into Patient Outcome and Death – NCEPOD, 2012; Urquhart et al., 2021). Failure to recognize relevant clinical information and hence failure to implement appropriate clinical decisions in timely manner was identified as an important factor for 'failure to rescue' patients with acute clinical deterioration. Nursing staff, as first responders, have important roles in conducting the initial patient assessment and recognizing the early sign and symptoms of deterioration. Therefore, the clinical management of deteriorating patients' conditions by the multidisciplinary team depends on the nurses' ability to recognize and accurately interpret those critical cues. The effectiveness of educational interventions to improve nursing judgement is unknown and issues of ineffective decision-making are still evident despite the research that has been carried out in this field. It is still unclear how to educate and prepare novice nurses to develop more effective clinical decision-making skills.

In recent years, clinical placements for students in 'real' settings have become significantly scarce and clinical simulation has become widely used as a learning strategy in nursing education. Despite this, there is inconclusive evidence to support the use of simulation-based approaches in teaching clinical reasoning and decision-making

#### Impact

- Contradictions in current understanding of clinical decision-making by student nurses suggest a need for theory-based and stronger, pluralistic research designs.
- Use of think-aloud and observation methods and application of Dual Process Theory identified a predominant use of inductive reasoning and 'cue acquisition' during the simulation and mostly deductive reasoning and 'cue interpretation' in the post-simulation debriefing.
- Inclusion of multi-methods within a pluralistic study design would benefit further research to develop clinical reasoning skills.

in nursing (Levett-Jones et al., 2011; Woda et al., 2017). Furthermore, nursing research in the field of CDM focused mainly on expert decision-making in natural setting, the use of self-report research methods and qualitative methodology (Lyneham et al., 2008). It is suggested that nurses frequently make decisions by applying pattern recognition and intuition that is based on their practice experience (Smith, 2009), whereas novice nurses often apply an analytical approach, though not always in an effective way (Hoffman, 2007). However, methodological issues have been recognized. In particular designs mostly have applied a single data collection method with a reliance on self-report tools a weakness of which being that they can only identify aspects of the decision-making process of which participants are aware, and so unconscious aspects of their decision-making are not usually reported. CDM process is complex and pluralistic research designs would more likely enhance understanding. For example, Hoffman (2007) and Aitken et al. (2011) applied both observations and 'think-aloud' protocol to explore how nurses make clinical decisions in critical care units. The application of both research methods produced a depth of analysis of nurses' clinical decision-making in natural settings. However, those studies provided little emphasis on nursing students.

Until relatively recently, nursing studies that examined the clinical decision-making process in simulation settings have largely used paper-based clinical scenarios which have limited simulation fidelity (Funkesson et al., 2007; Lamond et al., 1996). Nursing research that used high-fidelity simulation to examine CDM has mainly focused on the effect of simulation and there is a lack of examination of the decision-making process. High-fidelity clinical simulation presents opportunities to explore in detail how student nurses make clinical decisions and so better inform the development of educational applications, supported by better application of theory in order to improve nurses' decision-making skills (Thompson & Stapely, 2011). Dowding et al. (2011) reported that more research is needed to examine the impact of problem-based learning and clinical simulation on clinical decision-making. The present study therefore adopted Dual Process Theory (Croskerry & Nimmo, 2011) within a multi-method design.

### 1.1.1 | Dual process theory

Dual Process Theory (DPT; Croskerry & Nimmo, 2011) refers to a pluralistic approach to clinical decision-making and has grown in popularity in recent years. DPT describes two different types of decision-making: type 1 describes a non-analytical approach to decision-making, whereas type 2 refers to an analytical approach (Evans & Stanovich, 2013). The DPT suggests that the two types of CDM operate in parallel and that there is a continuous switch between the two during cognitive processing.

Features for type 1 include having a high level of automaticity, fast and reflexive processing, and decisions are subconsciously made. Type 1 refers to the use of intuition or pattern recognition, or automated behaviours, as conceptualized by Evans and Stanovich (2013). Intuition and automaticity have been identified in the literature as missing steps in the reasoning process. There is a slight difference between automaticity and intuition: intuition is described as a form of knowing but automaticity may have been developed by internalization of routines and procedures (Moors & De Houwer, 2006). Automatic behaviour therefore might not always reflect intuitions. Further, pattern-matching involves nurses immediately recognizing critical cues in the presented situation, comparing it to their experience and predicting what will happen next. Processing appears to entail application of cue-chunking and rapid connection to the long-term memory (LTM) to activate previously stored patterns with similarities to the current situation. However, while intuition based on experience is widely considered in the nursing literature as an effective approach to decision-making, it has been found to be more prone to cognitive biases and potential subsequent errors affecting the quality of decision-making (Croskerry & Nimmo, 2011). In contrast, type 2 features include being slow processing, deliberative and reflective, conscious and with low levels of automaticity. In doing so, it conforms to 'backward' (deductive) and 'forward' (inductive) reasoning and therefore entails an analytical approach to CDM.

For student nurses, however, they have limited practice experience to draw upon and so it might be expected that they have a greater reliance on type 2 decision-making based on their learning and understanding of biosciences. This paper therefore reports a study that evaluated reasoning processes by student nurses in relation to the DPT when making clinical decisions within a simulation setting.

## 2 | THE STUDY

### 2.1 | Aims

The aim of this study was to investigate nursing students' clinical decision-making using high-fidelity simulation of a deteriorating patient scenario. There were three main research questions for this study:

1. What are the types of clinical decision-making used by nursing students in managing acutely deteriorating 'patients' using high-fidelity simulation (HFS) experience?

2. Is there a difference in clinical reasoning measures for students after having HFS experience?
3. Does students' performance when they mainly use type 1 clinical decision-making during HFS experience correlate differently with measures of clinical reasoning to those who mainly use type 2?

### 2.2 | Design

A convergent parallel mixed methods design applied four methods: the Health Science Reasoning Test (HSRT; a quantitative, objective measure to assess clinical reasoning) prior to and after attending a simulation session, concurrent 'think-aloud' (TA) and observation, and retrospective TA in a debriefing review of the student's performance. Qualitative data collection using concurrent TA and observation occurred simultaneously to ensure complete data collection of all aspects of decision-making during a clinical scenario attended by students. The rationale for this research design is to correlate and corroborate the data, provide more depth of understanding of the decision-making process, and increase the validity of the findings.

Participants were asked to individually attend a simulated case scenario. The simulation was provided using a Human Patient Simulated manikin (SimMan Essential 3G™) within a simulated surgical ward to replicate a clinical acute care setting at the University clinical laboratory. The simulation experience for the participants lasted 60 min and included four stages. Prebriefing stage includes orientation and practising thinking aloud. During the performance stage, students were asked to think aloud and respond to patient's needs. Then the first author facilitated a debriefing session using an adapted debriefing tool (Ahmed et al., 2013) and tailored questions to seek clarification on students' actions. Finally, the facilitator introduced students to cognitive biases (e.g., anchored or being fixated on one possibility or action) and provided students with a list that describes common cognitive biases and de-biasing strategies (e.g., reflection, feedback from colleagues or use of simulation) to reflect on future clinical practice and to regulate their common biases (Croskerry et al., 2013). The first author (facilitator) is an expert critical care nurse and academic with 20 years of experience in this field. The author has also extensive experience facilitating and debriefing simulated scenarios using high-fidelity simulation as part of their academic job.

The high-fidelity simulator was programmed to respond appropriately to the students' interventions, whether it was correct or incorrect. To increase the likelihood of similar test conditions for all students, a similar simulation environment was created for each student and the same clinical scenario, physiological signs and trends were applied. All the participants worked individually and followed the same simulation design, time limits and same rooms.

The scenario (see Table 1) was based on a clinical experience of the first author. The patient in this case suffered from allergic reaction to blood transfusion. It was based on a similar patient case encountered in clinical practice. The case scenario was reviewed by a critical care practitioner experienced in post-operative care

TABLE 1 Case scenario

## Case scenario

Carol Stone 65-year-old female admitted to an acute ward post hip replacement surgery. Carol received 800 millilitres (mls) of Hartmann's solution intra-operatively. Post-operatively, her doctor continued Hartmann's solution at a rate of 50 ml per hour via an infusion pump and she was started on blood transfusion due to low Haemoglobin (Hb) level. She has just arrived in your ward, and she has a fast respiratory and heart rate. She is complaining of being breathless and getting anxious. Carol reported to you that she was frequently coughing last week

and an academic experienced in simulated practice. This approach was used to ensure face and content validity of the scenario and to enhance its believability. Students had to review patient's charts, examine the manikin, ask questions and review the presented data on the simulator monitor to find clinical cues. This approach allowed for a gradual progression of the simulated scenario. It ensured that students had the freedom to examine the clinical situation and to process the cues over time in order to mimic reality as closely as possible. Although high-fidelity simulation aims to produce closer conditions to reality, the simulated deteriorated patient scenario may be a different experience when these students are faced with reality.

## 2.3 | Participants

A convenience sample of 23 self-selected third year pre-registration nursing students who had enrolled in a Bachelor of Science (BSc) program in 2016 at one university in England were recruited for this study. The students were recruited from two subsequent cohorts attending the same degree. The data collection took place between October 2015 for cohort 1 and June 2016 for cohort 2. The two cohorts represented different intakes and were at the same stage of their studies. An invitation was sent to all students in those cohorts via their students' email and in a face-face session with course leader. All were in the last 6 months of their course so had prior experience with high-fidelity simulation and had prerequisite knowledge of the clinical context of the simulation experience. Students who were under the direct supervision of the first author, and those who could be assessed in their course by the author, were excluded from this study.

## 2.4 | Data collection

### 2.4.1 | Health science reasoning test (HSRT)

Prior to the simulated experience, the participant was asked to complete the HSRT (Insight Assessment, 2016). This is a survey tool that provides a measure of the individual's clinical reasoning and decision-making processes in a healthcare-related clinical context.

The tool was repeated after completion of the experience to allow analysis of any changes during the simulation experience.

According to Dual Process Theory, type 2 decision-making relies on 'forward' (inductive) and/or 'backward' (deductive) reasoning (Evans & Stanovich, 2013). The HSRT measures these approaches through cognitive domains of critical thinking and clinical reasoning (inductive and deductive) by analysing responses to 33 multiple-choice questions that take approximately 50 min to complete using a computer. The tool measures five different domains are measured as sub-scales using a total of 38 score points: induction (10 points), deduction (10 points), analysis (6 points), inference (6 points) and evaluation (6 points) (Insight Assessment, 2016). The test questions require the test taker to analyse provided data, to make interpretations, to draw inferences, reason the claims and to evaluate the quality of different arguments and options.

The tool therefore provides a score for each of the HSRT domains and a total overall score (maximum 38 points) that gives a measurement of the strengths and limitation of the test taker's skills in making a reasoned judgement. The designers (Insight Assessment, 2016) provide threshold scores for the tool. An overall score of  $\geq 26$  out of 38 is designated as "superior" and a score of 21–25 reflects a "strong" clinical reasoning skill. A "moderate" score of 15–20 suggests the student may have some difficulties with problem-solving and decision-making skills. Lastly, a "not manifested" score of 0–14 implies suboptimal effort when completing the test or possible comprehension problem that have been associated with poor performance in the workplace.

Insight Assessment (2016), the provider of the tool, report alpha reliability coefficients for the five sub-scales ranging between 0.77 and 0.83 and for overall internal consistency of 0.81 ( $n = 444$ ) measured by Cronbach's alpha. For this study, the overall internal consistency of HSRT was 0.79. All values are above the normally accepted coefficient value of 0.70. Content validity of the HSRT is supported by researchers and educators in the field of reasoning (Dreifuerst, 2012) and construct validity has been demonstrated by strong correlations between HSRT scores and a variety of other robust examinations for academic achievement (Huhn & Deutsch, 2011).

### 2.4.2 | Audio-video recordings

Performance of students during the scenario were audio-video recorded. The process was managed by the first author who also observed the performance and made notes accordingly. The simulation was stopped if students requested, or if the session had reached 20 min, or if the student called for the 'emergency team' to resolve the scenario. On completing the scenario, the student watched the video and commentary and was asked to review their perceptions of the scenario, the changing clinical parameters of the simulated patient, and the rationale for their choice of intervention. The debriefing interview was also audio recorded.



### a. Think aloud

Students were asked to think aloud while responding to patient's needs during the simulation and similar approach was used after the simulation during the debriefing. Think aloud (TA) is described as a process-tracing technique to elicit and explore what is happening in a person's mind while performing a task, solving a problem or making decisions (Ericsson & Simon, 1993). It provides extensive and rich verbal concurrent data about cognitive processes for analysis and provides stable results (Aitken et al., 2011). Concurrent and retrospective verbal reports were collected in this study.

Concurrent TA refers to verbalisation during the participant's performance which reflects the content of the working memory, in this instance as the student expressed their thoughts of their actions in real-time as the 'patient's' presentation changes. Retrospective TA interview refers to students' verbalisation and reflection after their performance. After completion of the simulation exercise a retrospective TA approach was applied by holding an audiotaped debriefing interview with the students. The debriefing session provided an opportunity for students to view the audio-video recording of their performance and retrospective think aloud enables students to access their long-term memory. This helps to ensure accurate recall of the cognitive processing behind their decision-making immediately after the experience and identify any differences in learning from both types of TA (Ericsson & Simon, 1993).

### a. Observation

Observational data were gathered by the first author during the student's performance by making notes, using a peer-reviewed answer guide for the scenario, and later through interpretation of the video recording of their actions. Observation is a useful method that allows the researcher to observe what the participants actually do, as opposed to what they think they do or would like others to think they do. Observation in a specific context can also help in interpreting the Verbal Protocol Analysis (VPA, see Data analysis, below) conducted on the think aloud and to recognize non-verbalized behaviours.

## 2.5 | Ethical considerations

Participation in this study was voluntary. Ethical considerations primarily related to maintaining confidentiality of transcripts, recorded data and data worksheets. All participants were given a participant information sheet and supplied written informed consent prior to the exercise data collection and were encouraged to ask questions regarding the study. Participants were not referred to by name but were provided with coded identifiers to enable the matching of participants responses pre- and post-scenario. All identifiers were stored in a secure document, only accessible to the first author. Participants were assured that they would not be identifiable in any dissemination medium, and they could withdraw at any point.

The University Research Ethics Committee approved this study (approval number SNM/DREP/14-014) and course leaders/senior managers at the University gave institutional approval.

## 2.6 | Data analysis

Data were analysed using statistical analysis involving HSRT data, and verbal protocol analysis (VPA) of the think aloud data, and content analysis of the observation data.

### 2.6.1 | Analysis of HSRT data

The HSRT score and participant demographic data were added into Statistical Package for Social Sciences software (SPSS Version 20; SPSS Inc., Chicago, IL USA) for statistical analysis. Data were analysed according to participants' scores on the HSRT total score, and the scale five domains' scores. This study used skewness and kurtosis, visual inspection using histograms and Shapiro-Wilk's test to assess approximate normality required for parametric tests.

A dependent (paired) t-test was used to assess differences between HSRT pre-scenario and post-scenario mean scores. Pearson product-moment correlation analysis ( $r$ ) was then applied to assess bivariate correlations between the HSRT scores and the clinical decision-making processes identified in the content analyses of the think-aloud and observational data described below. The statistical significance for all quantitative analyses was set at an alpha level at  $p < .05$ .

### 2.6.2 | Analysis of think-aloud data

The audio and videotapes were transcribed verbatim by the first author. The author reviewed all study transcripts to enable familiarity and to identify general impressions from the verbalized data. Think aloud recordings were analysed according to verbal protocol analysis (VPA). Verbal protocol analysis aims to describe the thinking path and gain insight into the participants' decision-making process. Since it allows the author to trace the students' decision-making process, it will yield information about the types of decision-making used at different tasks within the scenario, and can also be used for cross-checking the findings with HSRT scores. Coding through VPA consists of three sequential steps to trace the cognitive processes. For this, the think aloud (TA) transcripts were entered into NVivo software version 11 and coded according to the three VPA steps (Ericsson & Simon, 1993):

1. 'Referring Phrase Analysis' (RPA); this step began by encoding and organizing the transcribed verbal reports into segments or concepts, each corresponding to one sentence, clause or even a single word that represents as a single thought or the focus of attention. The referring phrase analysis coding is based on



care concepts such as airway, breathing and circulation, disability, exposure (ABCDE) initially described by (Jones, 1989) but expanded on by other nursing investigators (Greenwood et al., 2000; Hoffman, 2007; Johnsen et al., 2016). For example, attributes describing airway concept include patient's ability to speak, suctioning, airway opening manoeuvres. Attributes describing breathing concept include respiratory rate, pattern, depth and effort of breathing, oxygen saturation, positioning, oxygen therapy etc.

Once codified the frequencies of the 'referral to nursing' concepts were calculated for each concept and for each participant, and then the overall frequencies for each concept were totalled for all participants.

2. The 'Assertional Phrase Analysis' (APA); this identifies the cognitive operators such as operators 'collect' or 'interpret' that are responsible for moving the reasoning process between states of knowledge to solve a problem. Through this step, the first author identified the cognitive steps each participant used in processing the clinical information and how students made their decisions. The APA in this study is based on codes of cognitive operators that have previously been applied in related studies (Hoffman, 2007; Twycross & Powls, 2006). The utility of the thesis is identified in Table 2.
3. During the Script Analysis step; the types of cognitive operators and the order of how those operators were sequentially applied by participants is identified, and therefore through this step the researcher can ascertain the thinking path each participant took

to make decisions. This analysis identified the different reasoning processes such as inductive or deductive reasoning, pattern recognition and the stages of hypothetico-deduction. For example, 'pattern recognition' was identified through the identification of operators such as 'predict' and 'match' in participants' transcripts. This is usually identified when a participant notices critical cues and then immediately reaches a diagnosis or collect a specific related cue or taking immediate action based on familiar situation. It was also identified when a participant predicted how the patient's condition would progress by declaring in advance, and predicting possible intervention, outcome, situation or response.

'Cue interpretation', stage part of the hypothetico-deduction decision-making process, was identified through operators such as 'interpret', 'relate' and 'infer'. These decision-making processes are related to type 1 and type 2 decision-making types, respectively, as proposed by the Dual Process Theoretical framework (Croskerry & Nimmo, 2011) (see Table 3). The hypothetico-deductive model (type 2 CDM) has 4 four stages: *cue acquisition* and *interpretation*, *hypothesis generation* and *evaluation* (Elstein et al., 1978). The hypothetico-deductive model embraces two approaches to clinical reasoning; 'forward' (i.e., inductive) and 'backward' (i.e., deductive). During the third VPA coding step, the first author identified the types of CDM, the different stages of hypothetico-deductive model and the reasoning approaches used by students.

Through the VPA the direction and order of the stages of hypothetico-deductive model identified the applied reasoning approach. 'Forward reasoning' or data-driven method occurs where

Operator	Descriptors
Plan	Explain what is going to happen
Review	Review actions, go over drugs charts, records and results. Restate, reflect
Collect	To acquire cues, examine, measure, notice, observe and ask for further details
Interpret	To demonstrate understanding of the meaning of the collected cues based on professional knowledge
Relate	Connecting relevant signs and symptoms together, cues clustering to identify new patterns or relationships
Infer	Make deduction, include relevant and exclude irrelevant cues, draw logical conclusions based on the provided cues
Match	Critical cues that activate the recognition of a pattern
Predict	Anticipate how the patient condition would progress, declaring in advance and make prediction about intervention, outcome, situation or response
Diagnose	Reach definitive conclusion and identify the patient problem
Goal	Identify the desire outcome and achieving a target/aim within a time frame
Course of action	Describe, choose or select a course of action/s to manage the identified problem/s. Weighing different alternatives
Act	Performing action/s, or a description of what a nurse is doing, or what they want the patient to do
Rationale	To provide reasoning for a course of actions, how things work fit, explain events, links or the cause of effect
Evaluate	Verify the effectiveness of the actions

TABLE 2 Descriptors of cognitive operators

TABLE 3 Types of clinical decision-making and associated cognitive processes

Type	Process	Brief description	Example of associated operators
Type 1	Intuition Automatic	Effortless. Missing steps, straight to action, diagnosis or solution. Automatically the move straight to action and solution from the perception of information. Reflexive. Fast executed process.	Collect, act
	Pattern Recognition	Immediately recognizing or noticing critical cues that start the collection of specific and relevant information to the clinical situation based on their predication or previous experience.	Predict and match
Type 2	Hypothetico-deductive	Cue acquisition	Plan, collect, review
		Cue interpretation	Interpret, relate, infer, rationale
		Hypothesis generation	Diagnose, goal, course of action
		Hypothesis evaluation	Act and evaluate

information is gathered, and cues are collected in an inductive way that leads to the generation of a hypothesis. Evidencing forward reasoning may have operators arranged more or less in the following order

- Start with “plan” and/or “review” and/or “collect”, then
- “Interpret” and/or “relate” and/or “infer” and/or “rationale”, then
- “Diagnose” and/or “goal”, then possible to be followed by
- “Course of action” and/or “act”, then
- “Evaluate”

‘Backward’ or hypothesis-driven reasoning occurs when the students initially identify the problem and then collect data to deductively verify and provide a rationale for their conclusion. Backward reasoning may have operators arranged more or less in the following order:

- Start with “diagnose” and/or “review”, then
- “Relate” and/or “infer” and/or “rationale” and/or “interpret”, then
- “Course of action” and/or “act”
- “Evaluate”

These data were collated using NVivo software. NVivo codes for each concept provided reference statements for each occurrence. The software generated frequencies for each code/concept and provided a total frequency by adding the frequencies from all participants (Hoffman, 2007). This nominal quantification of the codes was then entered into the SPSS database towards statistical analyses. The VPA process therefore allowed the TA data to secondarily be quantified by collation of the frequencies of codes related to each VPA step, so following the principles described by Ericsson and Simon (1993).

Concurrent (during the simulation) and retrospective (post-experience) think aloud transcripts were analysed separately using the VPA steps to identify the type of clinical decision-making (CDM) being applied by the student. Results from both analyses were then

compared. This process adds depth of understanding of participants' CDM by highlighting any differences in processes identified by each method. Thus, the cues used by participants during their performance, the type of cues and their frequency, the accuracy of cue clustering and patterns, the accuracy of their interpretation, the identified problems and actions taken, could be identified.

### 2.6.3 | Analysis of the observational data

All videos were watched several times for familiarity and the actions used by the students were coded using NVivo 12 software to describe the content (i.e., codes of nursing concepts, cognitive operators and types of CDM; described above in relation to Think Aloud). As above, codes were subjected to a content analysis by calculating frequencies of extracted codes and entering the data into the SPSS database in the same way as for the VPA data. The analysis allowed the monitoring of what the student considered and the order and way by which it was acquired. Through content analysis, the first author also identified the number and types of cues used by participants during their performance, how cues were clustered and the accuracy of solving the main problems.

## 2.7 | Validity and reliability/rigour

This study had a complex design intended to provide a thorough evaluation of students' approaches to decision-making before and after experiencing the simulated scenario. This was achieved by application of a validated survey tool, the HSRT and identification of real-time examples of decision-making during the simulation experience through application of qualitative methods (think aloud and observation). Post-experience debriefing allowed ratification of the transcript extracts and also provided opportunity for any apparent differences arising from student reflection in discussion with the researcher. Rigour in the analysis therefore was ensured by all data

collected being analysed separately, in keeping with the pluralistic design, and compared and corroborated as appropriate (Creswell & Plano Clark, 2018).

The HSRT was selected because it has high content and construct validity. It was designed for application in healthcare and so has a lower risk of bias compared to other self-report CDM scales. The HSRT sub-scales and total scale have acceptable coefficients of internal reliability (Cronbach alpha >0.70). The Intraclass Correlation of Consistency (ICC) for the HSRT overall score and its five domains analysis was conducted using a Two-Way Mixed model. A good degree of reliability was found between the HSRT overall score, and a moderate to good degree of reliability was found between each of the HSRT five domains. The average measure ICC for the HSRT overall score was 0.79 ( $F(22) = 4.43, p < .001$ ). The average measures ICC for the HSRT five domains were 0.74 ( $F(22) = 3.28, p < .001$ ) for the induction score, 0.76 ( $F(22) = 3.76, p < .001$ ) for the deduction score, 0.73 ( $F(22) = 3.11, p < .01$ ) for the analysis score, 0.70 ( $F(22) = 2.95, p = .013$ ) for the inference score and 0.71 ( $F(22) = 2.97, p < .011$ ) for the evaluation score. All data produced were tested for normal distribution (parametric) and statistical testing was introduced accordingly. Regarding the qualitative methods used, think aloud and observations are established methods to obtain 'in-the-moment' thoughts of individuals. A critical reader and a Professor of Nursing reviewed the coding books for the qualitative methods, sampled more than 10% of transcripts and provided feedback. Organization of the extracted codes utilized NVivo software and could then be

evaluated for frequency. This quantification enabled comparison between the think-aloud, observational and HSRT data. This process, coupled with cross-referencing to the Dual Process Theoretical framework (Croskerry & Nimmo, 2011) provided rigour in the data analysis and interpretation.

### 3 | RESULTS

Participants in this study were 23 third-year nursing students from a School of Nursing and Midwifery in England. Most of the students were female (87%;  $n = 20$ ). The age of students ranged from 21 to 44 years (mean = 28 years,  $SD = 6.95$ ). At the time of the study, 47 per cent of the sample ( $n = 11$ ) had clinical placements in medical-surgical wards-only and 53% ( $n = 12$ ) had placement in a variety of wards including either emergency department or critical care units (see Table 4). No obvious differences were found in students' HSRT scores based on their demographical factors for both pre- and post-test.

#### 3.1 | Health science reasoning test (HSRT)

The normality analysis required for parametric tests showed a skewness of 0.85 (SE 0.48) and a kurtosis of 0.22 (SE 0.93) for the pre-test, and a skewness of 0.54 (SE 0.48) and a kurtosis of 0.63 (SE 0.94)

TABLE 4 Sample characteristics

Gender	Number (%)	Ethnicity	Number (%)
Female	20 (87%)	White	20 (87%)
Male	3 (13%)	Black/African/Caribbean	3 (13%)
Level Education	Number (%)	Type of clinical placement	Number (%)
Advanced level (A level)	20 (87%)	Mixed (medical and surgical) without ICU or emergency units	11 (47.8%)
Bachelor of Science (BSc)	2 (8.7%)	Mixed with emergency units	6 (26.1)
Master of Science (MSc)	1 (4.3%)	Mixed with ICU	4 (17.4%)
		Mixed with emergency unit and ICU	2 (8.7)
Learning difficulties	Number (%)	Previous healthcare experience	Number (%)
Has learning difficulties	20 (87%)	No experience - <2 years	14 (61%)
No learning difficulties	3 (13%)	≥2 - <4 years	3 (13%)
		≥4 years	6 (26%)
Age		Measures	Years
Range (years)	Number (%)	Mean (S.E.)	28
20-25	12 (52.2%)	Median	25
26-30	5 (21.7%)	Mode	25
31-35	1 (4.3%)	Range	23
36-40	3 (13%)	SD	6.95
>41	2 (8.7%)	Minimum	21
		Maximum	44

Abbreviations: ICU, intensive care unit; SD, standard deviation; SE, Standard error of mean.

for the post-test. Shapiro–Wilk's test for HSRT data showed that we must reject the null hypothesis for the HSRT pre-test data ( $W = 0.92$ ,  $p = .053$ ), and the HSRT post-test data ( $W = 0.94$ ,  $p = .19$ ) and conclude that data were approximately normally distributed.

Using a paired t-test, there was an increase in mean of the overall HSRT score for all students from 18.49 ( $SD 4.45$ ) in the pre-test to 20.52 ( $SD 4.02$ ) post-test, ( $t(23) = 2.82$ ,  $p = .01$ ). These values correspond to moderate CDM skills (range 15–20; see Methods). Effect size was estimated at 0.58 which indicates a medium-size effect on CDM scores. Closer examination identified 18 students (78%) who had a sub-optimal level of clinical reasoning scores according to thresholds (i.e., HSRT score below 15; Insight Assessment, 2016) before the simulation but for the post-test results, the number of students with sub-optimal performance scores was reduced to 12 (52%). Looking at the scoring of the HSRT subscales, there was statistically significant improvement only in scores for 'deduction' ( $t(22) = 2.97$ ,  $p = .01$ ) and 'analysis' ( $t(22) = 2.86$ ,  $p = .01$ ) suggesting an improvement and a shift in most students towards a more deductive approach (backward reasoning) post-simulation.

Correlation analysis revealed significant positive relationships between the backward reasoning and post-simulation HSRT deduction score ( $r = 0.37$ ,  $p = .04$ ) and analysis score ( $r = 0.46$ ,  $p = .02$ ). There was also a significant positive correlation between pattern recognition and post-simulation HSRT induction score ( $r = 0.39$ ,  $p = .034$ ). Therefore, high-fidelity simulation may have a positive influence in enhancing students' backward reasoning and pattern recognition skills.

### 3.2 | Clinical decision-making process: Think aloud (TA)

Three hundred and eight sections of extracted concurrent TA data were coded for nursing concepts (airway, breathing, circulation,

disability and exposure). From those, 114 (37%) sections were coded as breathing, 105 (34.1%) sections were coded as circulation, 38 (12.3%) sections were coded as disability, 31 (10.1%) sections were coded as airway and 20 (6.5%) sections were coded as exposure. Overall, therefore, students focused their clinical management on the 'patient's' breathing and circulatory systems with relatively little emphasis on the airway, disability and exposure aspects of the ABCDE approach to assessment and management.

Outcomes of verbal protocol analysis of the concurrent TA data, and the content analysis of the observation data, were largely similar regarding the decision-making approach. Thus, frequencies of codes in the concurrent TA broadly agreed with the application of cognitive operators identified in the observation method, with high frequencies of use of operators such as "collect" and "review" (see Table 5). Collectively, 51% of all codes from the concurrent TA data and 47% of those from the observation data were related to the 'cue acquisition' stage of the hypothetico-deductive approach (see Methods), and to 'hypothesis evaluation' using the operator "act". Such comparisons support the validity and application of the pluralistic design.

In contrast, some differences were apparent between the concurrent and retrospective TA data. Whereas data from the observations closely follow the coded data identified in the concurrent TA analysis, so supporting 'cue acquisition' as the main stage for decision-making, the subsequent retrospective TA data from the debrief interview identified participants largely focused on 'cue interpretation' (49.2%; Figure 1), primarily through the application of operators "interpret" and "relate", and 'hypothesis generation' (24.1%), mainly by application of the operator "diagnose". This concurs with the HSRT analysis, above. These findings suggest the influence of reflection in the post-experience debriefing discussion with the researcher. The implication also is that the TA methods and VPA were sensitive enough to distinguish between the different types of reasoning used by the participants during and after the simulation

TABLE 5 Frequency of cognitive operators

Operator	Operator frequency from concurrent TA	Operator frequency from retrospective TA	Operator frequency from observation
Plan	12.6%	0%	5%
Review	13.2%	5.8%	10.3%
Collect	25.3%	7.2%	31.6%
Interpret	10.2%	17.6%	12.2%
Relate	2.6%	21.5%	2.6%
Infer	2.1%	4.9%	1.2%
Rationale	8.5%	5.2%	3.1%
Match	0.6%	3.3%	1.5%
Predict	0.5%	1.4%	0.8%
Diagnose	2.9%	20.4%	6.4%
Goal	1%	1.8%	0.5%
Course	3.5%	1.9%	2.3%
Act	15.8%	2.2%	20.5%
Evaluate	1.2%	6.8%	2%

session. Inclusion of a debriefing of the student would appear to be important for similar, future studies.

To summarize, applications of intuition and automated behaviours, indicative of type 1 CDM, were identified in the analyses but were of very low frequency. They were more obvious in the observations when compared to codes from the TA protocol (see Figure 2). This confirms the difficulty in verbalizing those processes as the participants lack the awareness of using them. Similarly, the use of pattern recognition, also indicative of type 1 CDM, was relatively low and contributed to 10.1% and 16.8% of the concurrent and retrospective TA coding, respectively. Overall, the dominant type of decision-making in both concurrent and retrospective TA was of type 2, that is, 'forward' (i.e., inductive) or 'backward' (i.e., deductive) reasoning (Elstein et al., 1978). 'Backward reasoning' was more frequently identified in the retrospective TA during the debrief.

### 3.3 | Decisions made by students

Of the 23 students, eight did not recognize the main clinical problem and the key interventions. Five students from the 15 who managed to solve the main problem verbalized the correct course of action but hesitated in performing the actions and kept searching for more

cues. In many instances, students' actions were not related to the provided cues but rather related more to the procedural practice, for example students immediately measuring blood pressure despite the presented cues suggesting a serious respiratory problem. This automated practice was not always optimal and so caused delays in identifying and treating the clinical problem.

Students who collected between 21 and 30 cues were more successful in solving the main problem compared to those who selected fewer than 21 or more than 31 cues. Moreover, the usage of seven specific cues was associated with increased likelihood of solving the main problem: patient's ability to speak, oxygen saturation, presence of rash, time of starting blood transfusion, drainage and wound site, urine output and level of consciousness.

A higher average number of wrongly interpreted or clustered cues by students was associated with reduction in the students' ability to solve the main problem (see Table 6). For example, some students missed the identification of anaphylaxis to blood when the presence of rash was not recognized or when they inaccurately related the time of transfusion to identify the clinical problem. The retrospective TA data found that students justified their errors by suggesting that they did not have accurate knowledge so judged the situation based on a notion of a 'typical' presentation, which is a type of cognitive bias.

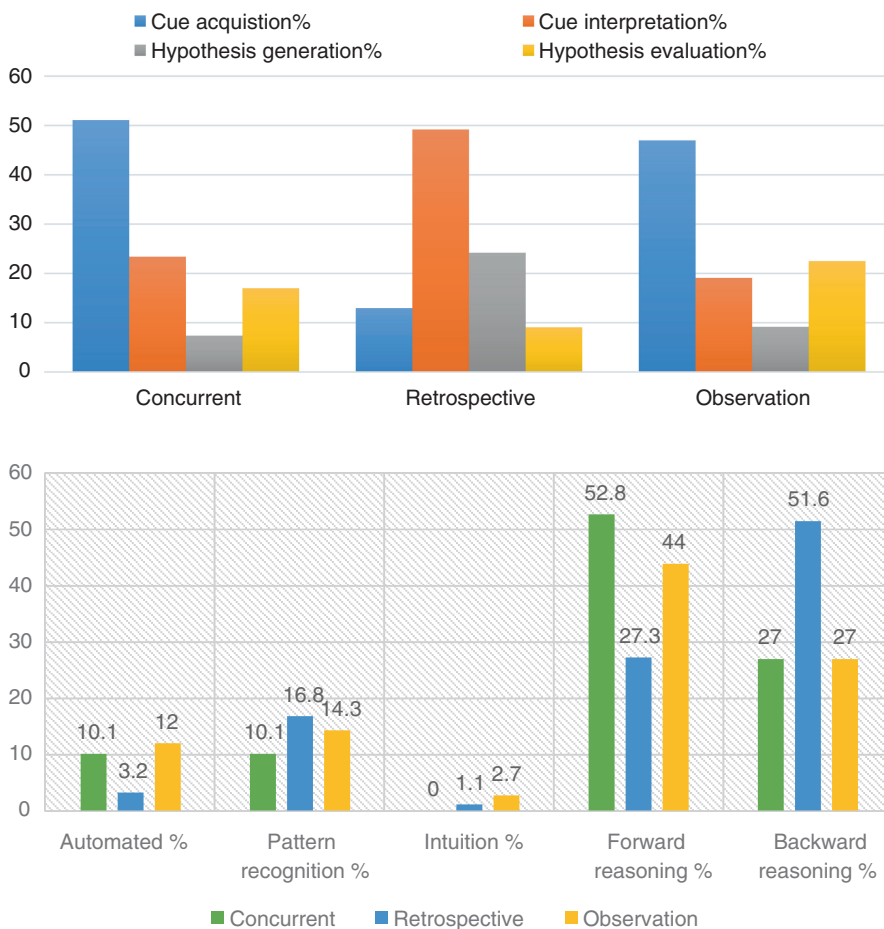


FIGURE 1 Comparison of the stages of hypothetico-deduction between think-aloud (concurrent and retrospective) and observation data.

FIGURE 2 Percentage of the frequency of occurrence CDM-processes between think aloud (concurrent and retrospective) and observation.

TABLE 6 Errors in cue interpretation and problem identification

	Main problem solved	Main problem not solved	Example of errors
Total average of wrongly interpreted cues	0.5	2.9	If the start time of blood transfusion is >15 minutes, then students ruled it out as cue for reaction Rash and itching caused mainly by sepsis
Total average of wrongly related or unrelated cues	1.5	2.7	Not relating (rash, shortness of breath, increase respiratory and pulse) to reaction The only explanation for (high temperature, low blood pressure and rash) is sepsis
Total average of wrongly inferred cues	.43	.44	Use typical presentation and prematurely inferring allergic reaction based on symptoms occurring after 15 min Inference the presence of hypovolaemia
Overall total of wrong interpretation, clustering and inference	2.43	6.04	

## 4 | DISCUSSION

This study examined the clinical decision-making (CDM) processes of nursing students while they were caring for a deteriorated 'patient' using manikin-based high-fidelity simulation. A combination of methods was utilized: a survey measure of CDM approach using the HSRT tool, concurrent and retrospective think-aloud data during and after the student had experienced the scenario, and observations made of the student's performance by the researcher. Quantification of all data meant that the types of CDM, cognitive processes, the utilization of 'clinical' cues collected by the students, and how this affected the accuracy of students' actions could be calculated and compared.

Finding a significant increase in the before-and-after simulation in HSRT score, with moderate effect size, suggests that the simulated experience may have led to an incremental improvement in students' clinical reasoning. In this respect, the results of this study reflect the findings of previous research in nursing education about the positive impact of high-fidelity simulation on students' clinical decision-making (Dreifuerst, 2012; Woda et al., 2017).

According to Dual Process Theory (DPT) individuals utilize two types of CDM when making treatment decisions (Croskerry & Nimmo, 2011). Type 1 CDM is characterized by automaticity based on previous experience whilst type 2 CDM relates to cue acquisition and interpretation leading to hypothesis generation or verification either through inductive ('forward' reasoning) and/or deductive ('backward' reasoning) cognitive processes. Much of early nursing research equated pattern recognition to intuition and others considered it as part of the analytical reasoning. In a study by Patterson et al. (2009) identified that pattern-recognition takes just 8s to make a decision based on the Recognition-Primed Decision (RPD) model (Klein's, 2008), which is considered fast processing that is also more characteristic of type 1 CDM. In our study the related cognitive operators reflecting pattern recognition contributed only 10.1% and 16.8% of the concurrent and retrospective TA coding, respectively, suggesting that type 2 CDM was predominant. The analysis identified that nursing students at times applied a combination of both types of CDM in solving the same task, though mainly type

2 remained the main process. The dynamic shift between the two types of CDM in processing the information suggests that CDM is not a linear process of one type or the other which is in line with Croskerry and Nimmo's (2011) description of the DPT. This is also consistent with findings from nursing staff in studies by Andersson et al. (2012), Hoffman (2007) and Kydonaki et al. (2016) suggesting application of both types of CDM occurs regardless of the individual's level of experience.

Present findings suggest application of type 2 CDM was predominant for CDM both during the simulation experience and in the reflections made in the post-experience debriefing. However, analysis of the think-aloud data for CDM processes identified that students mostly utilized 'forward' reasoning during the task performance and largely applied 'backward' reasoning during their debriefing discussion. This finding is consistent with findings from studies as novice nurses used forward reasoning (Johnsen et al., 2016; Twycross & Powls, 2006). This is not consensus as other nursing research has reported that 'backward' reasoning is mainly used by novice participants whereas it is the expert nurses who mainly use 'forward' reasoning (Lamond et al., 1996). One explanation for this apparent contradiction is that it could be related to limitations of previous studies design as they used single data method with limited research of applying both concurrent and retrospective think aloud (see Background). Furthermore, the hypothetico-deductive model (i.e., applying 'forward' and 'backward' reasoning) has long been suggested to be a model of reasoning by expert healthcare practitioners (Arocha et al., 1993) but this view was shifted after few years of research and it was considered as an approach predominantly used by novice healthcare practitioners (Elstein, 2009). Research findings above revealed that both forward and backward reasonings can be used by expert and novice practitioners.

The pluralistic, mixed-methods design of this study allowed for a more comprehensive data collection and added breadth to the findings to adequately evaluate the clinical decision-making processes. It added clarity and revealed that student nurses used forward reasoning during performance through concurrent think-aloud and backward reasoning during the debriefing through retrospective think aloud. Think aloud also identified that student nurses mainly



used 'cue acquisition' and 'interpretation' as the main focus in the concurrent think-aloud (TA) data during the simulation task performance, in agreement with findings of similar studies that examined nursing clinical decision-making in both simulated and natural settings (Greenwood et al., 2000), but the retrospective TA during the post-experience debriefing the students focused more on relating the cues to justify their actions and diagnoses. This highlights that performing a task and reflecting on performance through debriefing affect learning about CDM in different ways. Performing a task helped students in developing their forward reasoning, cue acquisition and interpretation skills but post-experience debriefing helped students to develop their backward reasoning, cue interpretation and hypothesis generation.

A number of nursing studies have reported that expert nurses were more effective than novice nurses in collecting and utilizing critical cues to presenting situations (Hoffman, 2007; Kydonaki et al., 2016). In this study, student nurses used a range of cues but focused more on specific symptoms that confirmed their provisional diagnoses. Cioffi (2000) found that novice nurses were more likely to use data that has no clinical utility for the judgement in question or that they may be placing significant clinical weight on a specific type of information and neglecting other important cues. Successful CDM by students in the present study was associated with collection of 21–30 cues but just seven specific clinical cues appeared critical as they increased likelihood of the student solving the main problem. This finding is in line with those of Levett-Jones et al. (2011) who identified that the average number of cues collected by students in their study was 8.89, and specific cues were associated with increasing the likelihood of identifying the problem.

Students in this study who identified only one, or perhaps very few key cues, then immediately made diagnoses or carried out actions some of which were erroneous were identified as using type 1 CDM. While such automaticity in type 1 CDM has the advantage of requiring low levels of attention to perform a task, it is also suggested to pose significant hazards for situational awareness and the overall performance. Incorrectly interpreting cues resulted in an increased number of unsolved problems has been reported elsewhere (Endacott et al., 2010). It was also reported that effective interpretation skills can increase the safety of medication administration among nursing students (Lee & Wessol, 2022). Reasoning can confirm or disconfirm the relevance and significance of clinical cues in generating a hypothesis; cue gathering, along with accurate cue interpretation, is closely associated with diagnostic accuracy. How people allocate clinical values to cues based on their knowledge and clinical experience therefore can impact on the accuracy of judgement of the situation. If ineffective this may lead to inaccurate diagnosis and poor decision-making.

#### 4.1 | Limitations

The strength of this study is its pluralistic design. Application of a survey tool (quantitative), think-aloud methods (qualitative) during

and after the simulation experience, and observation (qualitative) generated a volume of data which, when quantified, that enabled corroboration with the HSRT findings and hence ensured validity. Using VPA provided the scope to extend understanding of how students rationalized their decision-making. Thus, data from the think-aloud protocols, observations and the validated HSRT survey were comprehensively analysed to provide a depth of synthesis about the content, outcome and the process of clinical decision-making. The main limitation was that participants in this study were drawn from a single cohort of student nurses in just one university. Findings should be considered in that context, although the focus on learning process in an educational setting should make the findings transferable and of interest to courses elsewhere. Statistical analyses were limited by the small sample size and by the lack of a control/comparator arm to the study. This limited generalisability of these results and results from the study should be cautiously interpreted. Repeating a questionnaire after a short period of time risks familiarity bias in the post-test responses. This could not be evaluated but findings that HSRT scores were moderately increased post-simulation coincided with a shift in reasoning type in the post-simulation think-aloud analysis so supportive of the finding. The medium-sized sample compares well with other studies that also used think-aloud method.

## 5 | CONCLUSION

Using pluralistic methods this study identified that selecting relevant cues and effective cue interpretation are critical factors to reaching accurate decisions. An improvement of the HSRT score supports the potential positive effect of simulation on enhancing CDM. Application of the Dual Process Theory extends what is understood regarding processes of clinical decision-making in this study, identifying a change in approach by many students in the debriefing period (i.e., to 'backward' reasoning and 'cue interpretation') when compared to their approach during the performance (i.e., 'forward' reasoning and 'cue acquisition'). This understanding illustrates that different CDM processes are learnt from the different stages of simulation. Therefore, well-designed high-fidelity simulation experiences could be used in nursing education to optimize different aspects of the clinical decision-making process such as supporting the acquisition of critical cues, developing accurate cue interpretation and forming new clinical patterns. The findings further support a need for application of a theory-based simulation design to enhance the effectiveness of clinical simulation in teaching clinical decision-making skills. The use of both concurrent and retrospective TA to explore CDM in the same study has significant benefits to conducting future research in the field of CDM and to ensure that the CDM process is adequately examined.

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## PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15507>.

## DATA AVAILABILITY STATEMENT

Research data are not shared.

## NO PATIENT OR PUBLIC CONTRIBUTION

There was no active public or patient involvement in this study. The study explored nursing students' clinical decision-making process as they work through a hypothetical simulated case scenario based on a similar clinical case from the first author's clinical experience. The authors' knowledge of the national reports on deteriorated patients and their experience of educating nursing students for many years informed the study questions and design. Students were the participants but had no active involvement in the study design.

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# The impact of adverse drug reactions on medication adherence and outpatient treatment outcomes in female breast cancer: A review protocol

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## Abstract

**Aim:** Discover the impact of adverse drug reactions of hormonal and chemotherapy on medication adherence and outpatient treatment outcomes in the breast cancer patient population.

**Design:** A systematic review following the reporting guidance from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P) guided by the Joanna Briggs Institute methodology will be conducted.

**Data Sources:** A literature search will be conducted using the following databases: PubMed, CINAHL, Web of Science, Medline and Scopus.

**Review methods:** Studies published in English before 2022 that report adverse drug reactions with medication adherence and outpatient treatment outcomes as primary outcome measures, following the initiation of one or more oral hormonal, endocrine and chemotherapy agents in female patients with diagnoses of breast cancer will be identified. Observational studies will be included for review, and two reviewers will independently screen study titles, abstracts and full text for inclusion. The quality assessment will be conducted using the Joanna Briggs Institute tools. A meta-analysis will be conducted where sufficient data are available.

**Results:** This is a systematic review study protocol, and results are not available at the time of the submission. All results will be reported on the completion of this study.

**Discussion:** This systematic review will highlight the impact of medication non-adherence on the breast cancer patient population, support determining strategies to address this issue and identify areas for further research.

**Patient or public contribution:** This protocol article will identify the impact of adverse drug reactions on medication non-adherence and treatment outcomes in the female breast cancer patient population. A unique contribution of our study is to support determining strategies to address this ongoing public health issue and identify areas for further research.

**Trial registration:** This protocol has been registered with the International Prospective Register of Systematic Reviews (PROSPERO) database (registration number CRD 42021291364).

## KEYWORDS

adverse drug reactions, breast cancer, medication non-adherence, treatment outcomes

## 1 | INTRODUCTION

A total of 2.3 million women were diagnosed with breast cancer in 2020 worldwide, while deaths caused by breast cancer exceeded 6.8 million (World Health Organization, 2021). The surge of newly diagnosed breast cancer cases in the past 5 years has made it the second most common cancer in the world and the most prevalent malignancy among women. One in eight women were diagnosed with breast cancer in the United States, which accounted for approximately one-fifth of all female cancers worldwide (Lawlor et al., 2003; Momenimovahed & Salehiniya, 2019). The incidence rate of breast cancer varies among different parts of the world, ranging from 27 per 100,000 in Middle Africa and East Asia to 92 per 100,000 in Northern America. Additionally, the mortality and survival rates differ substantially among different world regions, which is primarily due to factors such as population structure, genetic factors, socioeconomic status and environment (Momenimovahed & Salehiniya, 2019). Although breast cancer is most prevalent in women in older age groups, the impact remains on women under the age of 45 (Center for Disease Control and Prevention, 2021). With the ongoing accelerated growth of breast cancer, healthcare systems worldwide and public health safety are undergoing significant burdens.

## 2 | BACKGROUND

Conventional hormonal and chemotherapy are commonly prescribed oral anticancer agents before and after neoadjuvant and adjuvant therapies to maintain remission and prevent recurrence. Females with invasive breast cancer, along with hormone receptor-positive expression, are recommended explicitly with the use of adjuvant endocrine therapies to increase overall survival (Treatment initiated for experimental therapies, n.d.). When prescribing oral anticancer agents in outpatient settings, the outpatient treatment outcomes reflect the patients' overall survival rates, progression-free survival, time to progression and quality of life associated with the use of oral hormonal, endocrine and chemotherapy agents. Despite the advantages of oral treatments, non-adherence to these medications prescribed in outpatient settings has become an ongoing concern for the growing population of breast cancer patients (Ades et al., 2017). Longitudinal studies in patients with breast cancer on oral endocrine treatments show the rates of medication adherence decline over time, while some studies reflected rates dropping approximately 50% adherence by 5-year follow-up (Greer et al., 2016).

Adverse drug reactions (ADRs) are defined as undesired and harmful events caused by pharmaceutical products (Khalil & Huang, 2020). Experiencing these occurrences is associated with lower medication adherence and poor treatment outcomes (Berhe et al., 2017). The World Health Organization defines an ADR as 'any response to a drug which is noxious and unintended, and occurs at normal doses used for prophylaxis, diagnosis, or therapy of disease, or the modification of physiological function (World Health Organization, 2008)'. ADRs have a profound negative impact on the

patients' quality of life, as well as creating an increased long-term burden on the healthcare system. With various disease complications and comorbidities, breast cancer patients often experience a higher prevalence of polypharmacy challenges and greater risk for drug–drug interactions, ADRs, hospitalizations and increased mortality (Berhe et al., 2017; Calip et al., 2017).

Although the impact of medication non-adherence on chronic disease has been well-established, limited studies are available that define the direct implications and causal relationship of ADRs on medication non-adherence and treatment outcomes in outpatient settings. According to the World Health Organization (WHO), medication adherence is defined as 'the extent to which the patient follows medical instructions corresponding with agreed recommendations from a healthcare provider'. This may reflect behaviours such as seeking medical attention, filling prescriptions, taking medication appropriately and visiting follow-up appointments (Sabaté & World Health Organization, 2003). ADRs are one of the growing causes of morbidity and mortality and will continue to be a significant public health issue, specifically within the breast cancer patient population (Berhe et al., 2017). Currently, there is a plethora of literature that discuss the impact of ADRs on medication non-adherence and treatment outcomes in various therapeutic areas; however, there is a lack of a robust systematic review that explicitly highlight this causal association within the breast cancer patient population in outpatient settings. Hence, this study aims to discover the impact of ADRs of hormonal and chemotherapy on medication adherence and outpatient treatment outcomes in breast cancer through a systematic literature review.

## 3 | METHODS

### 3.1 | Protocol registration

This systematic review is being conducted following the reporting guidance from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P) statement. This protocol has been registered within the International Prospective Register of Systematic Reviews (PROSPERO) database (registration number CRD 42021291364) (Lin & Lin, 2021). Any revisions to this protocol will be documented and published alongside the systematic review results.

### 3.2 | Study eligibility

#### 3.2.1 | Inclusion criteria

We will include all published literature in English before 2022 that report ADRs with medication adherence and outpatient treatment outcomes as primary outcome measures, following the initiation of one or more oral hormonal, endocrine and chemotherapy agents in female patients diagnosed with breast cancer. Studies with mixed-gender cohorts that enrolled at least 80% of females in the study or reported demographic and outcome data separately for women will



be included. Quantitative studies that included observational study designs, such as cross-sectional, cohort and case-control studies, will be retained for review. Study settings in outpatient, ambulatory and home care will be included. Additionally, studies conducted in any country and patient age group will be evaluated for inclusion.

### 3.2.2 | Exclusion criteria

Studies that do not report ADRs and outpatient treatment outcomes as primary outcome measures will be excluded. Studies reporting

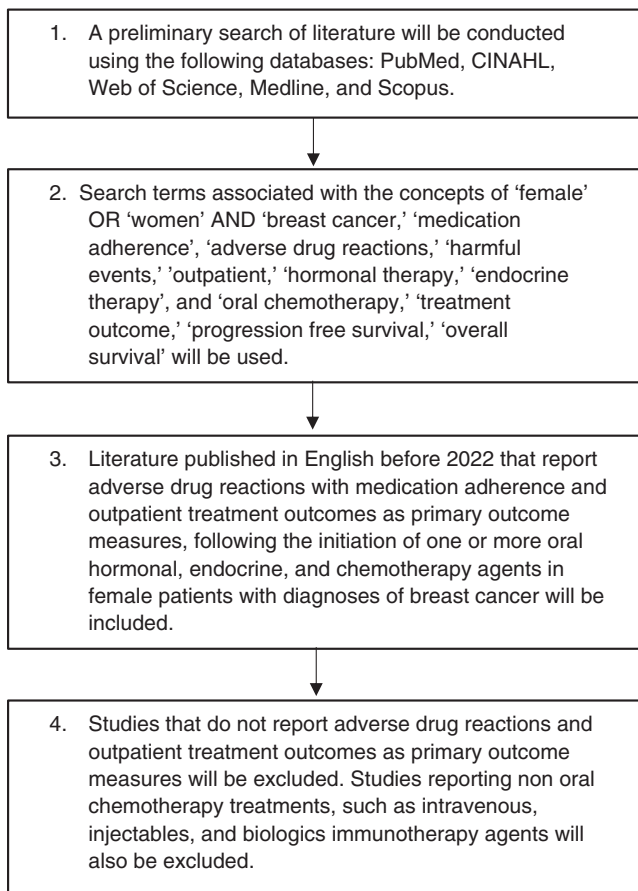


FIGURE 1 A schematic view of the systemic review process

TABLE 1 Study mock results

Citation	Publication year	Country	Study design	Sample size	Adherence measurement	Therapy	ADRs	Medication adherence	Treatment outcomes
Study 1									
Study 2									
Study 3									
Study 4									
Study 5									
Study 6									
...									

non-oral chemotherapy treatments, such as intravenous, injectables and biologic immunotherapy agents, will also be excluded. Additional exclusion criteria include patients treated with intravenous and injectable oncolytic for non-breast cancer oncological conditions or treatments initiated for clinical trial purposes.

### 3.3 | Outcome measures

The outcomes of interest will be medication adherence and outpatient treatment outcomes associated with oral hormonal, endocrine and chemotherapy agents. The reported medication adherence will be measured by direct pill counts, patient self-reports, electronic monitoring systems or other standard methods (e.g. calculated from pharmacy administrative/claims data), while treatment outcomes are measured by survival rate, remission rate and quality of life.

### 3.4 | Search strategy

The search strategy will include a 4-stage protocol (Figure 1). A preliminary search of articles will be completed using the following databases: PubMed, CINAHL, Web of Science, Medline and Scopus databases. The search consisted of keywords and controlled vocabulary used in the title and the abstract as free-text words. Terms associated with the concepts of 'female' OR 'women' AND 'breast cancer', 'medication adherence', 'adverse drug reactions', 'harmful events', 'outpatient', 'hormonal therapy', 'endocrine therapy', and 'oral chemotherapy', 'treatment outcomes', 'progression-free survival' and 'overall survival', were combined with terms related to 'breast cancer' AND 'breast ductal carcinoma'. Search limits were added to the searches to exclude non-English articles. All duplicated references will be identified and removed before further screening.

#### 3.4.1 | Quality assessment and quality appraisal

The quality assessment of this study will be conducted using the Joanna Briggs Institute (JBI) critical appraisal tools (Joanna Briggs Institute, n.d.). The appraisal tools are checklists that included yes, no, unclear and not applicable as the options for the reviewers to



TABLE 2 Quality assessment for cohort studies

	Study 1	Study 2	Study 3	Study 4	Study 5	Study 6	...
Cross-sectional studies							
Were the criteria for inclusion in the sample clearly defined?							
Were the study subjects and the setting described in detail?							
Was the exposure measured in a valid and reliable way?							
Were objective, standard criteria used for measurement of the condition?							
Were confounding factors identified?							
Were strategies to deal with confounding factors stated?							
Were the outcomes measured in a valid and reliable way?							
Was appropriate statistical analysis used?							
Cohort studies							
Were the two groups similar and recruited from the same population?							
Were the exposures measured similarly to assign people to both exposed and unexposed groups?							
Was the exposure measured in a valid and reliable way?							
Were confounding factors identified?							
Were strategies to deal with confounding factors stated?							
Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?							
Were the outcomes measured in a valid and reliable way?							
Was the follow-up time reported and sufficient to be long enough for outcomes to occur?							
Was follow-up complete, and if not, were the reasons to loss to follow-up described and explored?							
Were strategies to address incomplete follow-up used?							
Was appropriate statistical analysis used?							
Case-control Studies							
Were the groups comparable other than the presence of disease in cases or the absence of disease in controls?							
Were cases and controls matched appropriately?							
Were the same criteria used for identification of cases and controls?							
Was exposure measured in a standard, valid and reliable way?							
Was exposure measured in the same way for cases and controls?							
Were confounding factors identified?							
Were strategies to deal with confounding factors stated?							

TABLE 2 (Continued)

	Study 1	Study 2	Study 3	Study 4	Study 5	Study 6	...
Were outcomes assessed in a standard, valid and reliable way for cases and controls?							
Was the exposure period of interest long enough to be meaningful?							
Was appropriate statistical analysis used?							

select. The JBI critical appraisal checklist analytical cross-sectional studies consist of eight questions that review the inclusion criteria, study subjects, the exposure, study objective, confounding factors, strategies described to address confounding factors, outcomes and statistical analysis (Joanna Briggs Institute, n.d.).

The assessment tool for cohort studies consists of 11 questions that assess the study populations, the exposure measures for the exposed and unexposed groups, the validity and reliability of the exposure measurement, confounding factors, strategies to deal with confounding factors, participants free of the outcome at the start of the study, outcome measurement, the length and completeness of the follow-up time, strategies to address incomplete follow-up and the appropriateness of the statistical analysis.

Finally, the critical appraisal tool for case-control studies consist of 10 questions that evaluate the comparability of the study groups and controls, the criteria used for identifying cases and controls, measurements of the exposure, confounding factors, strategies to address confounding factors, outcome assessment, the length of the exposure period and the appropriateness of the statistical analysis. Two independent authors will assess the quality of each selected study. Disagreements among the reviewers will be discussed and resolved during consensus meetings.

### 3.5 | Data extraction

An extraction template will be used for data extraction that contains the authors' names, publication year, country, study design, sample size, adherence measurement, the type of chemotherapy, ADRs, medication adherence and treatment outcomes. Two independent authors will screen the full texts of each identified article and extract the data.

### 3.6 | Data synthesis and statistical analysis

The two primary reviewers will review the final data. The extraction template containing relevant data elements will be collected for statistical analysis. Data will be analysed using the SPSS 22.0 software (IBM Corp). We will use Kappa statistics and percentage agreement (kappa value of 0.8 or higher indicates excellent agreement) to assess the agreement between the two reviewers on study selection and quality assessment. A meta-analysis will be conducted using Review Manager (RevMan) Version 5.3 for Windows for each

outcome of interest under the situation where the outcome is assessed in at least two studies using similar measures. Heterogeneity will be evaluated using Cochrane's Q test and  $I^2$  to determine the random effect. A random-effect model will be used if  $I^2$  exceeds greater than 50%, which indicates a significant or considerable heterogeneity.

## 4 | RESULTS

Table 1 illustrates the mock result table of the study results. Table 2 depicts an example of the quality assessment checklist that will be performed by the reviewers.

## 5 | DISCUSSION

Breast cancer cases continue to grow worldwide and have become an urgent public health issue. Medication adherence is key to maximizing treatment outcomes, increasing survival rates and alleviating the healthcare burden. ADRs create a significant barrier to medication adherence, which highly impacts patients' treatment outcomes and quality of life. Hence, the roles of healthcare professionals in managing ADRs are crucial to help optimize treatment outcomes, provide symptom reliefs and maximize patients' overall quality of life.

Through identifying the impact of ADRs on medication non-adherence, this systematic review will shed light on the convoluted impact of medication non-adherence on the breast cancer patient population and support determining strategies to address this issue. This review will serve as the basis for further public health research examining health issues derived from medication non-adherence in the oncology patient population, which will be beneficial for the development and implementation of health initiatives and educational programmes to address this ongoing public health issue.

## 6 | CONCLUSION

This systematic review will provide evidence on the impact of ADRs on medication non-adherence and treatment outcomes in female breast cancer. We will conduct a meta-analysis to validate the relationship between ADRs on medication non-adherence and treatment outcomes when sufficient data are available. Overall, the review will complement the evidence based on the current

understanding of the effects of medication non-adherence in the female breast cancer population.

#### AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE\*): (1) substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content. \*<http://www.icmje.org/recommendations/>

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#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author;(K.L.), upon reasonable request.

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# Linking nursing outcomes classification to the self- and family management framework

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## Abstract

**Aim:** Establish linkages between components of the Self- and Family Management Framework and outcomes of the Nursing Outcomes Classification to evaluate the comprehensiveness of outcomes addressing self- and family management in the Nursing Outcomes Classification.

**Design:** Descriptive study.

**Methods:** Experts conducted a six-step process to establish linkages: (1) preliminary mapping of all relevant nursing outcomes to the framework; (2) development of checklists for team members serving as 'identifiers' and 'reviewers'; (3) mapping all relevant nursing outcomes to the framework; (4) final agreement on mapped outcomes; (5) establishment of inter-rater reliability; and (6) discussion of findings with authors of the Self- and Family Management Framework.

**Results:** Three hundred and sixty-three nursing outcomes were identified as related to the management of chronic disease across all components of the framework: outcomes related to patient self-management ( $n = 336$ ), family functioning ( $n = 16$ ) and family caregivers ( $n = 11$ ).

**Conclusion:** The Nursing Outcomes Classification outcomes comprehensively address self-management, and, less so, family functioning, and caregivers.

**Implications:** Established linkages can be used by nurses to track and support patient and family management outcomes across the care continuum.

**Patient or public contribution:** Linking standardized nursing outcomes to the Self- and Family Management Framework can assist in goal setting and measurement of nursing care during chronic disease management. This work can help describe to funders, policy makers and others invested in health care reform the specific contributions of nurses to self- and family management of chronic disease.

**Impact:** This paper demonstrates the linkages between components of the Self- and Family Management Framework and Nursing Outcomes Classification outcomes.

**Abbreviations:** NOC, Nursing Outcomes Classification; SFMF, Self- and Family Management Framework; SNTs, Standardized Nursing Terminologies.

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The results of this study offer the opportunity to quantify the impact of nursing care and enhance nursing practice for patients with chronic conditions as well as contribute to developing Nursing Outcomes Classification outcomes that consider self-management processes.

**KEYWORDS**

chronic illness, conceptual models of nursing, family, self-management

## 1 | INTRODUCTION

Chronic diseases such as heart disease, stroke, cancer, diabetes, obesity and arthritis require medical attention and affect activities of daily life (Centers for Disease Control and Prevention, 2022a). More than half of adults in the United States (U.S.) were diagnosed with at least one chronic condition in 2021 (Centers for Disease Control and Prevention, 2022b). The increasing burden of chronic diseases on individuals, families and the overall health care system, along with extended lifespans, demand effective patient education and active patient self-management (Toback & Clark, 2017). Self-management has been defined as the ability of the individual, in conjunction with family, community and health care professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural and spiritual consequences of chronic diseases (Wilkinson & Whitehead, 2009). Inadequate self-management can lead to worsening symptoms, rehospitalizations and decreased quality of life for patients with chronic diseases and their family caregivers (Toback & Clark, 2017).

Nurses play a key role in guiding self-management-based illness prevention and wellness programs in clinical and home settings (Anekwe & Rahkovsky, 2018). To exchange information about the health status of patients, nurses describe care needs, state nursing diagnoses and set measurable outcomes in delivering nursing care. The care plan process is a systematic way to identify nursing diagnoses, select desired outcomes, provide nursing interventions to address problems and evaluate nursing outcomes. In addition, sharing a plan of care supports interdisciplinary care team members in effectively managing and delivering patient-focused care.

The Self- and Family Management Framework (SFMF) (Grey et al., 2015), a theoretical framework that has been used to guide research and practice on self- and family management of chronic diseases, and the Nursing Outcomes Classification (NOC), a comprehensive, standardized classification of patient, family and community outcomes, can be synthesized to evaluate the completeness of outcomes addressed by nurses and other health care professionals for advancing self-management. We sought to establish linkages between components of the SFMF and outcomes of the NOC to evaluate the comprehensiveness of outcomes addressing self- and family management in the NOC.

## 2 | BACKGROUND

### 2.1 | The nursing outcomes classification (NOC)

Standardized nursing terminologies (SNTs) are commonly understood as sets of terms used to support nurses' clinical judgement when assessing patients to determine nursing diagnoses, select interventions and choose relevant patient outcomes in the documentation of nursing care (NANDA International [NANDA-I], 2022). NOC is a comprehensive terminology of patient, caregiver, family and community outcomes influenced by nursing care (Moorhead et al., 2018). Each outcome represents a concept that can be used to measure a state of a patient, caregiver, family or community before and after a nursing intervention (Moorhead et al., 2018). The impact of nursing care provided for patients and families can be evaluated using 5-point Likert-type scales (Gencbas et al., 2018).

The sixth edition of NOC contains 540 research-based outcomes for measuring health outcomes of individuals, family and community (Moorhead et al., 2018). The taxonomic structure of the classification has seven domains and 34 classes. For this study, the classes of Knowledge Health Condition, Knowledge Health Promotion and Health Management from the Health Knowledge and Behaviour Domains are considered most relevant to patients with chronic conditions (Table 1). In addition, there are 40 outcomes (e.g. Knowledge: Chronic Disease Management) focused on knowledge of clinical conditions such as cardiac disease and depression, 34 outcomes (e.g. Knowledge: Weight Management) focused on evaluation of knowledge of health promotion, and 29 outcomes (e.g. Self-Management: Chronic Disease) addressing self-management of clinical conditions. Also relevant to the SFMF are outcomes that focused on the family as a unit, that is, family functioning, and specific outcomes for the roles of family and caregivers (Moorhead et al., 2018). There are 51 outcomes directly focused on family and/or caregivers (e.g. Family Coping, Caregiver Emotional Health).

### 2.2 | The self- and family management framework (SFMF)

The SFMF is a theoretical framework that can be used to organize research that advances self- and family management science and



TABLE 1 The NOC taxonomy of sixth edition (Moorhead et al., 2018)

Level 1 domains	Domain I	Domain II	Domain III	Domain IV	Domain V	Domain VI	Domain VII
Level 2 Classes	Functional health (67 outcomes)	Physiologic health (124 outcomes)	Psychological health (46 outcomes)	Health Knowledge and Behaviour (184 outcomes)	Perceived health (53 outcomes)	Family health (47 outcomes)	Community health (19 outcomes)
	Energy Maintenance	Cardiopulmonary	Psychological Well-Being	Health Behaviour	Health and Life Quality	Family Caregiver Performance	Community Health Protection
	Growth and Health	Digestion and Nutrition	Psychological Adaptation	Health Beliefs	Satisfaction with Care	Family Member Health Status	Community Well-Being
	Mobility	Elimination	Self-Control	Health Management	Symptom Status	Family Well-Being	
	Self-Care	Fluid and Electrolytes	Social Interaction	Knowledge Health Condition		Parenting	
		Immune Response		Knowledge Health Promotion			
		Metabolic Regulation		Risk Control			
		Neurocognitive		Safety			
		Sensory Function					
		Therapeutic Response					
		Tissue Integrity					

to guide nursing care (Grey et al., 2006). The SFMF was originally developed by a group of faculty at the Yale School of Nursing in 2006 (Grey et al., 2006) and was revised in 2015 (Grey et al., 2015). Schulman-Green and colleagues have continued to refine the SFMF (Schulman-Green et al., 2012; Schulman-Green et al., 2016; Schulman-Green, Feder, Dionne-Odom, et al., 2021; Schulman-Green, Feder, Montano, et al., 2021). The SFMF has been used to guide research and practice on self- and family management of chronic diseases such as diabetes, cancer, heart failure and HIV/AIDS internationally (Schulman-Green, Feder, Montano, et al., 2021).

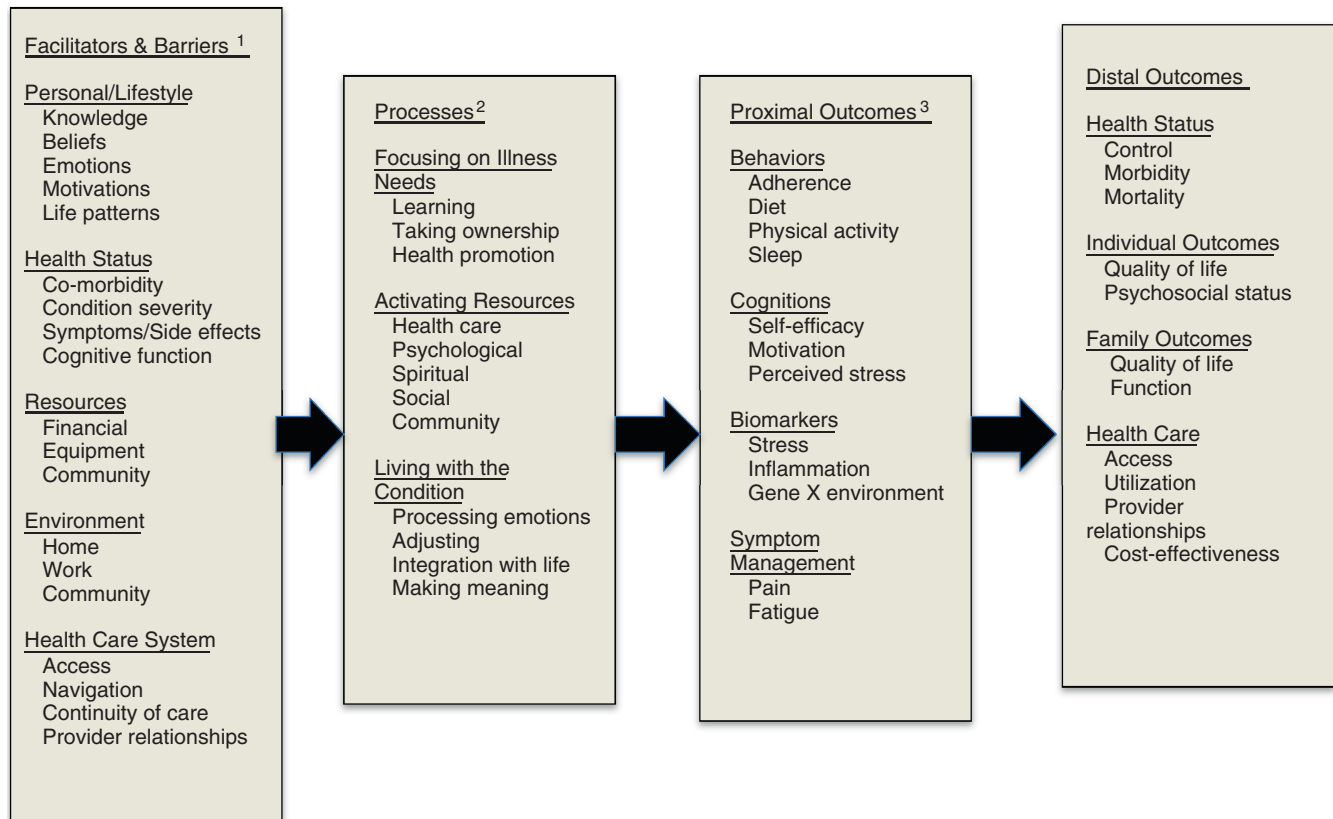
The 2015 version of the SFMF (Grey et al., 2015) depicts relationships among four components: Facilitators and barriers; processes; proximal outcomes; and distal outcomes of self- and family management (Grey et al., 2015). Facilitators and barriers influence self- and family management across chronic disease trajectories and is comprised of four categories—personal/lifestyle, health status, resources and health care system—with a total of 19 sub-categories. The processes component includes three categories—focusing on illness needs, activating resources and living with a chronic condition—with a total of 12 sub-categories. Proximal outcomes has four categories—behaviours, cognition, biomarkers and symptom management—with 13 sub-categories. Distal outcomes also have four categories—health status, individual outcomes, family outcomes and health care—with 12 sub-categories (Figure 1).

### 2.3 | Selection of the SFMF for linkage with the NOC

The SFMF was chosen to link to NOC due to its comprehensiveness in articulating facilitators and barriers to the adoption of self- and family management behaviours along with potential outcomes. Additionally, the framework supports the application of knowledge in real-life situations that matter to patients and families. As noted, NOC includes many outcomes for chronic conditions, self-management and family management which have the potential to measure numerous aspects of self- and family management. The SFMF components are evidence based and sufficiently complete to evaluate patient and family/caregiver outcomes of self- and family management. There is a need to develop linkages between standardized nursing terminologies and elements of the SFMF to facilitate research and practice in this area. This article focuses on the nursing outcomes relevant to the sub-categories of the SFMF.

### 2.4 | The value of the SFMF-NOC linkage

Nursing classification systems not only provide information about nursing care, but also offer the opportunity for critical thinking to aggregate nursing knowledge. A linkage can be defined as that which directs the relationship or association of concepts (Johnson et al., 2011). The use of NOC linkages for planning care has been developed for specific populations, such as elderly women with



<sup>1</sup>Schulman-Green, et al. (2014). Factors affecting self-management of chronic illness. Unpublished manuscript

<sup>2</sup>Schulman-Green, et al. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship*, 44,136-144.

<sup>3</sup>Ryan, P. & Sawin, K. (2009). The Individual and Family Self-Management Theory, *Nursing Outlook*, 57,217-225.

**FIGURE 1** The revised self- and family management framework (from Grey et al., 2015. *Nursing outlook*, 63, 162–170, with permission from Elsevier).

incontinence living in a nursing home (Gencbas et al., 2018), cancer patients requiring acute or chronic pain control in palliative care (Mello et al., 2016) and patients with COVID-19 (Moorhead et al., 2021; Swanson et al., 2021; Wagner et al., 2022). The linkage of NOC outcomes to the elements of the SFMF enables nurses to evaluate nursing outcomes in patients with chronic diseases to support clinical reasoning, quality and consistency of care.

### 3 | METHODS

#### 3.1 | Aim

The purpose of this study was to establish linkages between components of the SFMF and outcomes of the NOC to evaluate the comprehensiveness of outcomes addressing self- and family management.

#### 3.2 | Design

A descriptive study was carried out in six steps from July 2020 to July 2021: (1) preliminary mapping of all relevant NOC outcomes to the SFMF based on team expertise; (2) development of checklists for

team members serving as 'identifiers' and 'reviewers'; (3) mapping all relevant NOC outcomes to the SFMF; (4) final agreement on the results of the mapping process; (5) establishment of inter-rater reliability; and (6) discussion of findings and conclusions with authors of the SFMF. An iterative consensus-based approach has been used by previous researchers to implement the agreement-reaching process in group decision-making for this type of descriptive linkage study (Lucena et al., 2020; Moorhead et al., 2021; Swanson et al., 2021; Wagner et al., 2022).

We formed a team composed of five nurse experts with a range of 7 to 30 years of experience working with SNT as practicing nurses, researchers or developers of standardized terminologies. According to the Delphi technique used in the health sciences, a minimum of three experts should be invited to participate in this kind of study (Niederberger & Spranger, 2020), but the selection of qualified experts was considered more important for this study. It was essential that the reviewers for this project had a deep understanding of the taxonomy and extensive list of NOC outcomes. The team was formed based on the judgement of selected members of the NOC research team who are editors of the NOC (SM and ES) at the University of Iowa. All members of the team were involved in developing and validating NOC outcomes, including editors of the NOC (SM and ES) and former PhD students of the NOC (SC, HO and NCFO) at the University of Iowa.

Experts had one of two roles: identifier or reviewer. Identifiers were responsible for the identification of appropriate NOC outcomes aligned with the categories and sub-categories of the SFMF. To facilitate this process, we established conceptual definitions for each category and sub-category of the SFMF in preparation for linking NOC outcomes with the SFMF. The conceptual definitions of 16 categories and 54 sub-categories of the SFMF were specified (Oh et al., unpublished manuscript). To identify appropriate linkages between SFMF and NOC, identifiers read the conceptual definitions for the SFMF categories and sub-categories as well as the definitions of the NOC outcomes per the sixth edition of the NOC (Moorhead et al., 2018) and selected the NOC outcomes that aligned with the conceptual definitions of the SFMF.

Each reviewer's task was to evaluate whether the NOC outcomes chosen by identifiers for representation in a SFMF category were relevant to measuring the effectiveness of nursing interventions to improve self- and family management of chronic conditions. Reviewers also made suggestions for additional or new NOC outcomes if they perceived a better match than originally identified. For the identification and revision of linked NOC outcomes to the SFMF, we only considered NOC outcomes pertinent for the measurement of nursing interventions for the self-management of chronic diseases; we excluded NOC outcomes for acute conditions (e.g. Blood Loss Severity (0413)). The six steps undertaken by identifiers and reviewers are described below.

### 3.2.1 | Step 1: Preliminary mapping of all related NOC outcomes to the SFMF

The first step was to create the linkages (e.g. Knowledge: Chronic Disease Management under facilitators and barriers) for all the relevant NOC outcomes associated with the categories and sub-categories of the SFMF. This step was carried out independently by three identifiers (SC: facilitators and barriers, NCFO: processes and HO: proximal and distal outcomes). Each identifier considered all outcomes published in the sixth edition of NOC (Moorhead et al., 2018). Based on these preliminary linkages, research team members discussed limitations and challenges of creating linkages between NOC outcomes and categories/sub-categories of the SFMF and how we could move forward to further develop the linkages.

### 3.2.2 | Step 2: Development of checklists for identifiers and reviewers

In the second step, we developed checklists for the three identifiers and all reviewers. The checklists were intended to guide the identifiers and reviewers to link NOC outcomes and sub-categories of the SFMF of chronic conditions for consistency when doing their work. The checklists assisted team members in developing a more focused set of linkages to guide nurses in the care of their patients with chronic conditions and their family caregivers. They were

developed based on the vast team experience mapping concepts to NOC outcomes (Johnson et al., 2011; Lucena et al., 2020; Moorhead et al., 2021; Swanson et al., 2021; Wagner et al., 2022). The checklist for identifiers includes five items, for example, 'Read the definitions and indicators of the nursing outcomes from *Nursing Outcomes Classification (NOC) 6th Edition (2018)* you would select with the sub-category of the SFMF'. The checklist for reviewers consists of three items (definitions, representativeness, content relevance) and eight criteria, for example, 'Evaluate if the definition of the nursing outcome represents the sub-category of the SFMF'.

### 3.2.3 | Step 3: Mapping all relevant NOC outcomes to the SFMF

In the third step, we focused on the linkages of relevant NOC outcomes to the SFMF based on team expertise and guided by the checklist for identifiers described in Step 2. All 540 outcomes of the 34 classes of the NOC were reviewed to consider linkages with the sub-categories of the SFMF.

### 3.2.4 | Step 4: Final agreement on the mapping process

The fourth step was related to the final linkage agreement of NOC outcomes to the SFMF. NOC outcomes were confirmed as mapping to a SFMF category if they were representative and relevant to the categories and sub-categories of the SFMF by consensus among reviewers. After an identifier reviewed a domain extensively, all other team members reviewed the linkages for that domain. Next, the identifier led a discussion about the domain with all team members. Disagreements and newly suggested NOC outcomes were discussed until consensus was reached by all team members. For example, Psychosocial Adjustment: Life Change (1305) was initially mapped with Home under the Environment category for the component facilitators and barriers by one identifier, but the reviewers decided there were better matched sub-categories. Therefore, this outcome was mapped with multiple sub-categories: Emotions and life patterns under the facilitators and barriers component and adjusting under the processes component.

### 3.2.5 | Step 5: Establishment of inter-rater reliability

The fifth step of this study was the establishment of inter-rater reliability using two different approaches: Fleiss' Kappa value and Gwet's AC1. The inter-rater reliability of the mapped list of NOC outcomes was first determined by calculating the Fleiss' Kappa value (Fleiss, 1971). Kappa values range from -1 to +1 in which +1 represents a perfect agreement (Dettori & Norvell, 2020). Pre-established criteria have been used to judge the quality of a study; kappa greater than 0.8 demonstrates moderate concordance, and kappa greater

than or equal to 0.8 and less than 1 shows strong concordance. Although Kappa value and its modifications such as Fleiss' Kappa have been extensively used in research, the probability with which a rater will evaluate the nursing outcome as pertinent or not pertinent to the SFMF (prevalence) and frequency at which the raters choose a particular category (bias) can limit the results, producing lower Fleiss' Kappa values with high per cent agreement between raters (Dettori & Norvell, 2020). Due to the above-mentioned limitations of the Kappa value, we also calculated Gwet's AC1 statistic that provides a reasonable chance-corrected agreement measure considering the percentage level of agreement (Gwet, 2014). Although the interpretation of AC1 is similar to generalized kappa (Fleiss, 1971), AC1 provides a more robust measurement of inter-rater reliability.

### 3.2.6 | Step 6: Discussion with authors of the SFMF

We arranged a video conference with authors of the SFMF (DSG and colleagues) to discuss the mapping of NOC outcomes with sub-categories of the SFMF. We wanted to verify that the linkages were consistent with the intended focus of the framework. Two one-hour meetings occurred, and notes were taken to record main discussion points. A third meeting was held to address any issues identified prior to refinement of the results.

## 4 | RESULTS

In the first step, 560 linkages, including duplicates in different sub-categories, were identified. During a series of discussions, a total of 15 outcomes were added in the third step because the experts agreed that selected outcomes were pertinent to self- and family management. At the end of mapping process, duplicated outcomes were accounted for, and a total of 364 unique nursing outcomes were selected to create 540 linkages across the four components of the SFMF deemed appropriate for patients with chronic diseases and their family.

In some situations, outcomes were used more than once across the four components [e.g. Motivation (1209), Pain Control (1605)]. Tables 2–5 show the linkages between NOC outcomes and the four components of the SFMF. The outcomes are presented in alphabetical order. Two hundred and thirty-three outcomes were linked to facilitators and barriers, 183 outcomes were linked to processes, 61 outcomes were linked to proximal outcomes and 58 outcomes were linked to the distal outcomes component of the SFMF. Three hundred and sixty-four nursing outcomes were identified as related to the management of chronic disease across all components of the framework; 336 NOC outcomes related to patient self-management, 16 related to family management and 11 related to the role of family caregivers.

The facilitators and barriers component of the SFMF had the most linkages with NOC outcomes, followed by processes, distal outcomes and proximal outcomes. We could not match eight

SFMF sub-categories (i.e. co-morbidity Co-morbidityHealth Status category, Financial Resources category, Work under Environment category) with NOC outcomes because relevant nursing outcomes reflecting these sub-categories do not exist in the classification. Table 6 shows the inter-rater reliability for the NOC linkages of the four SFMF components. After three rounds of agreement surveys and several discussion sessions, we achieved 100% agreement, 1 of the Fleiss kappa values, and 1 of the Gwet's AC1 values for the four components, indicating a perfect agreement between the three raters in the fifth step.

## 5 | DISCUSSION

We developed NOC linkages with the SFMF for individuals with chronic diseases and their family caregivers and identified a reproducible and rigorous way to link nursing outcomes with the SFMF to assist in the application of self- and family management knowledge in practice. Achieving consensus among experts required several discussions and a thoughtful review of relevant categories while considering the characteristics of the complex dynamics of self- and family management. The linkages showed high agreement between SFMF and NOC outcomes. These results demonstrate that the SFMF aligns with nursing processes to improve self-management for patients with chronic diseases and their family caregivers. The sixth edition of NOC has a enough self-management outcomes to comprehensively support the strength of linkage work between the NOC and the SFMF. Regardless of the chronic condition, the identification of the facilitators and barriers and the development of patient-centric strategies to deal with challenges of self-management allow individuals to more effectively manage their illness and improve health outcomes (Anekwe & Rahkovsky, 2018).

### 5.1 | Advantages of linkage work for clinical nursing practice

From this study, a total of 363 unique nursing outcomes across the four components of the SFMF were identified as appropriate to evaluate interventions for patients with chronic diseases and their family caregivers. Nurses play important roles at the frontline of health care for patients with chronic diseases in a wide variety of settings, including health promotion and preventive care. They work with interdisciplinary teams who are responsible for understanding and addressing complex issues for patients with chronic diseases and for providing person-centred care. NOC outcomes linked with the SFMF can be used across the care continuum to follow patient outcomes throughout a chronic disease episode or over an extended period as the teams and family caregivers provide support.

When nurses create the care plan for patients with chronic disease, they can choose which outcomes will be evaluated based on nursing diagnoses and interventions with the perspective of the SFMF. As nurses assess facilitators and barriers and processes and

TABLE 2 NOC linkages to the revised self- and family management framework: Facilitators &amp; Barriers

Category	Sub-category	Code	NOC outcomes	Code	NOC outcomes
Personal/Lifestyle	Knowledge	3200	Knowledge: Allergy Management	3206	Knowledge: Human Immunodeficiency Virus Management
		1845	Knowledge: Anticoagulation Therapy Management	1837	Knowledge: Hypertension Management
		1831	Knowledge: Arthritis Management	1842	Knowledge: Infection Management
		1832	Knowledge: Asthma Management	1856	Knowledge: Inflammatory Bowel Disease Management
		3201	Knowledge: Autism Spectrum Disorder Management	1857	Knowledge: Kidney Disease Management
		1833	Knowledge: Cancer Management	1858	Knowledge: Lipid Disorder Management
		1834	Knowledge: Cancer Threat Reduction	3207	Knowledge: Lymphedema Management
		1830	Knowledge: Cardiac Disease Management	1808	Knowledge: Medication
		3202	Knowledge: Cardiac Rehabilitation	1838	Knowledge: Multiple Sclerosis Management
		3203	Knowledge: Celiac Disease Management	3208	Knowledge: Musculoskeletal Rehabilitation
		3204	Knowledge: Chronic Anaemia Management	1859	Knowledge: Osteoporosis Management
		1847	Knowledge: Chronic Disease Management	1829	Knowledge: Ostomy Care
		1848	Knowledge: Chronic Obstructive Pulmonary Disease Management	1843	Knowledge: Pain Management
		1849	Knowledge: Coronary Artery Disease Management	1860	Knowledge: Peripheral Artery Disease Management
		1851	Knowledge: Dementia Management	1809	Knowledge: Personal Safety
		1836	Knowledge: Depression Management	1861	Knowledge: Pneumonia Management
		1820	Knowledge: Diabetes Management	1811	Knowledge: Prescribed Activity
		1867	Knowledge: Diagnostic & Therapeutic Procedures	1802	Knowledge: Prescribed Diet
		1803	Knowledge: Disease Process	1862	Knowledge: Stress Management
		1852	Knowledge: Dysrhythmia Management	1863	Knowledge: Stroke Management
1853	Knowledge: Eating Disorder Management	1864	Knowledge: Stroke Threat Reduction		
3205	Knowledge: Epilepsy Management	1812	Knowledge: Substance Use Control		
1828	Knowledge: Fall Prevention	1865	Knowledge: Thrombus Threat Reduction		
1805	Knowledge: Health Behaviour	1814	Knowledge: Treatment Procedure		
1806	Knowledge: Health Resources	1813	Knowledge: Treatment Regimen		
1854	Knowledge: Healthy Diet	1841	Knowledge: Weight Management		
1855	Knowledge: Healthy Lifestyle	3209	Knowledge: Wound Management		
1835	Knowledge: Heart Failure Management				
1700	Health Beliefs	1703	Health Beliefs: Perceived Resources		
1701	Health Beliefs: Perceived Ability to Perform	1704	Health Beliefs: Perceived Threat		
1702	Health Beliefs: Perceived Control	2001	Spiritual Health		

TABLE 2 (Continued)

Category	Sub-category	Code	NOC outcomes	Code	NOC outcomes
Emotions		1214	Agitation Level	1210	Fear Level
		1211	Anxiety Level	1201	Hope
		2506	Caregiver Emotional Health	1203	Loneliness Severity
		2208	Caregiver Stressors	1204	Mood Equilibrium
		2508	Caregiver Well-Being	1306	Pain: Adverse Psychological Response
		2002	Personal Well-Being	1217	Panic Level
		2011	Comfort Status: Psychospiritual	1309	Personal Resiliency
		1302	Coping	1305	Psychosocial Adjustment: Life Change
		1208	Depression Level	1216	Social Anxiety Level
		2109	Discomfort Level	1212	Stress Level
Motivations		2600	Family Coping	2003	Suffering Severity
		2608	Family Resiliency	1311	Relocation Adaptation
		1209	Motivation	1205	Self-Esteem
		0006	Psychomotor Energy	1206	Will to Live
Life Patterns		1600	Adherence Behaviour	1603	Health Seeking Behaviour
		1601	Compliance Behaviour	1604	Leisure Participation
		1632	Compliance Behaviour: Prescribed Activity	2013	Lifestyle Balance
		1622	Compliance Behaviour: Prescribed Diet	1606	Participation in Health Care Decisions
		1623	Compliance Behaviour: Prescribed Medication	1638	Patient Engagement Behaviour
		1705	Health Orientation	1305	Psychosocial Adjustment: Life Change
		X	X		
		0705	Allergic Response: Localized	0909	Neurological Status
Co-Morbidity Condition Severity		0706	Allergic Response: Systemic	0910	Neurological Status: Autonomic
		1106	Burn Healing	0911	Neurological Status: Central Motor Control
		0414	Cardiopulmonary Status	0912	Neurological Status: Consciousness
		0916	Delirium Level	0913	Neurological Status: Cranial Sensory/Motor Function
		0920	Dementia Level	0917	Neurological Status: Peripheral
		2110	Dry Eye Severity	0914	Neurological Status: Spinal Sensory/Motor Function
		0007	Fatigue Level	2115	Peripheral Artery Disease Severity
		0603	Fluid Overload Severity	1913	Physical Injury Severity
		1015	Gastrointestinal Function	0415	Respiratory Status
		0607	Hypercalcemia Severity	0410	Respiratory Status: Airway Patency
		0608	Hyperchloremia Severity	0402	Respiratory Status: Gas Exchange
		2111	Hyperglycemia Severity	0403	Respiratory Status: Ventilation



TABLE 2 (Continued)

Category	Sub-category	Code	NOC outcomes	Code	NOC outcomes
		0609	Hyperkalemia Severity	2118	Seizure Severity
		0610	Hypermagnesemia Severity	2405	Sensory Function
		0611	Hypernatremia Severity	2401	Sensory Function: Hearing
		0612	Hyperphosphatemia Severity	2402	Sensory Function: Proprioception
		2112	Hypertension Severity	2400	Sensory Function: Tactile
		0613	Hypocalcemia Severity	2403	Sensory Function: Taste & Smell
		0614	Hypocholesterolemia Severity	2404	Sensory Function: Vision
		2113	Hypoglycemia Severity	0417	Shock Severity: Anaphylactic
		0615	Hypokalemia Severity	0418	Shock Severity: Cardiogenic
		0616	Hypomagnesemia Severity	0419	Shock Severity: Hypovolemic
		0617	Hyponatremia Severity	0420	Shock Severity: Neurogenic
		0618	Hypophosphatemia Severity	0421	Shock Severity: Septic
		2114	Hypotension Severity	0211	Skeletal Function
		0504	Kidney Function	1010	Swallowing Status
		0803	Liver Function	1011	Swallowing Status: Oesophageal Phase
		0619	Metabolic Acidosis Severity	1012	Swallowing Status: Oral Phase
		0620	Metabolic Alkalosis Severity	1013	Swallowing Status: Pharyngeal Phase
		0804	Metabolic Function	0503	Urinary Elimination
	<b>Symptoms/Side Effects</b>	2116	Chemotherapy: Disruptive Physical Effects	2106	Nausea & Vomiting: Disruptive Effects
		0008	Fatigue: Disruptive Effects	1306	Pain: Adverse Psychological Response
		0204	Immobility Consequences: Physiological	2101	Pain: Disruptive Effects
		0205	Immobility Consequences: Psycho-Cognitive	1407	Substance Addiction Consequences
		0707	Immune Hypersensitivity Response	2103	Symptom Severity
		2117	Lymphedema Severity		
	<b>Cognitive Function</b>	0919	Abstract Thinking	0905	Concentration
		0900	Cognition	0906	Decision-Making
		0901	Cognitive Orientation	2015	Health Literacy Behaviour
		0902	Communication	0907	Information Processing
		0903	Communication: Expressive	0908	Memory
		0904	Communication: Receptive		

TABLE 2 (Continued)

Category	Sub-category	Code	NOC outcomes	Code	NOC outcomes	
Resources	Financial	X	X			
	Equipment	3000	Client Satisfaction: Access to Care Resources			
	Community	2204	Caregiver-Patient Relationship	1504	Social Support	
		1503	Social Involvement			
Environment	Home	2612	Family risk control: Bullying	2601	Family Social Climate	
		2204	Caregiver-patient relationships	2609	Family Support During Treatment	
		2212	Family Performance: Dementia care	2203	Caregiver Lifestyle Disruption	
		2604	Family normalization	2210	Caregiver Role Endurance	
	Work	X	X			
		2700	Community Competence	2812	Community Risk Control: Environmental Hazards	
	Community	2807	Community Health Screening Effectiveness	2803	Community Risk Control: Lead Exposure	
		2800	Community Immune Status	2809	Community Risk Control: Obesity	
		2808	Community Program Effectiveness	2813	Community Risk Control: Suicide	
		2704	Community Resiliency	2810	Community Risk Control: Unhealthy Cultural Traditions	
		2811	Community Risk Control: Bullying	2805	Community Risk Control: Violence	
		2801	Community Risk Control: Chronic Disease	2702	Community Violence Level	
		2802	Community Risk Control: Communicable Disease	1910	Safe Health Care Environment	
		3000	Client Satisfaction: Access to Care Resources			
Health Care System	Access	3000	Client Satisfaction: Access to Care Resources			
	Navigation	3015	Client Satisfaction: Case Management	3003	Client Satisfaction: Continuity of Care	
Provider Relationships	Continuity of Care	3015	Client Satisfaction: Case Management	3003	Client Satisfaction: Continuity of Care	
		3014	Client Satisfaction	3007	Client Satisfaction: Physical Environment	
	Relationships	3001	Client Satisfaction: Caring	3008	Client Satisfaction: Protection of Rights	
		3002	Client Satisfaction: Communication	3009	Client Satisfaction: Psychological Care	
		3004	Client Satisfaction: Cultural Needs Fulfilment	3010	Client Satisfaction: Safety	
		3005	Client Satisfaction: Functional Assistance	3011	Client Satisfaction: Symptom Control	
		3016	Client Satisfaction: Pain Management	3012	Client Satisfaction: Teaching	
		3006	Client Satisfaction: Physical Care	3013	Client Satisfaction: Technical Aspects of Care	

TABLE 3 NOC linkages to the revised self- and family management framework: Processes

Category	Sub-category	Code	NOC outcomes	Code	NOC outcomes
Focusing on Illness Needs (continued)	Learning	2014	Financial Literacy Behaviour	1855	Knowledge: Healthy Lifestyle
		2015	Health Literacy Behaviour	1835	Knowledge: Heart Failure Management
		3200	Knowledge: Allergy Management	3206	Knowledge: Human Immunodeficiency Virus Management
		1845	Knowledge: Anticoagulation Therapy Management	1837	Knowledge: Hypertension Management
		1831	Knowledge: Arthritis Management	1842	Knowledge: Infection Management
		1832	Knowledge: Asthma Management	1856	Knowledge: Inflammatory Bowel Disease Management
		3201	Knowledge: Autism Spectrum Disorder Management	1857	Knowledge: Kidney Disease Management
		1833	Knowledge: Cancer Management	1858	Knowledge: Lipid Disorder Management
		1830	Knowledge: Cardiac Disease Management	3207	Knowledge: Lymphedema Management
		3202	Knowledge: Cardiac Rehabilitation	1808	Knowledge: Medication
		3203	Knowledge: Celiac Disease Management	1838	Knowledge: Multiple Sclerosis Management
		3204	Knowledge: Chronic Anaemia Management	3208	Knowledge: Musculoskeletal Rehabilitation
		1847	Knowledge: Chronic Disease Management	1859	Knowledge: Osteoporosis Management
		1848	Knowledge: Chronic Obstructive Pulmonary Disease Management	1829	Knowledge: Ostomy Care
		1849	Knowledge: Coronary Artery Disease Management	1843	Knowledge: Pain Management
		1851	Knowledge: Dementia Management	1860	Knowledge: Peripheral Artery Disease Management
		1836	Knowledge: Depression Management	1809	Knowledge: Personal Safety
		1820	Knowledge: Diabetes Management	1861	Knowledge: Pneumonia Management
		1867	Knowledge: Diagnostic & Therapeutic Procedures	1811	Knowledge: Prescribed Activity
		1803	Knowledge: Disease Process	1802	Knowledge: Prescribed Diet
		1852	Knowledge: Dysrhythmia Management	1862	Knowledge: Stress Management
		1853	Knowledge: Eating Disorder Management	1863	Knowledge: Stroke Management
		1804	Knowledge: Energy Conservation	1812	Knowledge: Substance Use Control
		3205	Knowledge: Epilepsy Management	1866	Knowledge: Time Management
		1828	Knowledge: Fall Prevention	1814	Knowledge: Treatment Procedure
		1805	Knowledge: Health Behaviour	1813	Knowledge: Treatment Regimen
		1806	Knowledge: Health Resources	1841	Knowledge: Weight Management
1854	Knowledge: Healthy Diet	3209	Knowledge: Wound Management		
<b>Taking Ownership</b>					
		1402	Anxiety Self-Control	3113	Self-Management: Autism Spectrum Disorder
		1409	Depression Self-Control	3114	Self-Management: Cancer
		1403	Distorted Thought Self-Control	1617	Self-Management: Cardiac Disease
		1411	Eating Disorder Self-Control	3115	Self-Management: Celiac Disease

TABLE 3 (Continued)

Category	Sub-category	Code	NOC outcomes	Code	NOC outcomes
		1404	Fear Self-Control	3116	Self-Management: Chronic Anaemia
		1405	Impulse Self-Control	3102	Self-Management: Chronic Disease
		1618	Nausea and Vomiting Control	3103	Self-Management: Chronic Obstructive Pulmonary Disease
		1615	Ostomy Self-Care	3104	Self-Management: Coronary Artery Disease
		1605	Pain Control	1619	Self-Management: Diabetes
		1412	Panic Self-Control	3105	Self-Management: Dysrhythmia
		1614	Personal Autonomy	3106	Self-Management: Heart Failure
		1620	Seizure Self-Control	3117	Self-Management: Human Immunodeficiency Virus
		0300	Self-Care: Activities of Daily Living	3107	Self-Management: Hypertension
		0301	Self-Care: Bathing	3118	Self-Management: Infection
		0302	Self-Care: Dressing	3119	Self-Management: Inflammatory Bowel Disease
		0303	Self-Care: Eating	3108	Self-Management: Kidney Disease
		0305	Self-Care: Hygiene	3120	Self-Management: Known Allergy
		0306	Self-Care: Instrumental Activities of Daily Living	3109	Self-Management: Lipid Disorder
		0307	Self-Care: Non-Parenteral Medication	3121	Self-Management: Lymphedema
		0308	Self-Care: Oral Hygiene	1631	Self-Management: Multiple Sclerosis
		0309	Self-Care: Parenteral medication	3110	Self-Management: Osteoporosis
		0310	Self-Care: Toileting	3111	Self-Management: Peripheral Artery Disease
		0313	Self-Care Status	3122	Self-Management: Pneumonia
		3101	Self-Management: Anticoagulation Therapy	3123	Self-Management: Stroke
		3112	Self-Management: Arthritis	3124	Self-Management: Wound
		704	Self-Management: Asthma	1608	Symptom Control
		1600	Adherence Behaviour	1900	Immunization Behaviour
		1621	Adherence Behaviour: Healthy Diet	1610	Hearing Compensation Behaviour
		1629	Alcohol Abuse Cessation Behaviour	1603	Health Seeking Behaviour
		1616	Body Mechanics Performance	1604	Leisure Participation
		1636	Cardiac Rehabilitation Participation	1637	Musculoskeletal Rehabilitation Participation
		1601	Compliance Behaviour	1634	Personal Health Screening Behaviour
		1632	Compliance Behaviour: Prescribed Activity	1635	Personal Time Management
		1622	Compliance Behaviour: Prescribed Diet	1625	Smoking Cessation Behaviour
		1623	Compliance Behaviour: Prescribed Medication	1611	Vision Compensation Behaviour
		1630	Drug Abuse Cessation Behaviour	1626	Weight Gain Behaviour
		1633	Exercise Participation	1627	Weight Loss Behaviour
		1602	Health Promoting Behaviour	1628	Weight Maintenance Behaviour
	<b>Health Promotion</b>				

TABLE 3 (Continued)

Category	Sub-category	Code	NOC outcomes	Code	NOC outcomes
Activating Resources	Health Care	3000	Client Satisfaction: Access to Care Resources	1806	Knowledge: Health Resources
		3015	Client Satisfaction: Case Management	1606	Participation in Health Care Decisions
		3002	Client Satisfaction: Communication	1638	Patient Engagement Behaviour
		3003	Client Satisfaction: Continuity of Care	1613	Self-Direction of Care
		2605	Family Participation in Professional Care	1639	Self-Direction of Instrumental Activities of Daily Living
	Psychological	1700	Health Beliefs	1704	Health Beliefs: Perceived Threat
		1701	Health Beliefs: Perceived Ability to Perform	1705	Health Orientation
		1702	Health Beliefs: Perceived Control	1201	Hope
		1703	Health Beliefs: Perceived Resources	1209	Motivation
		2001	Spiritual Health		
Spiritual	2601	Family Social Climate	1503	Social Involvement	
	2609	Family Support During Treatment	1504	Social Support	
Social	2807	Community Health Screening Effectiveness	2801	Community Risk Control: Chronic Disease	
	2808	Community Program Effectiveness			
Living with the Condition	Processing Emotions	2506	Caregiver Emotional Health	1310	Guilt Resolution
		2508	Caregiver Well-being	1204	Mood Equilibrium
		1304	Grief Resolution		
		1300	Acceptance: Health Status	2608	Family Resiliency
		1308	Adaptation to Physical Disability	1309	Personal Resiliency
	Adjusting	1200	Body Image	1305	Psychosocial Adjustment: Life Change
		2210	Caregiver Role Endurance	1311	Relocation Adaptation
		1302	Coping	1501	Role Performance
		2600	Family Coping		
		2604	Family Normalization	2611	Family Normalization: Dementia
Integration with Life	2613	Family Normalization: Autism Spectrum Disorder	2013	Lifestyle Balance	
	1307	Dignified Life Closure	1205	Self-Esteem	
Making Meaning	1215	Self-Awareness	1206	Will to live	

TABLE 4 NOC linkages to the revised self- and family management framework: Proximal outcomes

Category	Sub-category	Code	NOC outcomes	Code	NOC outcomes
Behaviours	Adherence	1600	Adherence Behaviour	1637	Musculoskeletal Rehabilitation Participation
		1629	Alcohol Abuse Cessation Behaviour	1615	Ostomy Self-Care
		1636	Cardiac Rehabilitation Participation	1620	Seizure Self-Control
		1601	Compliance Behaviour	1625	Smoking Cessation Behaviour
		1630	Drug Abuse Cessation Behaviour		
	Diet	1623	Compliance Behaviour: Prescribed Medication	2301	Medication Response
		1621	Adherence Behaviour: Healthy Diet	1411	Eating Disorder Self-Control
	Physical Activity	1622	Compliance Behaviour: Prescribed Diet		
		0200	Ambulation	1637	Musculoskeletal Rehabilitation Participation
		0201	Ambulation: Wheelchair	2004	Physical Fitness
		0202	Balance	0211	Skeletal Function
		1616	Body Mechanics Performance	2021	Transfer Performance
		1632	Compliance Behaviour: Prescribed Activity	1626	Weight Gain Behaviour
		0212	Coordinated Movement	1627	Weight Loss Behaviour
		1633	Exercise Participation	1628	Weight Maintenance Behaviour
Sleep	0208	Mobility			
	0004	Sleep			
Cognitions	Self-Efficacy	1701	Health Beliefs: Perceived Ability to Perform	1704	Health Beliefs: Perceived Threat
		1702	Health Beliefs: Perceived Control	1215	Self-Awareness
		1703	Health Beliefs: Perceived Resources	1205	Self-Esteem
	Motivation	1705	Health Orientation	1206	Will to Live
		1209	Motivation		
	Perceived Stress	1214	Agitation Level	1210	Fear Level
		1211	Anxiety Level	1216	Social Anxiety level
		2506	Caregiver Emotional Health	1212	Stress Level
		2208	Caregiver Stressors	1217	Panic Level
1302	Coping				
Biomarkers	Stress	X	X		
	Inflammation	0705	Allergic Response: Localized	0417	Shock Severity: Anaphylactic
		0706	Allergic Response: Systemic	0421	Shock Severity: Septic
		0707	Immune Hypersensitivity Response		
	Gene X Environment	1634	Personal Health Screening Behaviour		
Symptom Management	Pain	1306	Pain: Adverse Psychological Response	2101	Pain: Disruptive Effects
		1605	Pain Control	2102	Pain Level
	Fatigue	0007	Fatigue Level	0006	Psychomotor Energy
		0008	Fatigue: Disruptive Effects		

select appropriate proximal and distal outcomes, they can better guide patients and plan more effectively with them and their families to provide care that addresses all components of chronic illness management. Moreover, these linkages allow nurses to evaluate nursing outcomes in a more accurate and measurable way. This evaluation

involves the measurement of an individual (e.g. personal health status), family (e.g. family support during treatment) or community state (e.g., community risk control: chronic disease), behaviour (e.g. compliance behaviour) or perception (e.g. self-awareness). This is a critical step in the nursing process because the interpretation of the



TABLE 5 NOC linkages to the revised self- and family management framework: Distal outcomes

Category	Sub-category	Code	NOC outcomes	Code	NOC outcomes
Health Status	Control	2300	Blood Glucose Level	0804	Metabolic Function
		0414	Cardiopulmonary Status	1004	Nutritional Status
		0401	Circulation Status	1005	Nutritional Status: Biochemical Measures
		0606	Electrolyte Balance	1007	Nutritional Status: Energy
		1050	Gastrointestinal Function	0422	Tissue Perfusion
		0504	Kidney Function	0802	Vital Signs
		0803	Liver Function	1006	Weight: Body Mass
	Morbidity		X		
	Mortality		X		
Individual Outcomes	Quality of life	2008	Comfort Status	2012	Comfort Status: Sociocultural
		2009	Comfort Status: Environment	2006	Personal Health Status
		2010	Comfort Status: Physical	2000	Quality of Life
		2011	Comfort Status: Psychospiritual	2001	Spiritual Health
	Psychosocial status	1302	Coping	1203	Loneliness Severity
		1208	Depression Level	1309	Personal Resiliency
		2109	Discomfort Level	2002	Personal Well-being
		1201	Hope		
Family Outcomes	Quality of Life	2506	Caregiver Emotional Health	2508	Caregiver Well-Being
		2507	Caregiver Physical Health	2606	Family Health Status
	Function	2206	Caregiver Performance: Indirect Care	2603	Family Integrity
		2202	Caregiver Home Care Readiness	2605	Family Participation in Professional Care
		2203	Caregiver Lifestyle Disruption	2212	Family Performance: Dementia Care
		2205	Caregiver Performance: Direct Care	2612	Family Risk Control: Bullying
		2210	Caregiver Role Endurance	2610	Family Risk Control: Obesity
		2204	Caregiver-Patient Relationship	2601	Family Social Climate
2602	Family Functioning	2609	Family Support during Treatment		
Health Care	Access	3000	Client Satisfaction: Access to Care Resources		
	Utilization	X	X		
	Provider Relationships	3014	Client Satisfaction	3004	Client Satisfaction: Cultural Needs Fulfilment
		3001	Client Satisfaction: Caring	3016	Client Satisfaction: Pain Management
		3015	Client Satisfaction: Case Management	3008	Client Satisfaction: Protection of Rights
		3002	Client Satisfaction: Communication	3009	Client Satisfaction: Psychological Care
		3003	Client Satisfaction: Continuity of Care	3012	Client Satisfaction: Teaching
	Cost-Effectiveness	X	X		

collected data enables nurses to evaluate the impact of interventions provided by nurses or other health care professionals.

One of the benefits of linkages of SNT and theoretical frameworks is the strengthening the comprehensiveness of the plan of care for patients with chronic diseases and retrieving standardized

nursing practice data in a computerized information system (Chae et al., 2020; Johnson et al., 2011). There is fast-growing demand for the reuse of clinical data and electronic health interventions for high-quality health care and population health management (Meystre et al., 2017; Schulman-Green, Feder, Montano, et al., 2021). If NOC

TABLE 6 Percent agreement, Fleiss' Kappa, and Gwet's AC1 across four dimensions for NOC linkages in the SFMF

Dimension	Facilitators and barriers	Process	Proximal outcomes	Distal outcomes
Percent Agreement $\pm$ SD	0.893 $\pm$ 0.016	0.975 $\pm$ 0.009	0.925 $\pm$ 0.027	0.990 $\pm$ 0.010
Fleiss' Kappa $\pm$ SD	-0.057 $\pm$ 0.009	-0.013 $\pm$ 0.005	-0.039 $\pm$ 0.015	-0.005 $\pm$ 0.005
Gwet's AC1 $\pm$ SD	0.881 $\pm$ 0.019	0.974 $\pm$ 0.01	0.919 $\pm$ 0.031	0.990 $\pm$ 0.010
After final discussion	1	1	1	1

is used with the SFMF and coded in electronic health records (EHRs), nursing data can be included in national EHR datasets and can be analysed to determine the value of nursing care to improve practice (Chae et al., 2020; Johnson et al., 2011; Macieira et al., 2019).

## 5.2 | Advantages of linkage work for nursing research

We note many benefits of using the SFMF and the linked NOC outcomes. A potential challenge that researchers and practitioners may face while using this approach is a lack of expertise in the use of NOC. Continuous education of SNTs, expanding collaborative research opportunities using NOC, and operationalization of NOC outcomes are essential for the application of theories and models into nursing practice. These efforts help improve the quality of nursing care because they allow nurses to evaluate what they do for patients with chronic diseases for self-management in tertiary care hospitals, community hospitals, community agencies, nursing centres and nursing homes. The results of this study may contribute to developing NOC outcomes that consider self-management processes, improving self-management for patients with chronic conditions using measurable and quantifiable NOC.

## 5.3 | Methodological issues

The team confronted several methodological issues during this work. One was the question of whether NOC outcomes could be assigned to multiple components of the SFMF (e.g. Motivation (1209), Pain Control (1605) and Caregiver-Patient Relationship (2204)). If team members thought an outcome could only be listed in one part of the framework, the team had to decide which component was the best fit with the outcome. However, for Caregiver-Patient Relationship (2204), effective communication can be placed in several different components of the framework across facilitators and barriers, process or outcomes, therefore, we linked this outcome as well as others to multiple sub-categories. We also dealt with another question as to whether adaptation or adjustment are in the Processes or Outcomes components. We included emotions under facilitators and barriers, enabling us to link Personal Resiliency (1309) and Family Resiliency (2608) during the first linkage review. However, the definition of Family Resiliency (2608) is the capacity of a family to adapt

and function following a crisis or adversity (dealing with a chronic illness of a family member). The definition could also fit into a broader category of distal outcomes as this series of outcomes had multiple sub-categories. Therefore, Family Resiliency (2608) was placed under the facilitators and barriers and distal outcomes components. Finally, the definitions of several sub-categories (e.g., Co-morbidity under Health Status category, Financial under Resources category, Work under Environment category, Stress under Biomarkers category) in the framework did not connect with titles, definitions or indicators of any NOC outcomes. This finding suggests the need for development of additional outcomes related to these sub-categories in the NOC.

## 5.4 | Future work

In this study, we linked NOC outcomes to the SFMF, which strengthens the SFMF by creating clearer references to practice-based outcomes in the framework. In a future study, we suggest establishing NANDA-I or Nursing Interventions Classification (NIC) linkages to guide nursing practice for specific illness and conditions based on theoretical perspectives. It may be useful for the phases of the nursing process, NANDA-I, NIC and NOC classifications to be mapped with the SFMF, as these phases describe the elements of nursing care in different steps, including the specificities related to patients with chronic diseases and their caregivers. Future editions of NOC will provide additional opportunities to link new outcomes to the SFMF to better support the care of patients and families with the challenges of managing chronic illnesses.

## 5.5 | Limitations

Limitations of our study pertain to the SFMF and to the review team. About the SFMF, the framework captures adult self-management. Thus, applied NOC outcomes reflect adult versus paediatric populations. Additionally, while NOC outcomes related to family caregivers were applied, the 2015 version of the SFMF does not explicitly include family caregiver components. Facilitators and barriers to family management and family caregivers' management processes have been delineated by the SFMF team elsewhere (Schulman-Green, Feder, Dionne-Odom, et al., 2021). Family-related NOC outcomes were matched to SFMF sub-categories based on expert team members' opinion and review with the SFMF team.

About the review team, a potential limitation is that linkages were developed using a consensus process based on team members' expertise, and experiences and were not validated by other subject matter experts. In future validation of these linkages, we would include external reviewers to check their face validity. Another limitation is that the NOC experts might have had biases and preconceived ideas in defining terms of chronic diseases and how to manage chronic disease. Another consideration is the changing extent of illness in defining terms of chronic illness and managing chronic diseases (Walker, 2001).

## 6 | CONCLUSIONS

The degree of agreement found in the linkages between the SFMF and NOC outcomes is very high, demonstrating the value of the SFMF as a basis for the identification of outcomes for patients with chronic diseases. The nursing outcomes selected during this linkage process provide knowledge to support patients with chronic diseases and their family caregivers challenged by self-management and offer the opportunity to quantify the impact of nursing care and enhance nursing practice by promoting the use of standardized terminology. Adding standardized and measurable nursing outcomes from NOC to the SFMF can improve nursing care for the management of chronic diseases. Finally, these findings can be used to succinctly describe to funders, policy makers and others invested in health care reform the unique contribution made by nurses to patient self-management of chronic disease.

### AUTHOR CONTRIBUTIONS

SC, HO and NCFO were involved in conceptualization, literature review, methodology, data synthesis, writing—original draft preparation, reviewing and editing. DSG was involved in methodology, validation and writing—review and description. SM and ES were involved in conceptualization, methodology, writing—original draft preparation, reviewing and editing. All authors approved the final version for submission.

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All authors report no conflict of interest relevant to this article.

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# Development and psychometric evaluation of the Emotional Intelligence Test (EMI-T) for social care and healthcare student selection

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## Abstract

**Aim:** To develop an emotional intelligence (EI) test and evaluate its psychometrics for social and healthcare student selection.

**Design:** A cross-sectional methodological design.

**Methods:** The test was developed based on a systematic review and focus group interviews. Content validity was evaluated with expert panels, and preliminary psychometrics with two pilot studies. Descriptive statistics, correlations and item response theory were used.

**Data Sources:** Search was conducted in six databases 2018. Focus group interviews were conducted with educators and professionals in 2019. Expert panels with doctoral students, researchers and educators were conducted in 2020. Pilot tests with students were conducted 2020–2021. The developed test was administered to 4808 applicants 2021.

**Results:** The test included four subscales. Correlations support the test's theoretical structure. The items were mainly easy.

**Conclusion:** The test assesses EI objectively and comprehensively. The item-level distractor analysis can be used for further test development.

**Impacts:** Social care and healthcare students engage in clinical practice early in their studies, and these environments can be emotionally challenging. Assessing EI in student selection with adequate test can help the institutions of higher education to select the students with required abilities to succeed in the studies. The assessment of EI during student selection also provides information higher education institutions could use to develop and provide support interventions. The results may also encourage practice placements to include EI elements as learning objective. The results of this study and especially the use of IRT and detailed distractor analysis to evaluate the psychometric properties of EMI-T can benefit researchers and educators that develop or evaluate objective assessment tools with multiple choice questions.

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**Implications for the profession and/or patient care:** Emotional intelligence is important for students to enable professional interaction.

**KEYWORDS**

emotional intelligence, instrument development, nursing education, psychometric evaluation, social care and healthcare education, student selection

## 1 | INTRODUCTION

Emotional intelligence (EI) can be defined as a set of abilities including the perception, understanding, expression, management and utilization of emotions (Mayer et al., 2016). EI is important to assess in social care and healthcare student selection (Haavisto et al., 2019; Pienimaa et al., 2022). EI has a positive relationship with academic performance in healthcare students (Pienimaa et al., 2022). In particular, EI seems to improve performance in clinical practice (Lewis et al., 2017; Pienimaa et al., 2022). Social care and healthcare students engage in clinical practice early in their studies, and these environments are emotionally challenging. Abilities such as EI are needed to cope in such environments (Lewis et al., 2017). There is some evidence that healthcare students have higher than average EI (e.g. Aithal et al., 2016). However, a recent study reported significant variations in the EI of nursing applicants (Talman et al., 2020).

Social care and healthcare student selection is a vital topic because it affects numerous institutions of higher education and thousands of applicants worldwide annually. In the United States alone, over 220,000 applicants enrolled in entry-level baccalaureate nursing programmes in the academic year 2018 (American Association of Colleges of Nursing, 2019). Furthermore, the World Health Organization (2021) states that there is currently a lack of skilled health professionals, and it is estimated that there will be a global deficit of more than 7 million nurses and midwives by 2030. It is important for higher education institutions all around the world to select students with sufficient EI so that they can succeed in their studies and graduate on time (Pienimaa et al., 2022). Graduating social care and healthcare students are needed by society to achieve a sufficient workforce.

In Finland, there is a national digital entrance examination (UAS Exam), which purpose is to measure undergraduate social care and healthcare applicants' reasoning, language, mathematical, ethical and EI skills (Vierula, Karihtala, et al., 2021). The purpose of the EI domain is to assess applicants EI and to rank order applicants according to their EI score. The selection decisions are based on overall test performance, but applicant will need to achieve a minimum score from each domain (Vierula, Karihtala, et al., 2021). In Finland, undergraduate (bachelor's degree) social care and healthcare education is provided in Universities of Applied Sciences and the length of degrees varies from 210 to 270 ECTS credits. The expected time of graduation is from 3.5 to 4.5 years depending on the programme (e.g. nursing, social services, physiotherapy, public health nursing, midwifery and paramedic; Ministry of Education and Culture, 2021).

### Impact

#### What already is known?

- Students engage in emotionally challenging placements early in their studies.
- The assessment of applicants' emotional intelligence is suggested.
- Comprehensive and objective selection instruments are missing.

#### What this article adds?

- Theoretical structure of the developed test is supported.
- Applicants performed well indicating that the test was easy.
- The item response analysis enabled precise psychometric evaluation.

#### Implications for practice/policy

- The results may help educators to decide what to assess in student selection.
- The description of item-level analysis may benefit educators/researchers in developing objective assessments.
- The results may encourage practice placements to include emotional intelligence as learning objective.

#### Reporting Method: Strobe

#### What does this article contribute to the wider global clinical community?

- Assessing emotional intelligence in student selection aims to ensure students' success in studies.

#### No patient or public contribution:

The test was developed for student selection.

The comprehensive assessment of EI is relevant to ensuring students' abilities to cope with the demands of social care and healthcare studies, and the total EI score seems to be the best predictor of study success (Lewis et al., 2017; Pienimaa et al., 2022). Additionally, higher educational institutions are responsible for fair student selection



processes. The evaluation methods they use must be valid and objective to ensure equitable selection (Haavisto et al., 2019; Talman et al., 2020). However, few of the existing EI instruments can be considered objective and most of them assess only few EI categories. Furthermore, most objective instruments have licensing fees, so financial constraints make it almost impossible to use them for social care and healthcare student selection because of the high number of applicants. The assessment of EI has been previously suggested for the selection phase (Haavisto et al., 2019), but there is a lack of objective and comprehensive instruments and a need for the further operationalization of the concept in this context (Pienimaa et al., 2022; Talman et al., 2020). There are few instruments that can be used to assess EI for social care and healthcare student selection because most instruments have not been validated in these settings (Pienimaa et al., 2022). Furthermore, many objective EI instruments seem to measure only a few categories of EI (e.g. the Situational Test of Emotional Understanding and the Situational Test of Emotional Management; Pienimaa et al., 2022). Due to the lack of comprehensive (i.e. test including several different EI categories), objective and validated EI tests for social care and healthcare settings and especially in the student selection context, there is a need to develop a new objective test for the assessment of EI in the social care and healthcare student selection context.

## 2 | BACKGROUND

There are several definitions of EI. It can be defined as a set of abilities including the appraisal, expression and regulation of emotions, as well as the ability to use feelings to facilitate performance and solve problems (Mayer et al., 2016). Goleman (1995) introduced a broader definition that includes personality aspects. His definition includes contents such as self-awareness, self-regulation, motivation, empathy and social skills. According to Bar-On (2006), EI can be defined as a collection of personal, emotional and social skills and abilities that affect a person's capacity to successfully cope with environmental pressures and demands. There is some debate about the cultural aspect of EI and whether EI is a stable trait or ability that can be changed in time. Previous research is controversial. Some studies indicate that EI might be affected by cultural background (Johnsen et al., 2012; Zhang & Cross, 2011), although according to the Scherer et al. (2011) there is, evidence for intercultural similarity in perception of emotions. Furthermore, some studies indicate that EI can be improved (Foster et al., 2017; Salminen-Tuomaala, 2020) while others have not noticed improvement in EI during education (Orak et al., 2016) or have found mixed results (i.e. EI has enhanced in some subscales but declined in others) (Shanta & Gargiulo, 2014).

The multiple definitions of EI have led to its different constructions, such as trait EI (Petrides et al., 2007), ability EI (e.g. Mayer et al., 2016) and mixed EI, which refers to both the ability and trait constructs (Bar-On, 2006; Goleman, 1995). Trait EI includes emotion-related behaviours with multi-level personality hierarchies and is typically measured using self-report measures; ability EI includes emotion-related mental skills, such as reasoning validly with emotions and with

emotion-related information and is usually measured using objective ability-type measures (Mayer et al., 2016; Petrides et al., 2007).

Most EI instruments are mixed model tools with both ability-based content, such as emotional management, and trait-based content, such as self-awareness (e.g. Emotional Quotient Inventory, Emotional Competence Inventory-University Edition and different versions of Schutte's Emotional Intelligence Test/Scale). These are self-report instruments in which respondents assess their own EI abilities and personalities. Thus, such tools assess respondents' own perceptions and do not give objective evaluations (Bar-On, 2006; Goleman, 1995). Of the existing instruments, the Trait EI Questionnaire Short Form (TeiQue-SF) seems to be the only trait-based tool that has been used to assess the EI of healthcare applicants (Pienimaa et al., 2022). TeiQue-SF assess personality traits, such as self-esteem, self-motivation, empathy, happiness and optimism (Petrides et al., 2007). The most used ability-based EI instrument is the Mayer-Salovey-Caruso Emotional Intelligence Test (MSCEIT) (Pienimaa et al., 2022). The MSCEIT requires individuals to solve emotional problems that have correct and incorrect answers rather than to self-report their own perceptions of EI. It assesses EI abilities, such as perception, facilitation, understanding and management of emotions (Mayer et al., 2003).

The process of developing a test requires extensive conceptualization to ensure that the test is assessing comprehensively and distinctly the concept it is supposed to assess. Thus, the concept of EI has been analysed in detail in EI instruments. In a review by Pienimaa et al. (2022), six main EI categories were identified from existing EI instruments that have been used in social care and healthcare selection or education context (Table 1). The EI instruments generally included three to four main EI categories. In a study by Pienimaa et al. (2021), social care and healthcare educators and professionals identified a new EI category to be assessed during student selection—acceptance of emotions. This category is not included in any of the existing EI instruments. In this study, the concept of EI is based on the ability definition of EI (Mayer et al., 2016) and the objective assessment of EI. Trait EI is measured with self-report measurements, and these are not appropriate in student selection where results of the assessment have major impact both to the applicants and higher education institutions (Rankin, 2013). Instead, ability EI is the only construct of EI that can be measured objectively and that is the main reason why ability EI was used in this study. In the student selection context, the evaluation methods must be objective to ensure the fair selection of applicants.

## 3 | THE STUDY

### 3.1 | Aim and objective

The aim of this study was to develop an objective EI test (the Emotional Intelligence Test [EMI-T]) and evaluate its psychometric properties for social care and healthcare undergraduate student selection. The ultimate goal was to make social care and healthcare student selection equal and valid and to enable the selection of students

TABLE 1 Conceptualization of EI based on previous EI instruments (modified from Pienimaa et al., 2022)

Main categories of EI	Sub-categories of EI	EI instrument
Perception of emotions	Perception of emotions, perceiving of emotions	AES; SSEIT, MSCEIT
	Emotional self-awareness, attention to feelings, emotion recognition, intrapersonal characteristics; self-awareness, self-confidence	Genos; TMMS; GEC0; ECI-U II; EQSAC; EQ-i; TEIQue-SF
	Emotional awareness of others, recognition of emotion in others	Genos; TEIS
Understanding of emotions	Understanding emotion, emotion understanding, emotional understanding	MSCEIT; GEC0; STEU
	Clarity of feelings	TMMS
	Emotional appropriateness (ability to differentiate between similar emotions)	TEIS
	Recognize patterns	SEI
Emotional expression	Emotional expression, appraisal and expression of emotions, Intrapersonal characteristics; self-expression	Genos; SSEIT, EQ-i
Emotional management	Regulation of emotions, emotion regulation, emotion management, emotional management/Managing emotions	SSEIT; GEC0; MSCEIT; STEM
	Managing own emotions, emotional self-management, emotional self-control, regulation of emotion in the self, self-management, self-control, mood repair, exercise optimism, total mood (self-motivation; happiness, optimism), total mood (self-motivation; happiness, optimism)	AES; SSEIT; Genos; TEIS; TMMS; SEI; EQ-I; TEIQue-SF
	Managing others' emotions, emotional management of others, regulation of Emotion in others	AES; SSEIT; TEIS; Genos; ECI-U II; EQSAC
	Fighting against pressure (emotional management and regulation), stress management	EQ-i; TEIQue-SF
	Coping (change management), adaptability (flexibility, problem solving)	EQ-i; TEIQue-SF
Utilizing emotions	Use of emotions, using emotion, utilizing of emotions, navigate emotions	AES; SSEIT; MSCEIT; SEI
	Emotional reasoning, flexible planning (preference to base life decisions on emotions rather than logic)	Genos; TEIS
	Pursue noble goals	SEI
Social awareness and relations	Interpersonal characteristics (social awareness and interpersonal relationship), social awareness, Relationship management, social competence	TEIQue-SF; ECI-U II; EQSAC
	Empathy (being concerned with and affected by others feelings), increase empathy	TEIS (3); EQSAC; SEI

Abbreviations: AES, Assessing Emotions Scale; ECI-U II, Emotional Competence Inventory-University Edition Version 2; EQ-i, Bar-On Emotional Intelligence Questionnaire; EQSAC, Emotional quotient self-assessment checklist; GEC0, The Geneva Emotional Competence Test; Genos, Emotional Intelligence Inventory; MSCEIT, The Mayer-Salovey-Caruso Emotional Intelligence Test; SEI, Six Seconds Emotional Intelligence; SSEIT, The Schutte Self-Report Emotional Intelligence Test; STEM, The Situational Test of Emotional Management; STEU, The Situational Test of Emotional Understanding; TEIS, Tett's Emotional Intelligence scale; TEIQue-SF, Trait EI Questionnaire Short Form; TMMS, Trait Meta-Mood Scale.

with adequate EI skills, which may prevent unnecessary attrition (i.e. dropping out from the degree programme or prolonged studies).

The EMI-T was developed for social care and healthcare student selection because social and healthcare professionals often work together in multi-disciplinary teams to provide quality care to patients and clients. Furthermore, there is no indication that EI differs between social care and healthcare students or professionals (Snowden et al., 2015).

## 4 | METHODOLOGY

### 4.1 | Design

This study used a cross-sectional methodological design. The study consisted of two phases: (1) the development of the EMI-T and (2) the psychometric evaluation of the instrument. The scale development

process was adapted for both phases (DeVellis, 2017). The development phase included a systematic review, focus group interviews, item generation, expert evaluation and pilot tests. A methodological cross-sectional design was used in the psychometric evaluation of the EMI-T.

The psychometric evaluation was performed using item response theory (IRT) because in the student selection context the most important evidence of the validity is the degree to which the evidence supports the intended interpretation of test scores and their relevance to the proposed use, including specifying the construct the test is intended to measure (American Educational Research Association [AERA], American Psychological Association [APA] and NCME, 2014). Validation of the test's construct can be obtained with empirical evidence such as previous literature, use of the evidence of similar tests and expert judgement (American Educational Research Association [AERA], American Psychological Association [APA] and NCME, 2014) as we have done in this study. Even though the Classical Test Theory (CTT) approach has been applied successfully for many years, it has

some limitations compared with IRT in identifying the item-level evaluation (i.e. item-level difficulty and discrimination) (De Champlain, 2010). From the student selection perspective, the item-level difficulty and function are essential for validity of the test to rank order applicants. Thus, we used IRT approach to achieve a greater understanding of the item-level function and to be able to do full distractor (incorrect response) analysis (Li et al., 2019; Tavakol et al., 2014).

IRT analysis with the TestGardener software (Li et al., 2019) was used in the pilot testing and psychometric evaluation of the EMI-T. IRT is a scarcely applied method in nursing education research (Tavakol et al., 2014). To the best of our knowledge, only one previous study in the field of nursing science has used IRT with TestGardener software (Vierula, Talman, et al., 2021).

The focus of the evaluation in the IRT analysis is on the individual items, enabling the evaluation of different item parameters (DeVellis, 2017; Tavakol et al., 2014) and providing an informative way to analyse composite scales consisting of several categorical items that are summarized into a total score (Wellhagen et al., 2021). The TestGardener software applies modern statistical methods to produce accurate estimates of respondent characteristics using full data and enables item-level analysis and full distractor (incorrect response) analysis (Li et al., 2019; Ramsay et al., 2020). TestGardener can be used to evaluate problems with items and help test developers decide whether to rewrite items to clarify ambiguous wording or to modify incorrect options to make them more plausible. The software provides a visual S-shaped logistic curve (item characteristic curve [ICC]) in which different items' response options can be graphically analysed (Li et al., 2019; Ramsay et al., 2020). It is essential that the items are unambiguous (i.e. clarity of the items and response options) to ensure the applicants' equality. Furthermore, the idea of student selection is to set applicants in rank order, so both the difficulty level of the items is important and the test's ability to discriminate applicants (i.e. differentiate applicants' skills in the upper ability level; Gierl et al., 2017; Tavakol et al., 2014).

The item analysis in this study was based on a graphical analysis of ICCs with TestGardener (Li et al., 2019), in which an item difficulty, pseudo-guessing and the function of distractors are evaluated visually (Figure 1). Difficulty can be examined by evaluating the shift of the S-shaped curve of the correct response option at different quantiles (i.e. difficult: 75%–95%, moderate to difficult: 50%–75%, easy to moderate: 25%–50%, easy: 5%–25% and very easy: <5%). A

shift of the curve to the right indicates a more difficult item (Figure 1; Li et al., 2019; Ramsay et al., 2020).

The pseudo-guessing parameter provides information about the opportunity for low-ability applicants to answer items correctly. Pseudo-guessing can be studied by analysing the starting point of the S-curve along the vertical axis. The higher the starting point, the higher the opportunity of guessing the correct response. The 30% threshold can be considered the cut point for guessing the correct response (i.e. high probability of guessing: >30%; low probability of guessing: ≤30%; Tavakol et al., 2014).

The graphical analysis of ICCs enables a full distractor analysis, in which the curves of all response options can be studied. IRT distractor analysis evaluates whether distractors function properly and are unambiguous (Figure 1; Gierl et al., 2017; Tavakol et al., 2014; Vierula, Talman, et al., 2021).

Figure 1 shows an example ICC of all the response options for one item: the correct response option (blue line), three distractors (red, green and pink lines) and the fifth response option, indicating the applicants who did not respond to the item (orange line). The curve of the correct response option starts from below the 0.3 probability line, indicating that the correct response option is not easy to guess. The curve pierces the x-axis between the 5% and 25% quantile, indicating that the item is easy. One of the distractors (red line) functions accordingly, attracting lower ability test-takers. Other distractors are not functional, so most of the responders did not choose them at all.

## 4.2 | Development of the EMI-T

The EMI-T was developed in 2018–2021 for social care and health-care student selection purposes. The development phase included two stages: (1) structure and item generation of the EMI-T and (2) content validity evaluation and pilot studies (Figures 2 and 3). The development process included three expert panels and two pilot studies ensuring that, every time the EMI-T was modified, the new or revised items of the test were analysed before further development. The preconditions for the entrance examination were considered in the development process. These preconditions were that the exam was in a digital format, had minimum passing score and multiple choice questions with one correct answer option were used (Figure 2).

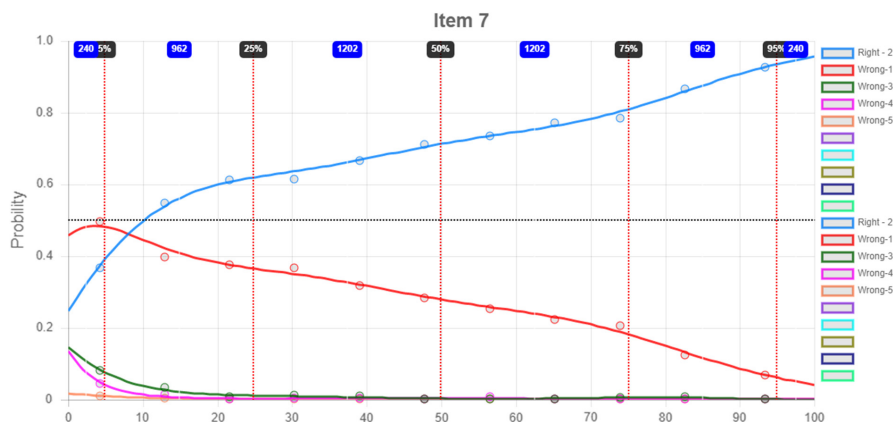
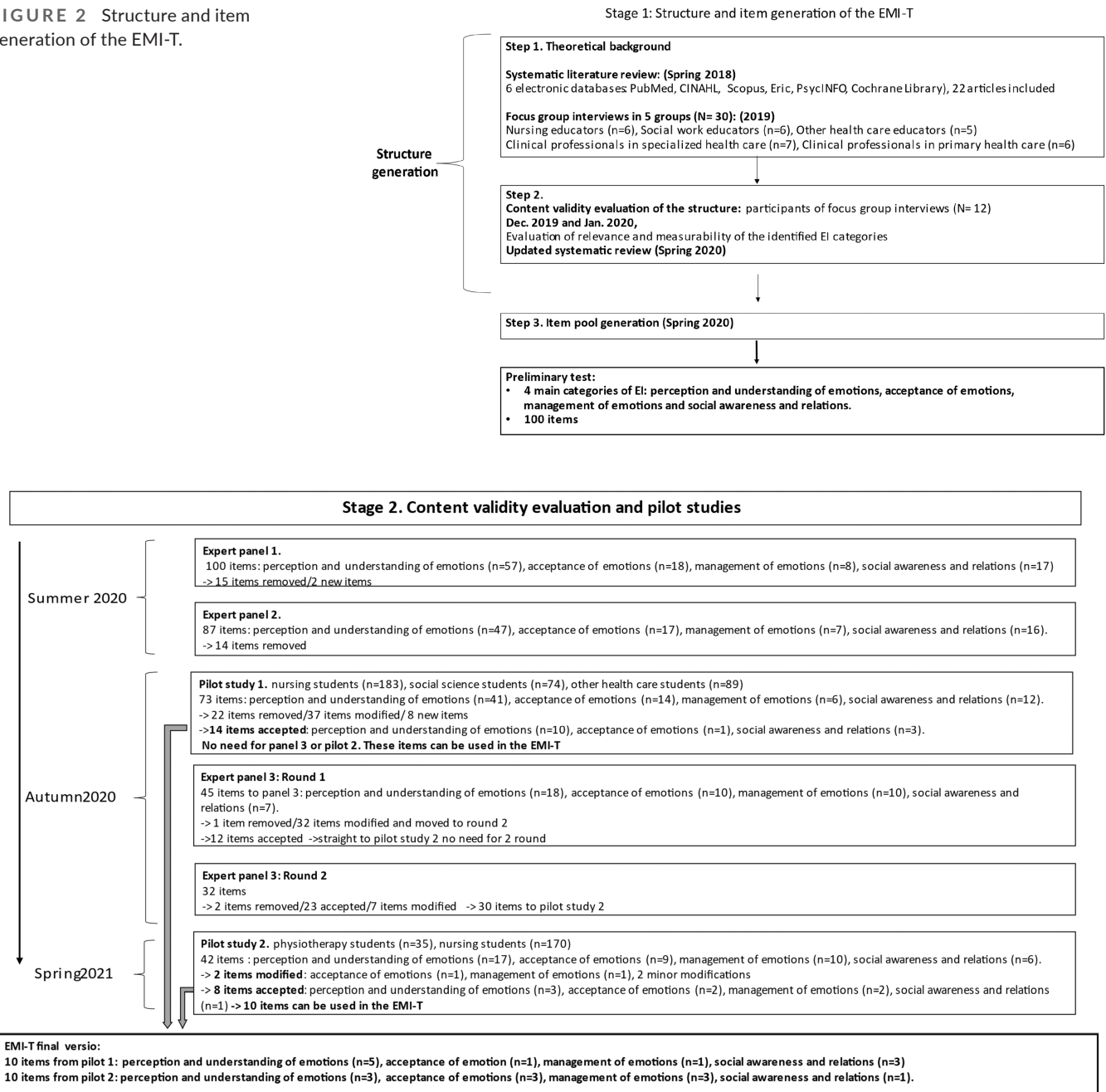


FIGURE 1 Example of a TestGardener item characteristic curve.

**FIGURE 2** Structure and item generation of the EMI-T.



**FIGURE 3** Content validity evaluation and pilot studies.

#### 4.2.1 | Stage 1: Structure and item generation of the EMI-T

This stage had three steps: (1) theoretical background (systematic review and focus group interviews), (2) content validity evaluation of the structure (expert panels and updated review) and (3) item pool generation (Figure 1).

##### *Step 1: Theoretical background*

The purpose of the theoretical background was to conceptualize EI specifically relevant to social care and healthcare student selection to be able to identify the structure of the EI test. First, a systematic review (n = 22) was conducted in 2018 using six electronic databases. Second,

five focus group interviews (n = 30) with social care and healthcare educators and professionals were conducted in 2019 (Pienimaa et al., 2021; Figure 2). The social care and healthcare educators were recruited via education managers at four universities of applied sciences and clinical professionals were recruited through nurse managers from the country's biggest hospital district and primary healthcare unit. The results of the systematic review were used as themes in the semi-structured focus group interviews. For each theme, the interview questions were as follows: How would you define this theme? What EI content should be assessed when selecting social care and healthcare students? The data were analysed using both deductive and inductive content analysis (Figure 2). The structure of the EMI-T was formed based on the results of the theoretical background.

### Step 2: Content validity evaluation of the structure

The content validity of the EI categories identified in step one was evaluated between December 2019 and January 2020. The purpose was to evaluate the relevance and measurability of the identified main EI categories from a student selection perspective. The participants from the focus group interviews ( $n = 30$ ; social care and healthcare educators and professionals; Pienimaa et al., 2021) were invited for the expert panel. Participants were asked to evaluate the relevance of the EI categories with a 4-point Likert-type scale, and measurability with a dichotomous scale (yes/no). For measurability of the categories, participants were instructed to evaluate if each category would be measurable in a digital entrance exam using objective assessment method with multiple choice questions. Item-related content validity indexes (I-CVIs) were calculated, and the acceptable limit for each category was set to  $CVI \geq 0.78$  (Polit & Beck, 2006). After the expert evaluation, the systematic review was updated prior to the generation of the item pool (spring of 2020) to ensure that no relevant new information was missed (e.g. new EI instruments with new categories; Pienimaa et al., 2022; Figure 2).

### Step 3. Item pool generation

The item pool was generated in spring 2020 based on the four EI categories. Throughout the study, the items were written by two researchers that were experienced with instrument development and were familiar with the concept of EI. The items were formed following four principles. First, the number of initial items had to be large in anticipation of item reduction during the instrument validation process, although there is no specific standard of how many items should be included to the initial pool (DeVellis, 2017). The aim was to generate many items to each subscale (at least twice the amount that was needed) that deleting several items from each subscale during the development process was not endangering the conceptual adequacy. Second, the items had to be relevant to the content of interest, that is, the items should comprehensively represent the EI categories. Third, the items tasks or questions and response options should be clear and unambiguous (DeVellis, 2017). Fourth, the number of response options had to be optimal to reduce the opportunity of guessing (Gierl et al., 2017).

## 4.2.2 | Stage 2: Content validity evaluation of the items and pilot studies

This stage had four steps: (1) two consecutive expert panels, (2) first pilot study, (3) third expert panel with two rounds and (4) second pilot study. The content validity of the items was evaluated with expert panels to ensure item clarity, relevancy and representativeness. Two pilot studies were used to undertake a preliminary item analysis and gain an understanding of the functionality and difficulty levels of the developed items (Figure 3).

First, two expert panels were conducted in June 2020 and August 2020. The first panel involved doctoral students ( $n = 6$ ) and postdoctoral researchers ( $n = 5$ ) who had knowledge of instrument

development (Figure 3). The second panel involved experienced social care and healthcare educators ( $n = 6$ ) who had an average of 18 years of working experience (5–34 years); almost all (five out of six) had experience with entrance examination organization, development or evaluation. Both expert panels evaluated the clarity and validity of the items. They also evaluated whether they agreed with the correct options. The experts were asked to make suggestions on how the items might be improved. The I-CVIs were calculated and items with I-CVI under 0.78 were rejected (Polit & Beck, 2006; Figure 3).

The first pilot study was conducted in September 2020. The participants were first year social care and healthcare students from two universities of applied sciences who started their studies in August 2020 ( $n = 346$ ) (Figure 3). They were mainly female (82.7%) and young adults (mean age: 22 years, age range: 18–54); over half were nursing students (52.9%) and had a previous degree (59.4%), often from practical nursing (36.4%). They answered the online version of the 73-item EMI-T version during class. Descriptive statistics were used to overview the data. Frequencies and percentages were calculated for each item. IRT analysis was conducted with TestGardener, and a graphical analysis of ICCs was conducted. The difficulty of items and the functionality of distractors were examined (Figure 3).

The third expert panel was undertaken at the end of 2020. It included two rounds and evaluated those items ( $n = 45$ ) that were modified based on the results of the first pilot study. This expert panel included experienced social care and healthcare educators ( $n = 10$ : round 1;  $n = 8$ : round 2) who also had experience in student selection. The experts evaluated the clarity of the items and whether they agreed with the correct options. In the first round, they evaluated the difficulty of the items (4-point Likert scale: 1 = easy, 4 = difficult). Because of a technical error, information for the I-CVIs was not obtained from round one. Thus, in this round, items were evaluated according to the experts' difficulty evaluation and comments. In second round, the I-CVIs on clarity and agreement for the correct options were calculated, and comments were considered. Items with I-CVIs  $< 0.75$  were rejected. In round two, the experts did not evaluate the difficulty level (Figure 3).

The second pilot study was conducted in January 2021 to evaluate the modified items ( $n = 42$ ) from the third expert panel. This study included healthcare students from two universities of applied sciences who started their studies in January 2020 ( $n = 205$ ). The participants were mainly female (81.1%) and young adults (mean age: 26.4 years, range: 19–54), and over half had a previous degree (68%), which was often practical nursing (35.7%). Descriptive statistics was used to overview the data. Frequencies and percentages were calculated for each item. The frequencies of all item options were overviewed in simple items to obtain more information about the selection of distractors and strengthen the decision to exclude poor distractors. IRT analysis was conducted with TestGardener, and a graphical analysis of ICCs was conducted. The difficulty of the items, pseudo-guessing level and the functionality of the distractors were evaluated (Figure 3).



### 4.3 | Psychometric evaluation of the EMI-T

After the development process, the EMI-T was psychometrically evaluated with IRT method. Data were collected using the EMI-T from undergraduate social care and healthcare applicants from 20 universities of applied sciences who gave their consent to participate in this study and took the digital entrance examination on 2 days, 31 May and 4 June 2021 ( $N = 4808$ ). The applicants received information about the study during the application process. Informed consent was obtained from the participants before the start of the digital entrance examination. Most of the participants were female and had a high school or vocational school education (Table 2).

First, descriptive statistics (frequencies, percentages, means and standard deviations [SDs]) were calculated for the participant demographics, each item (i.e. frequency and percentage of applicants who got the item correctly or incorrectly) and the total EMI-T score. The item analysis of the EMI-T was based on Pearson's correlation coefficients for item level (correlations between EI subscales, correlations between EI subscales and the total score, and individual items' correlations with one another) and IRT, including the graphical analysis of the ICCs with TestGardener. Graphical analysis included the evaluation of difficulty, pseudo-guessing parameters and the functionality of distractors. The data were analysed using Statistical Analysis Software (SAS 9.4®; SAS Institute Inc., 2015) and TestGardener (Li et al., 2019; software online version).

### 4.4 | Ethical considerations

This study followed the ethical principles specified by the National Advisory Board on Research Ethics (Finnish Advisory Board on Research Integrity, 2012). Permission to undertake the study was obtained from the institutions involved, and ethics approvals were sought from the ethics committee of the higher education institutions (for expert panels and pilot studies: 10 June 2020; for the

TABLE 2 Demographic information of the applicants ( $N = 4808$ )

Demographic information	N	%
Age (years)		
Under 20	712	14.8
20–24	1772	36.9
25–29	824	17.1
Over 29	1500	31.2
Gender		
Female	3862	80.3
Male	946	19.7
Previous education		
High school	2134	44.4
Vocational school	1920	39.9
Higher education	440	9.2
Other	314	6.5

psychometric evaluation of the EMI-T during the entrance examination: 14 May 2021). The participants were informed about their anonymity, their right to withdraw from the research and the voluntary nature of the study. Informed consent was obtained from the participants at all stages of the study.

## 5 | RESULTS

### 5.1 | Development of the EMI-T

#### 5.1.1 | Stage 1: Structure and item generation of the EMI-T

##### *Step 1: Theoretical background*

In the systematic review, 18 existing EI instruments that have been used in social care and healthcare selection or education context were analysed to conceptualize the EI. As a result, six EI categories (perception of emotions, understanding of emotions, emotional expression, managing emotions, utilizing emotions and social awareness and relations) were identified (Pienimaa et al., 2022). Furthermore, five focus group interviews ( $n = 30$ ) with social care and healthcare educators and professionals were conducted in 2019 (Pienimaa et al., 2021). The content analysis of the focus group interviews yielded a new EI category: acceptance of emotions. Furthermore, also the description of other EI categories was elaborated especially from the student selection perspective. Thus, the systematic review and focus group interviews yielded seven main categories of EI: perception of emotions, understanding of emotions, acceptance of emotions, management of emotions, emotional expression, utilization of emotions and social awareness and relations (Pienimaa et al., 2021).

##### *Step 2: Content validity evaluation of the structure*

The content validity of the EI categories identified in step one was evaluated between December 2019 and January 2020. The participants from the focus group interviews (step 1) were invited for the expert panel. The response rate was 40% (12/30).

According to the results, perception of emotions, understanding of emotions, acceptance of emotions, management of emotions and social awareness and relations were the most relevant and measurable categories of EI during social care and healthcare student selection. The EI categories of emotional expression and utilization of emotions were excluded from the test at this point because the I-CVI was under acceptable level 0.78 in these categories. Furthermore, the experts stated that objective evaluation of emotional expression during the digital entrance examination would not be possible, and that utilization of emotions is an ability that will most probably enhance during the education and this ability is not something that necessarily should be assessed in the student selection process. The categories of perception and understanding of emotions were combined based on the comments of the panel members about the difficulties in measuring these two categories separately. It was unclear



when the perception of emotions develops into the understanding of emotions. All in all, four EI categories were identified as relevant from the student selection perspective. The systematic review was updated prior to the generation of the item pool (spring of 2020) to ensure that no relevant new information was missed. Although six new studies were identified, the results did not yield to any new categories.

### Step 3. Item pool generation

After the structure and item generation of the EMI-T, its first version included 100 items in four subscales: 57 items in perception and understanding of emotions, 18 in acceptance of emotions, eight in management of emotions and 17 in social awareness and relations (Figure 3). All the items in the preliminary version included one correct response option and three to five distractors.

### Stage 2: Content validity evaluation of the items and pilot studies

First, two expert panels were conducted in June 2020 and August 2020. According to the results of these expert panels in 64 items, some minor changes were made to improve clarity. Altogether, 27 items were removed, and two new items were generated (Figure 3).

The first pilot study was conducted in September 2020. Based on the descriptive statistics, over half of the items ( $n = 40$ ) were extremely easy (>95% of the respondents chose the correct options). With these extremely easy items, the frequencies of all item options were overviewed to obtain more information about the selection of distractors and to strengthen the decision to exclude poor distractors. According to the graphical analysis of the ICCs, those items that seemed to be extremely easy—those whose distractors were not selected at all and for which the probability to guess the correct option was extremely high—were excluded (21 items). However, 19 easy items—in which applicants had selected distractors and for which the probability for guessing was not extremely high (over 0.8)—were further modified to increase the difficulty level. They were further evaluated in the third expert panel and the second pilot study. Some of the items ( $n = 34$ ) had six response options, and these were reduced to four (i.e. those poor distractors that only a few respondents chose were deleted) to make the items more difficult. This item reduction brought the response options closer to each other and standardized the response options in all items, that is, all items included four response options. Furthermore, in 37 items, the assignment and/or response options were modified or changed to enhance clarity and difficulty and to reduce guessing (Figure 3).

The third expert panel was undertaken at the end of 2020. It included two rounds and evaluated those items ( $n = 45$ ) that were modified based on the results of the first pilot study. In first round, items that were estimated to be easy and had no comments were considered suitable for the pilot study ( $n = 12$ ). All other items were sent to round two ( $n = 32$ ). After this round, one correct option was modified, and three items were removed (Figure 3).

The second pilot study was conducted in January 2021 to evaluate the modified items ( $n = 42$ ) from the third expert panel. Some of the items ( $n = 8$ ) were extremely easy (>95% of the respondents

chose the correct options), and in 12 items, between 90.78% and 94.18% of the respondents chose the correct options. The IRT method was not applicable to these items because of the small sample size and the high percentage of correct responses. These 20 items were removed prior to the IRT analysis, which included 22 items. Those items that seemed to be extremely easy and for which the probability of guessing the correct answer was high were excluded ( $n = 8$ ). Furthermore, items that were not unambiguous were removed (i.e. distractor was chosen as correct answer more often than the correct answer even with the high ability responders) ( $n = 6$ ). Overall, 10 items from the first pilot study, and 10 items from the second pilot study were included in the final EMI-T (Figure 3).

## 5.2 | Psychometric evaluation of the EMI-T

### 5.2.1 | The Emotional Intelligence Test

The EMI-T included 20 multiple choice items (case-based questions or questions related to facial expressions) in four subscales: perception and understanding of emotions (eight items), acceptance of emotions (four items), management of emotions (four items) and social awareness and relations (four items). The subscale of perception and understanding of emotions combined two EI categories, and thus, this subscale had twice as many items than the other subscales (Figure 3). Each item included one correct response option and three incorrect ones. Each correct response yielded one point. Negative points were not used. The minimum score was set to five points based on the fact that an applicant with zero EI ability cannot be selected. The EMI-T included eight pictures with facial expression and applicants needed to recognize different universal emotions from the pictures. Here is also a fictional example of the multiple choice item: Sara has met her best friend. How does she most probably feel? (1) Frustrated, (2) Happy, (3) Sad and (4) Angry.

### 5.2.2 | Descriptive results and correlations

The mean total score for the EMI-T was 15.92 (SD: 2.16), and the median was 16. The total score range was 0–20. Two-thirds of the applicants achieved a score of 17.00. Less than 1% ( $n = 19$ ) of the applicants failed to receive the minimum passing score (five points). Thus, most of the applicants performed well in the EMI-T.

There was a positive and statistically significant correlation between subscales and between subscales and the total score. The correlation estimates were classified from negligible to very strong (Schober et al., 2018). All subscales had a moderate to strong correlation with the total EMI-T score ( $r = 0.60$ – $0.74$ ) but had a lower correlation with one another ( $r = 0.18$ – $0.32$ ) (Table 3). The correlations between items were weak ( $r = -0.21$ – $0.27$ ). The item-to-total score correlations were positive ( $r = 0.18$ – $0.40$ ) and statistically significant ( $p < 0.05$ ; Schober et al., 2018).

**TABLE 3** Pearson correlation coefficients (*r*) for the subscales and total scores

	1	2	3	4	Total score
1	1.00 <sup>d</sup>	0.22 <sup>a</sup>	0.18 <sup>a</sup>	0.20 <sup>a</sup>	0.74 <sup>c</sup>
2	0.22 <sup>a</sup>	1.00 <sup>d</sup>	0.30 <sup>a</sup>	0.30 <sup>a</sup>	0.65 <sup>b</sup>
3	0.18 <sup>a</sup>	0.30 <sup>a</sup>	1.00 <sup>d</sup>	0.32 <sup>a</sup>	0.60 <sup>b</sup>
4	0.20 <sup>a</sup>	0.30 <sup>a</sup>	0.32 <sup>a</sup>	1.00 <sup>d</sup>	0.62 <sup>b</sup>
Total score	0.74 <sup>c</sup>	0.65 <sup>b</sup>	0.60 <sup>b</sup>	0.62 <sup>b</sup>	1.00 <sup>d</sup>

Note: Subscales: 1 = perception and understanding of emotions, 2 = acceptance of emotions, 3 = management of emotions and 4 = social awareness and relations.

$p < 0.05$ .

<sup>a</sup> 0.10–0.39 Weak correlation.

<sup>b</sup> 0.40–0.69 Moderate correlation.

<sup>c</sup> 0.70–0.89 Strong correlation.

<sup>d</sup> 0.90–1.00 Very strong correlation.

The correlations between subscales supported the theoretical structure of the test, indicating that EI is based on different categories that have a significant correlation with one another but an even stronger correlation with the total score.

### 5.3 | IRT analysis

The evaluation of the difficulty of the items showed that most of them proved to be very easy ( $n = 13$ ) or easy ( $n = 4$ ) (Table 4), indicating that either the correct response options were too obvious or that the incorrect response options failed to be functional distractors. Furthermore, over half of the items (13/20) were susceptible to guessing. Altogether, only five items were fully functional. They included functional distractors and did not exceed the 30% threshold for guessing the correct response (Tables 4 and S4).

## 6 | DISCUSSION

This study aimed to develop and evaluate the psychometric properties of the EMI-T to assess EI in the social care and healthcare undergraduate student selection context. EI is important to determine in healthcare student selection (Haavisto et al., 2019; Pienimaa et al., 2022), but there has been a lack of tests to assess it objectively and comprehensively in this context (Pienimaa et al., 2022). A fair and comprehensive assessment is crucial to ensure an equitable selection process (Talman et al., 2020). The development process of the EMI-T was versatile, including several phases (two stages and 10 steps), methods and content validity evaluation (three expert panels and two pilot studies). The EMI-T was based on the most relevant and objectively measurable EI categories to be assessed in social care and healthcare student selection. It is comprehensive, including four EI categories that have been incorporated into previous EI instruments (Mayer et al., 2003; Pienimaa et al., 2022), and it also has

**TABLE 4** IRT item difficulty and pseudo-guessing levels visually evaluated from the ICC plots

	Correct answer % (n)	Item difficulty levels <sup>a</sup>	Pseudo-guessing levels <sup>b</sup>
Perception and understanding of emotions			
Item 1	75.6 (3634)	0	1
Item 2	91.1 (4352)	0	1
Item 3	36.2 (1726)	4	0
Item 4	72.4 (3473)	1	1
Item 5	44.9 (2139)	3	0
Item 6	85.8 (4121)	0	1
Item 7	70.5 (3383)	1	0
Item 8	59.2 (2833)	2	1
Acceptance of emotions			
Item 9	94.5 (4538)	0	1
Item 10	86.3 (4134)	0	1
Item 11	93.5 (4473)	0	1
Item 12	67.9 (3247)	1	0
Management of emotions			
Item 13	94.2 (4518)	0	1
Item 14	85.9 (4112)	0	1
Item 15	89.5 (4281)	0	1
Item 16 <sup>c</sup>	95.3 (4582)	N/A	N/A
Social awareness and relations			
Item 17 <sup>c</sup>	99.1 (4765)	N/A	N/A
Item 18	76.4 (3638)	1	0
Item 19	92.00 (4397)	0	1
Item 20	88.6 (4226)	0	1

<sup>a</sup>Difficulty levels: 4 = Difficult (75%–95%), 3 = Moderate to difficult (50%–75%), 2 = Easy to moderate (25%–50%), 1 = Easy (5%–25%) and 0 = Very easy (<5%).

<sup>b</sup>Pseudo-guessing: 1 = High (>30%), 2 = Low (≤30%).

<sup>c</sup>Items 16 and 17 were extremely easy (less than 5% chose the distractors), the items were not estimated properly and IRT was not applicable.

a new category, acceptance of emotions, which is not included in any of the previous EI instruments (Pienimaa et al., 2021).

The psychometrical testing was based on descriptive statistics, correlations and graphical analysis of the ICCs with TestGardener, in which item-level analysis is possible, enabling more detailed information of the items and full distractor analysis (Gierl et al., 2017; Li et al., 2019; Tavakol et al., 2014). In the psychometric evaluation, the sample size was large enough for statistical analysis and larger than those of other similar student selection studies or studies evaluating EI instruments' psychometric properties. The sample represented the typical characteristics of the population. Previously, IRT with graphical analysis of the ICCs using TestGardener is a scarcely applied method in nursing sciences. The graphical interpretation proved to be excellent in facilitating item-level analysis, including precise distractor analysis. The

preliminary psychometric results during the development stage provided support for the content validity of the developed test, although in the psychometric testing the EMI-T proved to be easy. There was also a positive and statistically significant correlation between subscales and between subscales and the total score, which supports the theoretical structure of the EMI-T. The mean total score for the EMI-T (15.92/20 points) and the IRT analysis indicated that most of the items were easy and that most of the incorrect response options failed at being functional distractors, so the test failed to be very discriminative (i.e. ability to differentiate applicants' skills in the upper ability level). However, the mean total score was under 16 points and SD was 2.16, indicating that the EMI-T still discriminates at the upper ability level and that all applicants did not get maximum scores. Although very easy items are usually removed from the test, it might still be valid to include easy ones to maintain content coverage and ensure that the content is comprehensively measured with the test (Gierl et al., 2017). Including some easy items in the EMI-T was necessary to provide a comprehensive assessment of EI, including all relevant EI categories. Assessing EI extensively is relevant to ensuring students' abilities to cope with the demands of social care and healthcare studies (Lewis et al., 2017; Pienimaa et al., 2022).

Previous research shows that healthcare students seem to have higher than average EI (e.g. Aithal et al., 2016), and the minimum score for the test is currently set to be relatively low (5 points out of 20), so these factors might at least partly explain why the applicants scored high in the EMI-T. Furthermore, the aim of the EMI-T is to assess whether applicants possess reasonable EI to cope with emotional situations during their studies and be academically successful (Lewis et al., 2017; Pienimaa et al., 2022). The purpose of the EMI-T is to select not only those applicants who have tremendous EI but also those with adequate EI to be able to cope with the emotional demands of social care and healthcare studies.

The minimum score of the test is relatively low. This might require further consideration, and more research is needed to set the minimum score at the right level. There is no consensus on the optimal EI level (Davis & Nichols, 2016), although Li et al. (2015) implicated that moderate EI in nursing students could be associated with best coping in possible adverse situations. It is also argued that higher EI is not necessarily always better (Davis & Nichols, 2016). According to a review by Davis and Nichols (2016), those with high EI ability may have enhanced reactivity to stress, and high levels of EI might be related to poorer psychological health. Applicants EI scores at admission could be used to survey which kind of support the students admitted to the programme will need to cope with the emotional demands of the studies.

As stated earlier, incorrect responses mostly failed as functional distractors, which reflected the poor quality of these alternatives and yielded poor discrimination. The revision of the dysfunctional distractors and their further testing are needed to increase the difficulty level of the items. For example, in those items in which pseudo-guessing has been probably and most of the applicants have chosen the correct response (i.e. the items are also easy), the distractors

should be more difficult so that these could function better as distractors. In such items, the improvement should concentrate on making the distractors more difficult and less obvious. However, in those items in which pseudo-guessing has been probably but the items are not easy (i.e. distractors have been functioning properly), it is not enough to concentrate on making the distractors more difficult. The layout and wording of the assignment in these items should also be re-examined.

## 6.1 | Strength and limitations of the work

The strength of this study was several different and versatile methods used in the development process to ensure the content validity and psychometric validity of the EMI-T (i.e. systematic, review, several focus group interviews and expert panels and two pilot studies). Furthermore, in psychometric testing, the sample size was big enough for statistical analysis and large in comparison with sample sizes in other similar student selection studies or studies testing EI instruments' psychometric properties. This study had some limitations concerning the expert panels, the participants of the pilot studies and the psychometric evaluation. This study included three expert panels during the development process, including two rounds in panel three, following the recommended use of this method (Polit & Beck, 2006). However, the first two expert panels received a test version that included 73–100 items. The evaluation form was long and time consuming to fill out. This might have affected the quality of the items if the experts experienced the evaluation strenuous and did not have strength to comment the items at the end part of the form.

In the pilot studies, the study population included students who had just started their education prior to the pilot study. Thus, they represent applicants who have been selected for the programmes. Furthermore, the participants in the pilot studies took the EMI-T in class, but there was no such high-stakes situation in the entrance examination; this might have affected their responses compared with their answers during the actual entrance examination. IRT analysis was successfully performed, but several of the items during the development process were so easy (>95% of the participants chose the correct answers) that the IRT method was not applicable. Thus, a full psychometric evaluation was not possible for these items. Furthermore, the fact that EMI-T included several easy items was a limitation.

## 6.2 | Recommendations for further research

Further development and psychometric evaluation is needed to enhance EMI-T's difficulty and discrimination levels. Previously, IRT with graphical analysis of ICCs using TestGardener is a scarcely applied method in the nursing sciences. The graphical analysis proved to be excellent in facilitating item-level analysis, including precise distractor analysis. The results can be used for

further revision of the test, especially in relation to improving the distractor items, and thus, the difficulty and discrimination levels of the instrument. The predictive validity of the test should be evaluated in future research.

## 7 | CONCLUSION

The results of this study and especially the use of IRT and detailed distractor analysis during both the development process and an evaluation of the psychometric properties of EMI-T can benefit researchers and educators that develop or evaluate objective assessment tools with multiple choice questions. In the future, a follow-up study investigating whether applicants EI scores at admission have an impact on study success should be done. The results of this study can also be used to further development of the EMI-T for student selection purposes. Especially, the optimal cut-off level should be further defined. Social care and healthcare students engage in clinical practice early in their studies, and these environments are emotionally challenging. Assessing EI in student selection provides information that higher education institutions could use to develop and provide support interventions for those students that might have difficulties in EI. Furthermore, the results may encourage practice placements to include EI elements as learning objectives.

### AUTHOR CONTRIBUTIONS

Anne Pienimaa: Conceptualization, data curation, formal analysis, investigation, methodology, project administration, resources, validation, visualization, writing—original draft and writing—review and editing. Kirsi Talman: Conceptualization, data curation, formal analysis, investigation, methodology, project administration, resources, supervision, validation, visualization, writing—original draft and writing—review and editing. Jonna Vierula: Conceptualization, formal analysis, validation, visualization and writing—review and editing. Eero Laakkonen: Data curation, formal analysis, funding acquisition, validation, visualization and writing—review and editing. Elina Haavisto: Conceptualization, data curation, formal analysis, investigation, methodology, project administration, resources, supervision, validation, visualization, Writing—original draft and writing—review and editing. All authors participated in commenting on and revising the article critically for important intellectual content and agreed on the final version.

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### CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

### PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15557>.

### DATA AVAILABILITY STATEMENT

Author elects to not share data.

### IMPACT STATEMENT

Social care and healthcare students engage in clinical practice early in their studies, and these environments can be emotionally challenging. Assessing EI in student selection with adequate test can help the institutions of higher education to select the students with required abilities to succeed in the studies. The assessment of EI during student selection also provides information higher education institutions could use to develop and provide support interventions. The results may also encourage practice placements to include EI elements as learning objective. The results of this study and especially the use of IRT and detailed distractor analysis to evaluate the psychometric properties of EMI-T can benefit researchers and educators that develop or evaluate objective assessment tools with multiple choice questions.

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