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ORIGINAL ARTICLE OPEN ACCESS

The landscape of mental health care landscape in asia: issues and challenges

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Mental health care in Asia is an evolving field marked by both rapid advancements and persistent challenges. While some countries in the region have made significant strides in improving mental health services, others are still grappling with stigma, insufficient infrastructure, and limited access to care. Asia's unique cultural, socio-economic, and political factors further complicate this landscape, making mental health care a multifaceted issue that requires comprehensive yet tailored solutions for the respective countries.

Cultural Stigma and Misconceptions

The stigma associated with mental health conditions (MHCs) has been one of the most pervasive challenges across Asia. It is deeply rooted and reinforced by traditional beliefs that MHCs result from supernatural causes, moral failings, and even personal weakness. This results in shame faced by many patients and their caregivers alike, leading to social ostracism and discrimination.

For example, in countries like China, Korea, and Thailand, mental health is often not openly discussed, and individuals suffering from conditions like depression or anxiety are encouraged to "tough it out" or “snap out of it, I also can do it” rather than seek professional help (Lam and Sun, 2014, Zhang *et al.*, 2019). The stigma experienced by individuals with MHCs discourages them from seeking treatment, exacerbating their conditions and leading to severe consequences (Tan and Goh, 2023), including suicide (Targum and Kitanaka, 2012).

To address this issue, public awareness campaigns and education are crucial (Pang *et al.*, 2017, Zhang *et al.*, 2019). Governments, Non-Governmental Organisations (NGOs), and healthcare providers must work together to fight myths about MHCs and promote the idea that help-seeking in mental health is an essential step towards recovery. Although changing cultural attitudes within a society is slow, mental health professionals must spearhead this effort to create an environment where mental health is treated with the same importance as physical health.

Insufficient Infrastructure and Resources

Another significant challenge in mental health care across Asia is the lack of adequate infrastructure and resources. Many countries in this region face a shortage of mental health professionals, facilities, and funding. This shortage is particularly acute in rural areas, where access to mental health services is often non-existent.

For instance, in India, the ratio of psychiatrists to the population stands at only 0.3 per 100,000 people, with mental health services concentrated in urban areas, leaving rural populations underserved (Behere *et al.*, 2020). Similarly, in Indonesia, mental health services are limited, and the country has only about 1200 psychiatrists for a population of over 270 million people (Rayda, 2023). This lack of infrastructure is compounded by limited government funding for mental health care, resulting in inadequate facilities, outdated treatment methods, and insufficient support for mental health professionals (Ng, 2018).

To overcome these challenges, governments need to invest in mental health care, expand the training and recruitment of mental health professionals, develop accessible community-based mental health services (Tan and Goh, 2022) and even explore using online platforms to reach underserved populations (Wainberg *et al.*, 2017, Alegría *et al.*, 2022).

Integration of Mental Health Service into Primary Health

Another challenge for mental health services is to integrate them into primary care. In many countries, mental health care is still seen as a speciality, separate from general health care. This creates barriers to access, as individuals must navigate the healthcare system to receive the help they need. In countries like Thailand and Malaysia, efforts are being made to integrate mental health care into primary care settings, the implementation is slow, and many primary care providers lack the training and resources to effectively manage mental health conditions (Ng, 2018, Lemon *et al.*, 2023).

Successful integration requires training healthcare providers in mental health and ensuring that primary care facilities have the necessary resources, such as access to psychiatric consultations, medications, and support services. There is also the need to have a mindset shift where mental health gains recognition as an essential component of overall well-being rather than a separate issue (Funk *et al.*, 2008, Ooi *et al.*, 2021).

Emerging Challenges: Technology and Mental Health

While technological advancements offer new opportunities for improving mental health care, they also present new challenges. The rise of digital mental health platforms and telemedicine can potentially expand care access to underserved communities in remote areas. However, these technologies also raise concerns about data privacy, the quality of care provided, and the potential for over-reliance on digital solutions at the expense of face-to-face interactions.

In countries like South Korea and Japan, where digital health care is rapidly developing, clear guidelines and regulations must ensure that the services are safe, effective, and accessible to all. Moreover, while technology can be a valuable tool in mental health care, it should complement traditional mental health services rather than replace them.

Another emerging challenge is the impact of social media and the internet on mental health. The widespread use of social media platforms has been linked to increased incidences of depression and anxiety particularly among young people (Plackett *et al.*, 2023, Koh *et al.*, 2024). In countries like India, where internet usage is rapidly increasing, there is a growing need to address the mental health implications of using social media (Chandra *et al.*, 2023).

Conclusion

The challenges facing mental health care in Asia are complex and multifaceted, requiring coordinated efforts from governments, NGOs, and mental health professionals. While there are significant changes in many areas, much work remains to be done to ensure the accessibility of mental health services across all individuals in Asia. Addressing the stigma surrounding mental illness, improving infrastructure and resources, integrating mental health into primary care, tackling socio-economic determinants and navigating the challenges of technology are all essential steps towards creating a more inclusive and effective mental health care system in Asia. The journey is long, but meaningful change is within reach with sustained commitment and collaboration.

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Critical care nurses' perceptions toward withdrawal of life-sustaining treatments: a phenomenology study

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ABSTRACT

Introduction: Withdrawing life-sustaining measures involves complex legal and ethical considerations, and few healthcare providers have received specialized training in this area. This study explored critical care nurses' perceptions of withdrawing life-sustaining treatment.

Methods: A qualitative phenomenological design was used, a purposive sample of 15 individuals of both sexes for nurses working in the ICU for at least six months. The study was conducted in seven critical care units at four hospitals at Ain Shams University. The data collection process involved audio recordings of semi-structured open-ended interviews and the data were analyzed based on Tesch's method.

Results: Study results revealed that the sample age ranged from 24 to 38 and ranged from 1 year to 14 years working in ICU at various levels starting from nursing staff to head nurses. Critical care nurses' perceptions were reflected through four main themes and related subthemes. The main themes that shaped nurses' perceptions were attitudes toward withholding and withdrawing life-sustaining treatments, ethical perceptions, beliefs impact, and legal framework.

Conclusions: Nurses face difficult experiences influencing their perceptions of life-sustaining treatment withdrawal, emphasizing the importance of policy guidance to prevent decisions based only on beliefs. Therefore, further qualitative and quantitative studies are required.

Keywords: life-sustaining treatments, Perceptions, qualitative design, themes, withdrawal

Introduction

Life-sustaining treatments are medications or medical devices to maintain or support vital organ function. This includes mechanical ventilation, pharmacological or mechanical hemodynamic support, and hemodialysis(Bandrauk et al., 2017).The withdrawal of life-sustaining therapies is to remove those that help terminally ill patients die more slowly but no longer offer any benefit. For many individuals, getting the most comfortable death possible is a major priority.(Lobo et al., 2017). Removing life-sustaining treatments necessitates balancing ethical, legal, and medical concerns. Not all medical professionals have received specialized training in the ability to remove life-sustaining treatments (LSTs) and there are no established protocols to guarantee that patients and their families receive the best possible care(Downar et al., 2016).

The burden of chronic access to life-sustaining care has increased worldwide. The use of these medicines has given rise to ethical issues, especially when dealing with poor prognosis. Regarding this dilemma, it is acceptable or even necessary to withdraw and withhold LSTs(McPherson et al., 2019). Resources for intensive care units are limited, and administering unnecessary therapies to patients may compromise their sense of dignity. As a result, the significance of research and instruction in advanced care planning, end-of-life care, and withholding and withdrawal of life-sustaining measures has grown(Lee et al., 2020).

Hospital resources were strained by their breakpoints during the epidemic. Owing to pre-pandemic deficiencies, ventilators are in low supply in many nations. Intensive care units can adapt to a rise in demand to a certain extent. Healthcare systems in this circumstance need to handle potentially life-saving therapies using evidence-based policies(Cardona et al., 2020). Stopping life-extending therapy can be more difficult for medical practitioners than choosing not to start in the first place. However, these fears should not take precedence over clinical judgment and should not prevent patients from obtaining potentially beneficial treatment or forcing them to continue receiving ineffective treatment(Ursin, 2019). When handling end-of-life situations, nurses may experience emotional conflicts, stress, and worry. Religious and belief disputes arise as no clear policies and guidelines are controlling the process of life-sustaining treatment withdrawal. Therefore, these patients may require additional assistance. To help nurses in critical care units manage end-of-life concerns better, we should be aware of their viewpoints and assist them as doctors make decisions, but nurses live with it(Kostka, Borodzicz and Krzemińska, 2021).

Nurses experience moral distress when unable to solve clinical issues. This may occur if nurses provide care that goes against ethical standards. Concerns among nurses arise from their lack of participation in decision-making(Barlow et al., 2017). The codes of ethics, legal framework, and knowledge specific to nurses are all available to them. They also have a systematic strategy to help design treatments. Additionally, nurses must build strong connections with patients and their families to understand their preferences for the process of making end-of-life decisions(González-Rincón, de Herrera-Marchal and Martínez-Martín, 2019). Withdrawing life-sustaining care remains an issue of dispute in the intensive care perceptions of the nurses involved. Therefore, exploring critical care nurses’ perceptions toward withdrawal of life-sustaining treatments as part of multidisciplinary teams could be a great support for minimizing burnout syndrome, relieving stress, stopping mental exhaustion, and emotional draining for nurses, as well as improving the understanding of this process and providing guidance to facilitate the process.

Materials and Methods

Study design

A qualitative phenomenological design was used to achieve the study's aims. A qualitative approach was chosen to explore critical care nurses' perceptions toward withdrawing life-sustaining treatments and enrich the interpretation of the phenomena of interest. According to Creswell and Poth (2016), phenomenological design is the best approach for the researcher to gather deep information and perceptions through qualitative methods such as interviews representing it from the perspective of the research participants. This approach has been beneficial, and appropriate, and helped to explore critical care nurses' perceptions of withdrawal of life-sustaining treatments.

Study Setting and Participants

The study was conducted in seven critical care units at four hospitals at Ain Shams University: The participating ICUs were seven different adult ICUs (Ahmed Shawky Geriatrics ICU, Medical ICU, Trauma ICU, Neurology ICU, Isolation ICU, CCU, and GIT ICU. In phenomenological research, researchers interviewed the participants to obtain considerable data. A purposive sample was taken of critical care nurses who agreed to participate in the study who worked part-time or full-time and had at least six months of experience.

The power of purposive sampling in qualitative research lies in selecting information from rich cases for in-depth study, from which the investigator can learn about the phenomena under study. In qualitative designs, predetermination of the number of participants is almost impossible because the sample size is not determined by the number of participants, but by achieving data saturation (Mwita, 2022).

The Faculty of Nursing Ain Shams University approved letter facilitated the data collection process in hospitals. The first researcher started to visit areas repeatedly to find volunteers who agreed to conduct interviews. Referral sampling was used via the snowball sampling method to recruit participants after showing their willingness to participate in the study. Fifteen critical care nurses (ten men and five women) agreed to participate in the study. After nine interviews, 80% of the data was collected. Information saturation was achieved after fifteen interviews. The aim of the study was clarified to participants included in the study and the confidentiality and privacy of participants were assured. The researcher utilized interview codes in the form of numbers to ensure the privacy of data and confidentiality. Before starting interviews, all of their rights were explained and their right to withdraw at any time was guaranteed if they felt uncomfortable disclosing any difficult situation they had witnessed. Data collection interviews were terminated when participants were exhausted by describing phenomena under study.

Instrument

Data collection was performed using semi-structured interviews. The interview was developed by the first researcher guided by previous literature and supervised by other team researchers. It was also revised by four experts from the Faculty of Nursing who have academic experience, not from the research team. The tool was developed by using the mother language in conversation based on a review of relevant recent related literature in which the researcher simply guided the participant in an extended discussion. The interview covered two parts, as the following: Part I: Demographic data: Critical care nurses' data such as gender, age, religion, educational level, place of work, and years of experience. Part II: Open-ended semi-structured interviews: Several audio-recorded online meetings were organized by the first researcher and participants because of the difficulty in conducting meetings during work time and precautions of the pandemic. The researcher conducted the interviews using an interview guide containing 13 open-ended questions. To ensure the recording of comprehensive, accurate, and true reflective descriptions of critical care nurses' perceptions on the withdrawal of life-sustaining treatments, interviews were conducted using a high-quality recording application. Pieces of research were fitted together through true reflective descriptions of critical care nurses' perceptions of the withdrawal of life-sustaining treatments.

Data Collection

After receiving institutional approval, data were collected from February 2022 to July 2022. The first researcher recruited fifteen nurses, and contact was initiated; the researcher and participants organized online meetings due to difficulty in conducting meetings during work time and precautions of the pandemic, and interviews were recorded using a high-quality recording application on a laptop. The purpose, significance, and nature of the study were explained before data collection. All participants provided verbal consent for inclusion in audio-recorded interviews. All interviews were conducted in the native language (Arabic). Each interview lasted from 20 to 50 minutes, covering the required questions. Interviews ended when participants had completed discussing the phenomenon being studied; when no new codes, categories, or themes had developed; and when participants had repeated the same information (data saturation). The interview guide had 13 open-ended questions designed by the first researcher who had previous experience working in ICU based on the literature to allow deeper exploration and lead to a rich description and understanding of their experiences. Questions were simply explained to participants in their own words to understand and express themselves freely. After each question was discussed, the researcher checked whether their understanding of the participants' opinions given in the interview truly reflected the participant's experiences.

Data Analysis

The first researcher transcribed the interview and codes made after revision and agreement of other researchers. Data analysis was done manually according to Tesch's method (Creswell and Poth, 2016). Once all the interviews were transcribed, the transcriptions were read, and short notes were made. Each document was read to make meaning of its content and all the identified topics or units of meaning were then listed. Similar topics were then clustered together as major and unique topics. The topics were abbreviated as codes, which were written next to the appropriate sections of the text. The most descriptive wording for the topics was identified and the topics were formulated into categories. The data belonging to each category were gathered and analysis was performed. Thematic analysis was conducted once the process had been completed with all the transcribed interviews.

Trustworthiness

Conformability, dependability, credibility, and transferability were the four criteria used to increase the rigor of the study. All the research team was included in technical implementation. Credibility was ensured by including copies of the transcribed interviews. Researcher triangulation was undertaken as the interviews were revised by all researchers. Participant triangulation ensured that multiple perceptions were obtained when the study included participants from different intensive care units. Transferability was ensured through in-depth descriptions of the study performed, providing details of the characteristics of researchers, collection and analysis procedures, sampling strategies, and the data collection and analysis procedures. Conformability was ensured by data accurately representing the information that the participants provided, and the researcher didn't influence participants or guide them.

Ethical Considerations

The research approval was obtained from the ethical committee in the Faculty of Nursing at Ain Shams University before starting the study with the number 24.02.214. Verbally recorded consent was obtained from participants. confidentiality of participants was preserved, and their data were only accessible to the research team.

Results

The age of nurses ranged from 24 to 38 years and their professional experience in ICUs ranged from 1 to 14 years. The participants' distribution by gender was five women and 10 men. Four main themes were identified based on the findings regarding critical care nurses' perceptions of withdrawing life-sustaining treatment: (a) Attitudes toward the process of withholding and withdrawing LSTs, (b) Ethical perceptions, (c) Beliefs impact, and (d) Legal framework.

Theme 1: Attitudes toward the process of withholding and withdrawing LSTs

Attitudes toward withholding and withdrawing of LST was a master theme with four subordinate themes: discontinuation of treatment; the distinction between withholding and withdrawing of LST; limited access to ICU care and withholding and withdrawing of LST, and palliative care and proximity.

Discontinuation of treatment

Most of the participants were against discontinuation of life-sustaining treatments and confirmed that it should never be stopped even if the patient appears to be dying because miracles happen, while some of them see that life-sustaining treatments frequently prolong the dying process without providing any real benefit to the patient.

An example of attitudes toward the process of withholding and withdrawing of LSTs theme; is discontinuation of treatment subtheme; a 38-year-old female participant reported:

A 38-year-old female participant reported: *"I don't agree to withdraw life-supporting treatments, and I've never been involved in this process before."*

A 24-year-old female participant stated: *"Many patients in the intensive care unit are in a state that is considered irreversible. Consequently, there is no reason to continue administering life-sustaining medications once hope for recovery is lost. However, upon admission, physicians typically initiate all necessary medications and aggressive courses of antibiotics."*

Distinction between withholding and withdrawing of LST

Participants found a great difference between withdrawal and withholding LSTs. An example of the distinction between withholding and withdrawing of LST (life-sustaining treatments) subtheme;

a 32-year-old male participant, expressed that *"If we start and withdraw it, I see that is a crime or a greater mistake, but if we withhold from the beginning, it may be a lesser mistake."*

A 24-year-old male participant expressed no clear difference between withholding and withdrawing LSTs. The treatment has a beginning and an end. Withdrawing treatment is like withholding it, as the patient does not benefit.

Limited access to ICU care and withholding and withdrawing of LST

Many of the participants linked the lack of ICU beds and resources with the necessity of withdrawal of LSTs.

An example of the relation between limited access to intensive care units and the withholding of life-sustaining treatments subtheme is in a 38-year-old female participant who expressed that: *"Yes, there is a relation. It is possible to affect the withdrawal of treatment, not just withholding it. If there are no available beds and the doctor sees that the patient's condition is not going to improve and there is no hope for recovery, then the withdrawal of treatment may begin."*

Palliative care

All of the participants agreed with applying the concept of palliative care and its great importance.

For the subtheme of palliative care, a 33-year-old male participant reported: *"Yes, of course, it has value. The patient goes through several stages of illness, but unfortunately, palliative care is not widely available in our setting. It may be more available in oncology hospitals."*

Theme 2: Ethical perceptions

For the ethical perceptions theme, there were four subthemes found: patient autonomy, justice, telling the truth, and ethical decision-making.

Patient autonomy.

Participants reported the necessity of applying patient autonomy principles and advocating their rights.

An example of ethical perceptions theme; autonomy subtheme; a 25-year-old female participant, reported that: *"One of patients' rights guaranteed by World Health Organization and applied here if the patient requested or refused a specific treatment, we had a cancer patient in a late stage she asked not to be resuscitated."*

Justice.

Patients are equally treated by all participants and there is no difference in delivering care. For the subtheme of justice, a 38-year-old male participant reported that: *"Justice is applied in general between all patients but sometimes as we are in a governmental hospital there are some types of discrimination, especially with recommended patients."*

Telling the truth

Most participants prefer telling the truth and avoiding false assurance. For the subtheme of telling the truth, a 26-year-old male participant reported that: *"We disclose all details of patient condition clearly";* a 24-year-old male participant reported that *"It's not beneficial for the patient if I tell something that could affect their psychological or physical health, as some patients may become fearful. However, we can clarify the situation to the patient's family."*

Ethical decision-making.

A sense of inferiority and lack of authority in the decision-making process was described by most of the participants.

For the subtheme of ethical decision-making, a 38-year-old male participant reported: *"We have no participation in these decisions even if it happens; it will remain according to the doctor's orders."*

Theme 3: Beliefs toward withdrawal of LSTs

There were two subthemes for the theme of beliefs toward withdrawal of LSTs: beliefs impact and religion impact.

Beliefs impact

Some participants reported they should try to keep their patients alive on machines for as long as possible, no matter how uncomfortable the machines are, while others see that, if a patient is dying, it is best not to prolong his life by LSTs.

An example of a beliefs impact theme is a 30-year-old female participant, who reported: *"I believe that everything has a predetermined time, and we provide treatment for the patient until their time will come."*

A 26-year-old male participant reported: *"No matter how much we work on a patient who has lost hope in their recovery, such as a lung cancer patient, we know that, although how hard we try, there will be no positive outcome and the patient will die later."*

Religion impact.

Religion has a great role in forming participants' opinions toward those sensitive dilemmas. For the subtheme of religion's impact, a 38-year-old male participant reported: "*Yes, the concept of religion has an impact. First and foremost, every patient in my view should receive their care in a complete pattern."*

A 29-year-old female participant reported: *"I don't have a religious background about these concepts, but if a doctor asked me to withdraw a certain treatment, I would feel dissatisfied and if the patient died, I would feel that it may be due to my negligence."*

Legal framework

For the theme of a legal framework, three subthemes were found: malpractice and negligence, euthanasia, and DNR.

Malpractice and negligence

Some participants reported incidences of malpractice and negligence with the patient appearing to be dying.

An example of a legal framework theme, malpractice, and negligence subtheme is a 29-year-old female participant who reported: *"To be honest, yes, I have seen such cases, but it is a rare occurrence. I feel that the nursing staff can't try with the case. They see that it's not going to make a difference in the end because they will die already."*

Euthanasia

Participants showed a low level of knowledge regarding euthanasia and its types. For the subtheme of euthanasia, a 38-year-old female participant reported: *"I'm not sure, to be honest. I have never heard of it before; a 25-year-old male participant reported "It is not legal in Egypt, but it exists outside Egypt."*

DNR

The lack of policies guiding DNR orders in hospitals was reported by most of the participants. For the subtheme of DNR, a 25-year-old male participant reported: *"No one writes 'do not resuscitate' in patient documents. This may only be a verbal agreement. Sometimes, I wrote it on the treatment sheet, but they asked me not to write it."*

A 25-year-old male participant reported: *"recently, the doctor writes in the medical notes that the patient should not receive cardiopulmonary resuscitation and the matter should be officially documented as it is counted in the mortality rate statistics."*

Discussions

The current study aimed to explore critical care nurses' perceptions of withdrawal of life-sustaining treatments. The findings of the study provided insights into the low level of knowledge of ICU nurses regarding ethical and legal issues in end-of-life care, especially the process of life-sustaining treatment withdrawal and the need for structured guidelines and policies which help the multidisciplinary team be able to share in these decisions and tolerate stress arise from implementing these steps. The goal was accomplished through a structured discussion of the sociodemographic traits of the participants, along with the study topics and associated subtopics. Data were gathered from the study participants through in-depth interviews to capture their perceptions, feelings, thoughts, and hopes that arose from their experiences caring for end-of-life patients.

Regarding the subtheme of discontinuation of treatment, the results indicated that most participants were unwilling to discontinue life-supporting treatments, even in cases in which the patient's prognosis was poor. This may be attributed to religious beliefs and a lack of clear policies and procedures to address ethical dilemmas. These findings are consistent withTaylor et al. (2020) who detailed the tensions experienced by nurses during the LST withdrawal procedure. Concerning the subtheme of distinction between withholding and withdrawing life-sustaining treatments, the study results showed that most participants found that the two processes were not equal; they thought it was a crime or a greater mistake, but if was withheld from the beginning, it may be a lesser mistake, while some of them saw that they are equal and there is no difference between withdrawal and withholding life-sustaining treatments These findings agree with Ursin (2019),who reported that some healthcare members may find it more difficult to withdraw LSTs than to decide not to start it in the first place, as they would feel responsible for the patient's death. These results are not supported by the findings of Larcher et al. (2015) who reported withholding, withdrawing, and limiting life-sustaining treatments ethically the same.

Regarding the subtheme of the relation of limited access to ICU care, withholding and withdrawing of LST, some of them found no relation and interfering in these situations, but most participants said that there is a direct relation between lack of ICU beds and the decision to withdraw life-sustaining treatments, especially during the pandemic, when there was a lack of ICU beds there were patients who needed care more than end-stage patients. They confirmed this relationship if asked about the number of ICU beds compared to the number of patients, saying the ratio was disastrous due to the lack of intensive care beds. These findings are consistent with Cardona et al. (2020) who reported a lack of hospital resources during the COVID-19 pandemic and hospital resources reached their limits. Several countries face a shortage of ventilators. ICUs have some capacity to respond to increased demand; in this situation, healthcare systems need to have policies to judge the withdrawal LSTs process.

Regarding the subtheme of palliative care, all participants noted the value and necessity of providing palliative care but reported that they did not have these departments in their hospital, as the concept of palliative care in Egypt still needs to be paid attention to and to cooperate with the Ministry of Health, the private sector, and community resources to offer palliative care centers. These findings agree with Sameh Eltaybani et al. (2020), who reported a lack of adequate funding for palliative care facilities, the absence of a national organization dedicated to the field, the exclusion of palliative care from the country's healthcare agenda, and inadequate training of medical professionals in the field.

Regarding the subtheme of patient autonomy, all participants confirmed applying patient rights, especially in fully conscious patients and highly educated patients. Families who can make decisions otherwise have the upper hand, especially in governmental hospitals, but doctors and nurses explain, clarify, and share with patients and families in medical decisions. This result is consistent with the findings of Molina-Mula and Gallo-Estrada (2020) who mentioned the importance of establishing strategies to enhance patients' ability to make decisions and increase their autonomy.

Concerning the subtheme of justice, all participants informed that all patients were equal in providing care even if some recommended patients had their care and treatment without distinction. From a researcher's point of view, it is an ethical obligation to be fair in providing healthcare in governmental or private hospitals, which enhances the concept of humanity. This finding agrees with Manda-Taylor et al. (2017) who reported that everyone should be treated equally, fairly, and impartially according to the definition of justice. According to the principle of justice, we must consider the perspective of the entire community.

Regarding the subtheme of telling the truth, most participants described that they prefer telling the truth about patient's condition to patients and their families. They try to be careful and kind while delivering these messages, especially to patients, to avoid affecting their psychological condition badly, while some of them stated that giving information about patient condition is not one of their responsibilities. From the researcher's point of view, nurses should follow hospital policies regarding this issue, especially in breaking bad news. These findings are in harmony with Chamsi-Pasha and Alba (2017) who reported that the patient had the right to be aware of his health and prognosis. The patient should be provided with additional information if needed.

Participants of the study stated in the subtheme of ethical decision-making that they have no authority in making decisions regarding the withdrawal of life-sustaining treatments and that they considered these medical decisions. They felt empowered less in these situations, especially when a few doctors allowed nurses to participate in these decisions. These findings are not consistent with Vanderspank-Wright et al. (2018) who stated that LSTs withdrawal decision involves all members of healthcare teams and not limited to physicians and nurses only.

Concerning the subtheme of beliefs, some participants were against the withdrawal of life-sustaining treatments, and they felt an obligation to complete with the patient until the end, as each person had a time of death. They found it more humanistic than scientific, while some of them stated that we should not waste our resources in hopeless conditions, and they hoped to generalize guidelines and policies to control this subject, especially with a lack of resources and ICU beds. These findings are in harmony with Taylor et al. (2020) who described challenging scenarios that emotionally impacted nurses, causing them to feel stressed and lose the motivation to engage in this process.

Regarding the subtheme of the impact of religion, most participants were honest when they explored that religion has a significant role in forming directions and ways of thinking regarding the withdrawal of life-sustaining treatments, and defined religion as a reference to solve these debates. These findings completely agree with O'Neill et al. (2017) who described that recent studies have demonstrated that Islamic culture and religion may impact those who live and practice in Muslim nations. For instance, in our society, talking about death is taboo.

Related to the subtheme of malpractice and negligence, some participants reported witnessing malpractice due to hiring nurses who are not highly qualified and sometimes nurse aid may be assigned to patients during a severe shortage of nurses; they also witnessed some nurses who neglected delivery of care for patients at the end stage of life, especially when they were responsible for many patients. Still, most of them were honest and tried to deliver nursing care to all patients regardless of their condition. These findings agree with Myers, Heard and Mort, (2020) who reported malpractice claims involving critical care nurses, seeking to prevent patient harm and close monitoring for skin integrity.

Participants showed unfamiliarity with the subtheme of euthanasia, and they did not know its process, as it is not legal in Egypt and against Islamic rules. These findings are consistent with those of Cayetano-Penman, Malik and Whittall (2021) who concluded that euthanasia challenged nurses in their aim to provide care. It is necessary to provide comprehensive education, professional guidelines, and awareness of current nurse regulations.

Regarding the subtheme of DNR, participants showed a variety of policies, some of which reported that this type of order must be documented and considered legal, whereas others reported that DNR orders have no legal criteria and may be only oral orders. These findings are consistent with those of Goodarzi et al. (2022) who conducted a study on the knowledge, attitude, and decision-making of nurses in the resuscitation team toward terminating resuscitation, and they reported in their conclusion that the lack of nurses' knowledge regarding DNR is considered an ethical challenge. Nurses must have clear standards regarding DNR orders to avoid legal or psychological challenges. This enhances their engagement with the decision-making process.

The findings have demonstrated that nurses play an integral role in the process of withdrawal of life-sustaining treatments. Every new nurse entering critical care should get advanced training on removing life-sustaining measures, and regular updates to support the development of skills and confidence in this procedure. Establishing protocols for discontinuing life-sustaining treatments can reduce the source of conflict during this phase of treatment withdrawal. To establish optimal practices, it would be helpful to critically evaluate current treatment withdrawal protocols and clinical practice recommendations, as well as how these guidelines are implemented in intensive care.

These results imply that professional education on LST withdrawal's religious and cultural aspects can influence nurses' views toward the process. Stress among nurses might probably be decreased by increasing cultural awareness and improving perceptions. ICU nurses could have a better experience participating in the withdrawal of life-sustaining treatment if they frequently attend multidisciplinary meetings where all parties are involved in discussions on treatment withdrawal.

The findings of this study explored critical care nurses' perceptions of withdrawal of life-sustaining treatments. An educational program can be adopted to enhance nurses' knowledge about end-of-life issues, especially the process of sustaining treatment withdrawal. One of the research limitations is that the data may not cover all perceptions of nurses regarding the withdrawal of life-sustaining treatments. Another limitation of the study was the difficulty of conducting face-to-face interviews because of hospitals' pandemic precautions.

Conclusion

It can be concluded that critical care nurses who were participants of the current study showed several feelings, experiences, and perceptions toward withdrawal of life-sustaining treatments that were reflected through four themes and related subthemes that included attitudes toward withholding and withdrawing LST, ethical perceptions, beliefs impact, and legal framework.

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Conflict of Interest

The authors declare no conflict of interest.

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ORIGINAL ARTICLE

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The effect of therapeutic regimen education on improving the self-efficacy in cancer patients undergoing haemodialysis: a quasi-experimental study

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ABSTRACT

Introduction: Cancer treatments often comes with varying adverse effects on both functional and physiological status of cancer patients, such as reduced kidney function, necessitating haemodialysis. The aim of this study was to determine the effect of therapeutic regimen education on the treatment self-efficacy of cancer patients undergoing haemodialysis.

Methods: This study used a quasi-experimental method, involving 136 participants divided into control and intervention groups. The intervention group was given therapeutic regimen education that lasted for 4 weeks. The self-efficacy score was measured before and after intervention in both groups. Pre- and post-intervention scores were measured using the Chronic Kidney Disease Self-Efficacy instrument ($r = 0.845$). Paired t-test and independent t-test were used, respectively.

Results: The results show that the patients who received therapeutic regimen education had significant increases in self-efficacy scores ($p < 0.001$). The mean (SD) score for all sub-variables increased after treatment: autonomy, from 15.07 (4.29) to 26.50 (1.74); personal integrity, from 11.63 (3.92) to 23.68 (2.59); problem-solving, from 10.66 (3.98) to 18.85 (0.82); and seeking social support, from 7.13 (2.38) to 14.06 (1.62). From the statistical test results, a significant difference in each dimension of self-efficacy was found between before and after treatment ($p < 0.001$). When the post test scores between intervention and control were compared, it showed significant different between them ($p < 0.001$).

Conclusions: Therapeutic regimen education can increase treatment self-efficacy in cancer patients undergoing haemodialysis treatment, which can affect the patient's healing process.

Keywords: cancer patients, haemodialysis, self-efficacy, therapeutic regimen education

Introduction

Cancer is one of the main causes of morbidity and mortality worldwide, with an estimated 19.3 million new cancer cases and nearly 10 million cancer-related deaths. At Dharmais Cancer Hospital, 6,135 new patients in the outpatient unit were recorded in 2022. Based on the patient medical records in its out-patients cancer clinic, breast cancer patients accounted for the highest percentage (62%) of cancer patients in the second quarter of 2022, followed by those with nasopharyngeal cancer (8%), colon cancer (7%), and cervical cancer (6%). Currently, there are several cancer therapy options available, including surgery, radiotherapy, chemotherapy, or a combination of these therapies (Debela et al., 2021). As a consequence of these treatments, cancer patients experienced various functional and physiological side effects which include hematological, heart, and nephrotoxic problems (Altun

& Sonkaya, 2018; Aslam et al., 2014). A study in France investigating the severe adverse effects suffered by cancer patients revealed 5.8% of the population experienced renal and urinary disorders (Ingrand et al., 2019). Patients with renal complications often require additional treatment, including undergoing hemodialysis.

The number of cancer patients undergoing hemodialysis is increasing every year. At Dharmais Cancer Hospital, 262 patients underwent hemodialysis in 2018. This number almost doubled in 2022, where 431 patients underwent hemodialysis, not including those undergoing the treatment outside of the hospital clinic. The cancer treatment puts a burden on patients and hemodialysis adds to the burden both physically and financially (Husebø, et al., 2023; Irragori et al., 2021). By observation, many patients feel greatly burdened by having to undergo hemodialysis twice a week during their treatment course with chemotherapy and radiotherapy. The perceived burden, along with other elements of treatment should factor into the patient's compliance against therapy and treatment regimen. Accordingly, one of such factors is the patient's self-efficacy. This is related to low treatment self-efficacy and uncertainty about the effectiveness of hemodialysis in reducing complications associated with impaired kidney function.

Bandura's self-efficacy theory emphasizes that patients' beliefs about their own abilities influence their feelings, thoughts, and motivation toward their actions and behaviors. Studies have shown that educational interventions based on self-efficacy have a positive effect on dietary treatment compliance and fluid restriction in patients undergoing hemodialysis (Ramezani et al., 2018), which leads to increased self-efficacy, treatment compliance, and improved quality of life (Xu et al., 2021). Nurses as the forefront health professional in cancer patients' care play an active role in assisting patients through nursing interventions to increase patients' self-efficacy.

The self-efficacy of cancer patients has been researched for many years. However, there is a knowledge gap regarding interventions that could positively impact the patients' self-efficacy in Indonesia. Therefore, the researchers suggested the need to investigate educational interventions that could effectively increase patients' self-efficacy. This study aimed to examine the effect of education intervention on treatment self-efficacy in cancer patients undergoing hemodialysis at the Dharmais Cancer Hospital.

Materials and Methods

Study design and setting

This research used a quasi-experimental study design in which study respondents received an intervention, thus the effect of the treatment was assessed. The quasi-experimental design used in this research was the non-equivalent control group design. The respondents were divided into a control group and an intervention group from which their responses were collected using questionnaires both before and after the intervention was given. The treatment regimen education curriculum was focused on providing scheduled education and supporting tools to increase understanding and compliance with therapeutic regimens. Hence, this study used a cross-sectional model in which the data were compiled from the observed results through the questionnaires.

Population and sample

The research was conducted in the hemodialysis room at Dharmais Cancer Center Hospital, Jakarta, from the first week of February 2023 to August 2023. The study respondents were selected from the patients registered at the hemodialysis room of Dharmais Cancer Center Hospital who satisfied the study inclusion criteria. Convenience sampling technique was used. The inclusion criteria were patients undergoing hemodialysis (HD) treatment in relation to cancer treatment; patients were on their first or second HD; and patients who were able to communicate effectively. Patients on their first or second HD treatment were chosen in consideration of their exposure to general health education during visits to better observe the difference between the control and intervention groups.

Accordingly, the same respondents would be required to complete questionnaires at two different times, namely before and after the intervention was given to the intervention groups. Therefore, the number of samples was determined using the paired numerical analytic formula (Dahlan, 2010). The study required 68 respondents for each group, resulting in 136 respondents in total.

Research Instrument

The independent variable of this research was the therapeutic regimen education, and the dependent variable was the self-efficacy. The therapeutic regimen education was comprised of two instruments namely, the program plan and educational tools as patient education instruments. Furthermore, a modified Chronic Kidney Disease Self-Efficacy (CKD-SE)

Table 1. Homogeneity Test According to Numerical Data on Respondent Characteristics

No.	Variable	N	Mean	SD	MD (95% CI)	t	df	p Value
1	Age							
	Intervention	68	49.18	15.44	6.5 (1.77–11.26)	2.71	134	0.07*
	Control	68	55.69	12.35				
2	Social Support							
	Intervention	68	28.57	7.99	−9.81 (−12.3 to −7.29)	-7.73	134	0.00*
	Control	68	18.76	6.75				
3	Self-efficacy							
	Intervention	68	42.96	13.32	0.19 (−4.38 to 4.76)	0.08	134	0.93
	Control	68	43.15	13.65				

*Significant at α = 0.05, with independent t-test

questionnaire was used as an instrument for assessing patient self-efficacy. The questionnaire consisted of six questions used to measure treatment compliance as the dependent variable. Sociodemographic statuses as the confounding variables were assessed using sociodemographic questionnaire which inquired the patient’s age, education level, marital status, income, disease status (disease duration and time since diagnosis) and social support (the use of external assistance in hemodialysis attendance, motivation, dietary management, fluids, medication, and family support). The social support inquiry used seven statements on a 5-point Likert scale. The CKD-SE Questionnaire has been tested for validity and reliability with the result of 0.59±0.91 for validity and r=0.845 for reliability (Lenggogeni et al., 2021).

The respondents in both groups were then given a questionnaire that assessed self-efficacy using the CKD-SE instrument prior to receiving the intervention. Furthermore, in the control group, the patients were given general health education as per the hospital’s protocol before and after the treatment. For the intervention group, the patients were given the treatment regimen education as per the researchers’ program plan. The program consisted of four session spanning four weeks). The patients in the intervention group were given education about hemodialysis, interdialytic weight gain, Benson's relaxation technique, and a booklet (list of activities, food and drink, and treatment schedule) in the first week. In the second week, the patients were showed an educational video and discussed the problems they encountered during the treatment. In the third week, the patients discussed their goals, their achievements in relation to their treatments, and were given support to set a treatment goal. Patients were expected to be able to practice a simple relaxation technique by the fourth week. The treatment re-evaluation was later conducted by distributing the questionnaires in the fourth week.

Statistic Analysis

The data were edited after collection to see the completeness of the questionnaire answers, and then coding and data entry were carried out based on the answers. Data cleaning, processing, and analysis were performed using the computer software. The univariate analysis was applied to all variables to gain characteristic description. Bivariate analysis was used to investigate the effect of therapeutic regimen education on patients’ self-efficacy and the difference in score for self-efficacy

Table 2. Homogeneity Test According to the Categorical Data of the Respondents' Characteristics

Characteristic	Control (n=68)	Intervention (n=68)	p Value
	n (%)	n (%)	
Sex			
Female	41 (46.6)	47 (53.4)	0.37
Male	27 (56.3)	21 (43.8)	
Level of Education			
Primary School	12 (63.2)	7 (36.8)	0.20
Junior High School	12 (66.7)	6 (33.3)	
High School	34 (44.7)	42 (55.3)	
University	10 (43.5)	13 (56.5)	
Marital Status			
Married	67 (52.3)	61 (47.7)	0.06
Not yet	1 (12.5)	7 (87.5)	
Income			
≤Regional Minimum wage (IDR 4,6M)	57 (49.1)	59 (50.9)	0.81
>Regional Minimum wage (IDR, 4,6M)	11 (55.0)	9 (45.0)	
Disease Duration			
<1 year	5 (31.3)	11 (68.8)	0.18
≥1 year	63 (52.5)	57 (47.5)	
Type of Cancer			
Gynaecological	28 (50.9)	27 (49.1)	1.00
Non-gynaecological	40 (49.4)	41 (50.6)	

*Significant at α = 0.05, with independent t-test

Table 3. Changes in Self-efficacy Scores Before and After Therapeutic Regimen Education

Variable	Group	Mean	SD	MD (95% CI)	T	df	p Value
Self-efficacy	**Intervention**						
	Before	42.96	13.32	−40.16	−24.58	67	0.000*
	After	83.12	6.112	(−43.42 to −36.90)			
	Control						
	Before	43.15	13.65	−33.76	−19.93	67	0.000*
	After	76.91	1.88	(−37.14 to −30.38)			

*significant at p<0.05, with paired t-test

before and after the intervention. The type of bivariate analysis used was decided according to the distribution of the collected data; the paired t-test would be used for normally distributed data. The post-test scores between intervention and control were compared with independent t-test.

Ethical Consideration

This study complied with the ethical principles of research. This study has gone through ethical testing at Dharmais Cancer Center Hospital, Jakarta, and has been approved with the approval No: 074/KEPK/II/2023.

Results

The homogeneity and normality tests were performed to test the data distribution of each variable. The homogeneity test was the Levene test (significant at p>0.05). The test result in Table 1 shows that the age and social support variables in the intervention and control groups were not equal (p < 0.05). The mean (SD) age in the control group was older (55.69 [12.35] years vs. the intervention group (49.18 [15.44] years). The mean (SD) social support score in the control group was lower (18.76 [6.75]) than that of the intervention group (28.57 [7.99]).

Table 2 shows that 88 respondents were women, 46.6% of whom were in the control group and 53.4% were in the intervention group. Most respondents had a high school education, but the percentage in the intervention group was higher (55.3%) than that in the control group (44.7%). Most respondents were married, with the control group having a higher percentage of married respondents (52.3%) than the intervention group (47.7%). A total of 116 respondents had incomes lower than the regional minimum wage, while 20 respondents had incomes higher than the regional minimum wage. Most respondents have had cancer for more than one year, with 63 in the control group and 57 in the intervention group. More respondents were diagnosed with non-gynecological cancer (81 respondents) than gynecological cancer (55 respondents). An equality analysis based on the homogeneity test revealed that the intervention and control groups had equality based on gender, educational level, marital status, opinion, illness duration, and type of cancer among the respondents before treatment.

Data were analyzed using paired t-test to examine the significance of the difference of means before and after the intervention. Table 3 shows that, before treatment, the intervention group had a lower mean (SD) self-efficacy score than the control group (42.69 [13.32] vs. 43.15 [13.65]). After the intervention, the self-efficacy score increased significantly in both groups but were higher in the intervention group than in the control group (83.12 [6.112] vs. 76.91 [1.88]). The analysis result was that both control group and

Table 4. Changes in Self-efficacy Scores in the Sub-variables of Autonomy, Self-Integration, Problem-Solving, and Seeking Social Support Before and After the Therapeutic Regimen Education (n = 68)

Sub-variable	Intervention Group	Mean	SD	MD (95% CI)	t	df	p Value
Autonomy	Before	15.07	4.290	−11.42 (−12.46 to −10.36)	−21.9	67	0.000*
	After	26.50	1.740				
Self-integration	Before	11.63	3.920	−12.01 (−13.1 to −10.93)	−22.16	67	0.000*
	After	23.68	2.590				
Problem-solving	Before	10.66	3.980	−8.19 (−9.14 to −7.23)	−17.12	67	0.000*
	After	18.85	0.820				
Seeking Social Support	Before	7.13	2.380	−6.93 (−7.58 to −6.27)	−21.06	67	0.000*
	After	14.06	1.620				
Total	Before	42.96	13.32	−40.16 (−43.42 to −36.90)	−24.58	67	0.000*
	After	83.12	6.112				

*significant at p<0.05, with paired t-test

Table 5. Differences in Mean Self-efficacy Scores After Education on Therapeutic Regimens and Differences in Self-efficacy Scores Between the Intervention and Control Groups

Variable	Group	Mean	SD	MD (95% CI)	t	df	p Value
Self-efficacy	**After**						
	Control	76.91	1.88	−6.206	−8.0	134	0.000*
	Intervention	83.12	6.11	(−7.74 to −4.67)			
	Difference						
	Control	33.76	13.96	−6.397	−2.71	134	0.007*
	Intervention	40.16	13.47	(−11.05 to −1.74)			

*significant at α 0.05, with independent t-test

intervention group showed a significant difference in self-efficacy scores after education (p < 0.001).

Table 4 shows that, after treatment in the intervention group for four weeks, the self-efficacy scores increased for the following sub-variables: autonomy, self-integration, problem-solving, and seeking social support. The mean (SD) score for the following sub-variables increased after treatment: autonomy, from 15.07 (4.29) to 26.50 (1.74); personal integrity, from 11.63 (3.92) to 23.68 (2.59); problem-solving, from 10.66 (3.98) to 18.85 (0.82); and seeking social support, from 7.13 (2.38) to 14.06 (1.62). From the statistical test results, a significant difference in each dimension of self-efficacy was found between before and after treatment (p < 0.001). For overall dimension the self-efficacy scores increased significantly (p < 0.001).

Discussions

This study aimed to investigate the effect of therapeutic regimen education on the self-efficacy of cancer patients undergoing hemodialysis treatment related to their cancer diagnosis. This study was conducted to 136 participants divided into two groups (intervention and control group). The study was conducted between March and August 2023. Patients in the control group were undergoing treatment as per the hospital protocol, while the patients in the intervention group received an intervention model aimed to improve patients' self-efficacy in undergoing hemodialysis treatment.

In this study, therapeutic regimen education was selected as the intervention method. The initial session emphasized the importance of treatment self-efficacy and compliance through delivering knowledge on hemodialysis using audio visual media, followed by delivering relaxation guidance using Benson's method. The patients received a booklet detailing activities, dietary guidelines, and treatment schedules. The pivotal first session aimed to motivate patients toward a better life. Subsequent weeks involved patients sharing their challenges, collaboratively problem-solving with nurses in the second week, and setting goals in the third week. This approach provided patients with the necessary information to adhere to the prescribed treatment.

Cancer patients' sociodemographic characteristics

This study recruited 136 participants with 68 participants in each control and intervention group. More than 50% of the participants were female. However, more were diagnosed with non-gynecological cancer than gynecological cancer. These results were consistent with the research on cancer incidence in Asia by Huang et al. (2022) which showed that more countries presented increasing trends of cancer incidence in women. The research also highlighted, that greater incidence of lung cancer and gastrointestinal cancer was reported than gynecological cancer. With the shift to an urban lifestyle, long-term exposure to air pollution (Gabet et al., 2021), and higher awareness of cancer detection, it is expected the rate of incidence to remain at the increasing trends in Indonesia.

This study findings also showed most participants were married and had low to mid-level income. More married patients being diagnosed by cancer has been consistently observed in most research in Indonesia. This phenomenon was in part factored by the influence of eastern culture in Indonesia which favors earlier marriage. More presentation of patients coming from low to mid-income was expected as well, as Indonesia is a middle-income country according to the World Bank.

Self-Efficacy of Cancer Patients Undergoing Hemodialysis Therapy

This study found that the self-efficacy of the cancer patients in both groups was below the middle score (on a scale of 100) in which the control group's self-efficacy mean score was 43.15 and 42.96 in the intervention group. As observed in Table 3, the mean score of the intervention group was also lower than the mean score of self-efficacy in the control group. This result was similar to the study of Wasalamah, Alim, and Widyandana (2022). which showed that the intervention group had lower self-efficacy scores than the control group before the intervention was given Low levels of self-efficacy in patients undergoing hemodialysis was also observed in another study in Egypt (Qalawa, Eltahry, & Aly, 2022). The low level of self-efficacy might be a result of a number of factors. The lack of adequate knowledge about the therapy, its use, and how it factored to the cancer treatment that they were undergoing could be an influence. Moreover, as hemodialysis put a burden to the patients' physiological status and financial situation, the prospect of having to undergo such treatment continuously should prove to be daunting.

The adverse effects of the therapy, such as nausea, fatigue, and loss of appetite, could affect the patient's level of self-efficacy in terms of treatment compliance and quality of life (Kurt & Sarikaya, 2022). In a research conducted by Suryani et al. (2023), it was stipulated that self-efficacy is the strongest predictor of self-management among patients. Therefore, self-efficacy can be recognized as the beliefs and confidence that motivate the patients to see through the treatment they are receiving whilst having the awareness necessary regarding the treatment.

Self-Efficacy Score Differences in the Intervention Group Before and After Intervention

This study employed the therapeutic regimen education model as the intervention with the purpose to increase the self-efficacy of cancer patients undergoing hemodialysis therapy. In the intervention group, the patients were educated based on the guidelines and schedule created. After the self-efficacy was measured, the results were analyzed using the paired t-test to investigate the difference in means of self-efficacy in the control and intervention group before and after the intervention. The result of the analysis is described in Table 3. As shown, it can be stipulated that there was a statistically significant increase in self-efficacy scores after the intervention, with the intervention group scoring higher than the control group.

The result of this study signified that the therapeutic regimen education had a positive effect on patients' self-efficacy in undergoing the hemodialysis treatment. A study in India found that an adequate level of self-care knowledge given through an education model as cancer patients undergo their treatment proved to raise the self-efficacy of cancer patients to a higher level (Sivakumar & Susila, 2021). Another study in Saudi Arabia also supported this study's findings, stipulating that health education improves the self-efficacy of patients (Yakout et al., 2023). Therapy regimen education as part of the health education model provided patients with much-needed knowledge to help them navigate through the treatment they were undergoing. With sufficient knowledge, patients would be able to recognize the purpose of the treatment, the challenges they were facing, and the methods they could use to overcome them. This should factor into the increased self-efficacy levels after the intervention was given.

In addition, this study result also showed a significant difference in means score on all four sub-variables of self-efficacy investigated in the study. As shown in Table 4, the intervention group experienced an increase in autonomy, self-integration, problem-solving skills, and social support seeking behavior after the intervention. Similar findings were gained in a study conducted by El-Metwaly et al. (2017) that demonstrated the value of each sub-variable of self-efficacy increased in the intervention group after educational intervention. Therefore, the researchers believed that the education model used in this study had the adequate design to improve all sub-variables of self-efficacy to achieve a higher level of self-efficacy. Good self-efficacy is needed by cancer patients in treatments such as chemotherapy, surgery, radiation and other treatment. Low level of self-efficacy could lower the patients' readiness to face challenges in their illness journey (Nuraini et al., 2023). Additionally, patients' self-efficacy can further influence their behavior through cognitive processes (such as planning for the future) and motivational processes (such as increased commitment to goals), as well as potentially disruptive affective processes (Suryani et al., 2023).

Furthermore, this study's results showed a statistically significant difference in pre-test and post-test self-efficacy scores, with the intervention group showing a greater difference than the control group (Table 5). A recent study by Ramezani et al. (2019) found similar phenomenon where the intervention group had a statistically significantly higher self-efficacy score than the control group. It can be inferred from the results that the therapeutic regimen education substantially improves self-efficacy.

While the general education did provide improvement as the patients in the control group underwent more treatments, the therapeutic regimen education was shown to have a more positive effect. The positive effect of the therapeutic regimen education might be derived from the more comprehensive and supportive model of learning, as well as the design of the education model that provided patients in the intervention group with an additional instrument to discuss challenges and problem-solving methods. A study of unmet supportive needs in Indonesia found that illness and side effect information, information on how partners can support cancer patients as well as methods to reduce the patients' stress were reported by cancer patients' partner as unmet supportive needs (Afiyanti et al., 2021). The education program used in this study could provide relief to these unmet needs, assisting the change in how patients and caretaker view the illness and its entails which could affect existing beliefs and built confidence that improves self-efficacy.

Therapeutic educational interventions are multidimensional strategies that improve self-management skills and treatment engagement, reduce complications, and provide health and financial benefits for patients with chronic diseases (Champarnaud et al., 2020; Taibanguay et al., 2019). Therapeutic regimen education is also a basic and long-lasting component for patients (Champannaud et al., 2020). It enables people with chronic illnesses to manage their illnesses, increasing self-efficacy, treatment compliance, and psychological health (Correia et al., 2023; Deif et al., 2015).

Cancer patients who must follow hemodialysis therapy experience various physical and psychological problems, which can affect their motivation to adhere to treatment. Nurses, as frontline care providers, play a role in assisting cancer patients to follow the treatment program. The therapeutic regimen education program that has been created in this study can be used as a guide for nurses to improve the self-efficacy and compliance of cancer patients, especially those who follow the hemodialysis program.

The study demonstrated that cancer therapeutic regimen education effectively enhanced treatment self-efficacy and compliance in patients undergoing hemodialysis. Given the severity of cancer and the additional challenge of hemodialysis, maintaining strong treatment self-efficacy and compliance is crucial. Nurses, as the patients' support, could provide assistance to address various challenges—physical, psychological, social, spiritual, and sexual—faced by cancer patients, requiring high motivation to access health services.

This study was conducted in a public hospital and cannot describe the self-efficacy of patients who went to private hospitals to receive treatment. This study also employed a small sample size, which restricts generalizing the cancer patients' self-efficacy. In addition, this study has not investigated other factors that may affect the self-efficacy of cancer patients undergoing hemodialysis treatment.

Conclusion

The general treatment self-efficacy scores and each sub-variable scores (autonomy, self-integration, problem-solving, and seeking social support) increased after therapeutic regimen education in the intervention groups. These results have statistical significance, indicating the effectiveness of the intervention. The effect of therapeutic regimen education on treatment self-efficacy showed a significant difference between the control and intervention groups after therapeutic regimen education was provided.

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Conflict of Interest

The authors declared they have no conflicting interest.

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ORIGINAL ARTICLE

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Leadership competencies and managerial competencies of nurse managers in Kuala Lumpur Hospital, Malaysia

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ABSTRACT

Introduction: The roles of nurse managers are crucial to the success of healthcare organizations, requiring specific skills and competencies. Accordingly, nurse managers are expected to possess leadership and management skills. Therefore, it is essential to investigate the relationship between leadership and managerial competencies among hospital nurse managers. This study seeks to determine the impact of three different leadership competencies, namely administrative skill, interpersonal skill, and conceptual skill, on the managerial competencies of nurse managers at Kuala Lumpur Hospital.

Methods: This cross-sectional quantitative study adopted Northouse's (2019) leadership competencies questionnaires and Mind Tool's (2018) management skills assessment tool. A total of 247 participants, all of whom were nurse managers at the Kuala Lumpur Hospital, Malaysia, were recruited for this study. Multiple regression analysis was used to test the hypothesis.

Results: The findings revealed that nurse managers at Kuala Lumpur Hospital possessed high levels of all three leadership skills and managerial competencies. However, the only significant predictor of managerial competencies among the respondents is the conceptual skill of leadership (beta = 0.820, $p < 0.01$).

Conclusions: This study emphasizes conceptual skills (cognitive abilities, analytical reasoning, and decision-making) in predicting managerial competencies among nurse managers. Developing these skills is critical for effective leadership and smooth healthcare organization operations.

Keywords: administrative skill, conceptual skill, interpersonal skill, leadership competencies, mental health

Introduction

The healthcare environment and nursing facilities are continually evolving, presenting nurse managers with the challenge of equipping themselves with critical managerial competencies to provide high-quality and secure patient services (Chua et al., 2022; Paarima et al., 2020). Increased workloads and the necessity for effective leadership and management skills create significant challenges (Nazari et al., 2018). Poor healthcare organizational leadership can lead to increased operating costs, decreased productivity, and lower effectiveness of nursing care, ultimately resulting in employee dissatisfaction and decreased patient satisfaction and health status in society (Ghiasipour et al., 2017). Effective nurse leaders are crucial in healthcare organizations, as they must excel in both clinical and administrative roles, managing resources, communication, negotiation, motivation, and influence (Moghaddam et al., 2019).

Nurse managers are vital in daily healthcare operations, impacting the organization's performance through close interactions with patients, families, and other healthcare team members (Goktepe et al., 2018). Studies indicate poor communication and leadership are the primary causes of issues within healthcare systems, leading to inadequate management (Ghiasipour et al., 2017). Effective leadership fosters a quality-focused organizational culture, reduces conflicts, enhances team efficiency and productivity, boosts staff satisfaction, and improves hospital performance.

In recent decades, technological advancements, a multigenerational workforce, management accountability, performance measurement, resource limitations, the growth of inter- and intra-professional teams, and increased consumer expectations have significantly impacted healthcare (Jiang et al., 2023; Li et al., 2020). Leadership is vital for nurses, especially in overcrowding, bed shortages, material resource scarcity, and insufficient staffing (Ferreira et al., 2020). This study seeks to address gaps in the literature by examining the predictors of managerial competencies among nurse managers in Kuala Lumpur Hospital. It focuses on administrative, interpersonal, and conceptual skills, aiming to provide insights into the qualities necessary for effective leadership in today's healthcare landscape (Dewald & Reddy, 2020).

Managerial Competencies

Effective management roles involve designing and implementing strategic priorities that prioritize patient safety (Pathmanathan et al., 2022; Weiss et al., 2019). Nurse managers play a crucial role in strategy framing, development, execution, and embedding to demonstrate efficiency. As such, a nurse manager must possess a variety of skills and abilities that allow them to make strategic decisions effectively (Arsat et al., 2022; García et al., 2020). They must possess cognitive abilities, self-awareness, emotional resilience, and personal motivation to make strategic decisions. Nurse managers must monitor the delivery of consistent and high-quality patient care within the constraints of human, financial, and material resources. However, the success or failure of nurse managers is directly related to overall organizational efficiency and productivity (Wang et al., 2021).

Nurse leadership success is determined by leaders who recognize and hold themselves accountable for creating vibrant practice environments. Successful managerial positions allow nurse managers to contribute to the organization's agenda and objectives while following its values in their actions (Little et al., 2018). Evidence shows that effective nurse leadership has a positive impact on patient safety, the development of a safe environment, lower patient mortality and patient satisfaction, and safe medication practices (Farag et al., 2017). Furthermore, different nursing leadership styles have been shown to improve nurse job satisfaction, nurses' intention to stay, nurse commitment, and nurse creativity and incivility (Hall et al., 2022; Specchia et al., 2021). Nonetheless, ineffective nurse leadership has led to lower nurse satisfaction, efficiency, and productivity, as well as an increase in complaints (Hughes, 2018). In today's complex, ever-changing healthcare system, effective nurse leaders are critical. Therefore, nurse managers need to understand the relationship between leadership and managerial competencies, which may be more important now than ever in history.

The nurse managers in the health system are expected to possess eight core abilities, which include decision-making, relationship management, communication skills, active listening, leadership, conflict management, adherence to ethical standards, cooperation, and team management skills (García et al., 2020). First, they need to understand team dynamics and foster healthy interactions. Understanding how teams operate is critical to successful management. It is worth mentioning that teams often follow a predetermined pattern of creation: developing, norming, storming, and executing. During this transition, it is vital to encourage and promote individuals so that the team can become fully functioning as quickly as feasible (Thapa et al., 2022). Second, nurse managers need to identify and develop the appropriate personnel. Finding and developing new team members, as well as cultivating the abilities required for the team's success, is a crucial component of team building (Rahman, 2022). Efficient delegation is crucial for team success, as simply having the right personnel and knowledge is not enough. Managers must also understand how to delegate tasks efficiently, as some managers, especially those with technical skills, may attempt to complete most tasks themselves, believing they can do them correctly and efficiently. Motivation is a crucial management skill, as it is a personal process that varies among individuals. Nurse managers can inspire their staff by getting to know them on a personal level and providing daily input. This keeps them informed about individual team members' status. Nurses who know what to expect from their nurse managers are happier and have faith in their abilities (Ellis, 2021). As a manager, it is crucial to promptly deal with individual performance difficulties to prevent any negative influence on the rest of the workforce and customers. Inadequate performance has a detrimental effect on customer service, team accomplishments, and overall performance. As such, the manager's inability to consistently achieve targets may lead to demotivation and negatively impact the whole team (Chirwa et al., 2023).

Effective communication is a crucial management skill, especially in nursing management. Nurse managers must keep their staff informed about their roles and practices, such as through team briefings. Communication styles significantly impact their ability to contribute to a high-functioning team, improving business and educational outcomes (Kerr et al., 2020). Nurse managers should also possess intelligence, cognitive and functional abilities, beliefs, attitudes, experiences, and behaviors that are effective in managing organizational performance (Wei et al., 2020). They should also have management abilities to cooperate with others and contribute to a high-performing team. Overall, effective communication is essential for nurse managers to contribute to a successful healthcare environment. Nurse managers often excel in planning, decision-making, and problem-solving due to their experience and analytical skills. However, they often neglect their people and team management skills, highlighting the importance of self-development in their professional development (Cummings et al., 2021). Nurse managers should avoid common managerial mistakes by enhancing their facilitation abilities and preventing management challenges (McCauley et al., 2020). Common mistakes include relying solely on technical expertise and asking superiors to solve problems. Effective organizations prioritize internal improvements and change, with nurse managers serving as role models for change and providing encouragement and coordination (Maurya & Sharma, 2017).

Leadership Competencies

Leadership is essential for managing resources, which is one of the most difficult challenges for any manager whose resources include staff, time, facilities, and access to care (Ellis, 2021; Tang et al., 2024). Leadership in this way is exercised by examining the strengths and weaknesses of a wide variety of theories as they relate to public, private, and non-profit organizations (Northouse, 2019). Leadership is a highly valued asset for individuals in positions of authority who wish to increase the effectiveness of their businesses (Zhao et al., 2024). This study examines leadership through the lens of trait theory and concludes with an exploration of transformational process theory (Teoh et al., 2022). It also addresses the advantages of situational, contingency, path-goal, and leader-member interaction theories, devoting significant time to explaining the implications of the merging and more modern psychodynamic leadership approaches. Administrative skill, interpersonal skill, and conceptual skill are outlined as the three perspectives for leadership that were proposed. In this new era, nursing leadership competencies enable the transformation of nursing and play a vital role in caring for patients, and families, and promoting healthy communities, with a focus on reducing health disparities (Arsat et al., 2023; Morse et al., 2021).

The provision of high-quality healthcare, characterized by assurance, empathy, responsiveness, tangibility, and dependability, is directly correlated with patient satisfaction throughout their hospital stay (Magfiroh et al., 2023). The strategic priorities that need to be addressed must be defined transparently and tactfully. The issue of medical care quality at work is highlighted, with a particular emphasis on nursing services and the role of the nurse, who is a representative of the highest management body and who significantly contributes to improving the quality of nursing services (Wasik, 2020). According to Ballantyne (2019), identifying contexts for change and taking the time to evaluate and benchmark the nursing care provided through measurement and audit within a professional environment can contribute to a team's clinical governance and is a strong leadership skill. Nurses will play a key role in the management of these audits and in the critical implementation of any substantive changes required as a result of the audit results. The nurse who leads the audit and review of the root cause acts to encourage an operational approach implemented to support both patient outcomes and hospital financial planning. The nurse faces the difficulty of conducting an audit and learning root cause analysis skills as well as the complexities of working with a diverse range of stakeholders, many of whom may hold opposing viewpoints. These are all excellent leadership qualities and nurse leaders' insights (Ballantyne, 2019).

Interpersonal skills encompass a wide range of abilities related to interacting with others. Failure to establish interpersonal relationships is the most cited cause of derailment by nurse managers, preventing them from establishing relationships with bosses, colleagues, individuals who report directly to them, patients, and their relatives (Martens et al., 2018). Healthcare practitioners must collaborate effectively within the team in order to provide continuous quality healthcare that aligns with organisation mission (Wei, 2022). Successful interprofessional teamwork relies on effective communication, which includes team coordination, active listening, and clear communication to ensure a shared understanding of decisions, establishing common goals, and distributing responsibilities (Brown et al., 2021). Other communication and teamwork challenges have been linked to a varied skill mix, a lack of familiarity with ward procedures and assigned patients, as well as busy, pressured working environments. Such findings demonstrate that improvements in the nursing team can benefit both patients and staff (Oldham et al., 2020). Effective communication requires a nurse manager to possess precise speaking and writing skills, as well as attentive listening abilities. Listening is a crucial talent for a nurse manager to possess to properly engage with others, assign tasks efficiently, and make clear decisions.

Conceptual skills facilitate comprehension of complex scenarios and are further enhanced by cognitive capabilities, analytical reasoning, and decision-making, which eventually lead to cognitive problem-solving and critical thinking with innovative solutions (Ahmady & Shahbazi, 2020). These skills are valuable in management because those who possess them can deal with difficult workplace situations in a variety of ways. Leaders with conceptual abilities are regarded as strategic leaders due to their ability to strategize about future situations and how to overcome them. The ability to approach a problem creatively and abstractly is highly valued at higher levels of management. Nurse managers must demonstrate success in creating and shaping the organization's vision, as well as in communicating and embodying the vision. For example, nurse managers serve as role models by acting in ways that represent the ideals and values inherent in the vision, demonstrating trust, self-belief, tenacity, and dignity in the pursuit of the vision, challenging actions that do not comply with the vision, defining organizational symbols, and avoiding rituals and routines that are incompatible with the vision (Ballantyne, 2019).

Present Study

While numerous studies have explored various facets of nurse leadership, there is a noted deficiency in a comprehensive analysis that distinguishes the direct impact of distinct leadership competencies—administrative, interpersonal, and conceptual—on managerial capabilities within hospital settings. This identified gap is significant, as understanding the differential impact of these competencies may facilitate targeted developmental programs for nurse managers, ensuring they are effectively equipped to handle the multifaceted challenges of modern healthcare environments.

The primary purpose of this study is to examine the relationship between leadership competencies (administrative, interpersonal, and conceptual) and managerial competencies among nurse managers at Kuala Lumpur Hospital. The investigation seeks to determine which competencies significantly predict managerial effectiveness, providing empirical evidence to support targeted training and development initiatives. This research aims to deepen the understanding of how varied leadership skills contribute to effective management in healthcare, ultimately aiming to enhance patient care and organizational efficiency through more competent leadership.

Several hypotheses were formulated. Firstly, it is hypothesized that administrative leadership skills positively affect managerial competencies among nurse managers. Secondly, interpersonal skills are also expected to positively impact managerial competencies. Lastly, conceptual leadership skills are anticipated to significantly influence managerial competencies, highlighting their importance in the effective leadership of nurse managers.

Materials and Methods

Study design and setting

The relationship between leadership and managerial competencies among nurse managers at Kuala Lumpur Hospital was investigated using a quantitative method with a cross-sectional design. The Kuala Lumpur Hospital, also known as Hospital Kuala Lumpur (HKL), has 53 departments and units. Hospital Kuala Lumpur is the Malaysian Ministry of Health's largest hospital and a tertiary referral hospital. Over 7,000 people work at HKL, representing nearly 100 professions in a wide range of fields and disciplines. Out of the total number of staff, there are 32 matrons and 221 charge nurses, both referred to as nurse managers (Devex, n.d). All matrons and nurses were recruited as samples in this study via purposive sampling.

This study focuses on Kuala Lumpur Hospital in Malaysia with nurse managers categorized under specific job grades, including U32, U36, U41, U42, and U44. These grades represent different levels of managerial responsibility and expertise within the Malaysian public healthcare system. Grades U32 and U36 typically indicate entry-level management positions. Grade U41 denotes a mid-level management role. The higher grades, U42 and U44, reflect senior managerial positions. Nurse managers on study leave, maternal leave, medical leave, or who had been a nurse manager for less than six months were excluded from the study.

Instruments

A questionnaire set comprised of three parts was created. Part A contains social demographic items, Part B contains leadership competencies items and Part C contains managerial competencies items.

Social Demographic Data

The first part, consisting of seven questions, is to identify the baseline data of the nurse managers' socio-demographic characteristics and management experience, which include age, gender, educational background, working experience, and current working area.

Leadership Skills

The researcher uses and adapts Northouse's (2019) Leadership Skills Questionnaire, which contains a total of 18 items. It is designed to assess the participants' professional knowledge and competencies in the context of the objectives and content of the leadership skills. The Leadership Skills Questionnaire is intended to assess three types of leadership skills: administrative, interpersonal, and conceptual. A higher score indicates a broad skill set, whereas a lower score indicates a limited skill set. All items were scored on a 5-point Likert scale, with 1 indicating not true and 5 indicating very true. Cronbach's alpha values range between 0.660 and 0.833.

Managerial Competencies

For managerial competencies, the researcher used Mind Tools' (2018) management skills assessment tool, which contains 20 items in total. It is designed to assess the participants' professional knowledge and competencies in the context of the objectives and content of the managerial skills. The assessment tool is based on eight essential skill areas where managers should concentrate their efforts. The nurse manager's score of 20-46 indicates that she urgently needs to improve her management skills. If the nurse manager receives a score of 47-73, she is well on her way to becoming a good manager. If the nurse manager receives a score of 74-100, she is doing an excellent job managing her team. All items were scored on a 5-point Likert scale, with 1 indicating not at all and 5 indicating very often. The Cronbach's alpha coefficient is 0.830.

Research Instrument

This study used self-administered questionnaires via Google Forms, with the researcher sending the link to the Google Form to all respondents via WhatsApp. The hospital director and the head matron of Kuala Lumpur Hospital both gave their approval for this study. The data were collected over three weeks in August 2021. The researcher obtained the list of respondents from the head matron of Kuala Lumpur Hospital, and she assisted in providing the link to them. Prior to completing the questionnaires, respondents were given an explanation of the study's design, purpose, and methodology. Each respondent gave their consent after receiving appropriate information.

Statistic Analysis

Statistical Packages for the Social Sciences (SPSS) 28.0 was utilized for the data analysis. Multiple types of statistical testing were performed to ensure that the study's goals were met. The data were subjected to descriptive analyses to determine the prevalence of each respondent's demographic and each research variable. The correlations between administrative skill, interpersonal skill, conceptual skill, and managerial competencies were then investigated using Pearson correlation analysis. The final step was to use multiple regression analysis to look at the specific factors that predict competencies. All statistical tests were performed at the 0.05 level of significance.

Ethical Consideration

Before conducting the study, the researcher obtained ethical approval from the Ministry of Health's Medical Research and Ethics Committee (MREC) through the National Medical Research Register (NMRR) [Approval code: KKM/NIHSEC/ P21-1255(3)].

Participants were informed about the study and consented to participate voluntarily. The participant information sheet stated their right to participate or

Table 1. Demographic Characteristics of the Respondents (N=247)

Variables	n	%
Age		
31-40 years	21	8.5
41-50 years	164	66.4
51-60 years	62	25.1
Educational Background		
Diploma	138	55.9
Degree	79	32.0
Master	30	12.1
Duration of Working as Nurse Manager		
11-20 years	53	21.5
21-30 years	194	78.5
Current Working Area		
Medical Ward	55	22.3
Surgical Ward	25	10.1
Orthopedic Ward	18	7.3
Nephrology Ward	3	1.2
Pediatric Ward	12	4.9
Obstetrics and Gynecology Ward	8	3.2
Administration	13	5.3
Others	113	45.7

withdraw from the study at any time without fear of harm, retaliation, or prejudice. Personal data collected during the research were treated as highly confidential and used solely for analysis by the researcher. The researcher upheld professional etiquette to ensure participants did not feel vulnerable or offended by their participation in the study. All participants gave their written consent before completing the questionnaires. They were instructed not to write their names to protect their confidentiality and ensure complete anonymity.

Results

Data analysis reveals that all 247 respondents were female. The majority of respondents (66.4%) fell within the age range of 41 to 50, followed by 25.1% aged 51 to 60, and 8.5% aged 31 to 40. There is a significant concentration of respondents in the middle age group. Most respondents held a diploma (55.9%), followed by bachelor's degrees (32.0%), and a smaller proportion held master's degrees (12.1%). There were no respondents with PhD qualifications. Respondents varied widely in terms of their experience as nurse managers, with the largest proportion (37.2%) having 1 to 5 years of experience, followed by 6 to 10 years (29.1%), 11 to 20 years (23.5%), and the smallest proportion (10.1%) having 21 to 30 years of experience. The respondents were distributed across various working areas, with the highest proportion (22.3%) working in medical wards, followed by surgical wards, orthopedic wards, administration, pediatric wards, obstetrics and gynecology wards, and nephrology wards, each accounting for smaller percentages.

Table 2 displays the leadership competencies, including three skills: administrative skills (mean = 23.77), interpersonal skills (mean = 22.38), and conceptual skills (mean = 22.92). According to the study's findings, nurse managers at Kuala Lumpur Hospital exhibited a high level of leadership skills, with each competence falling within the range of 21 to 25. Additionally, Table 2 indicates a high level of managerial competency (mean = 75.42). Nurse managers at Kuala Lumpur Hospital received scores ranging from 74 to 100, showcasing their skills and experience for their positions. Furthermore, Table 2 presents the Pearson correlation findings between administrative skills, interpersonal skills, conceptual skills, and managerial competencies. There is a positive relationship between administrative skill ($r = 0.579$, $p < 0.01$), interpersonal skill ($r = 0.485$, $p < 0.01$), and conceptual skill ($r = 0.680$, $p < 0.01$) in leadership and managerial competencies among nurse managers at Kuala Lumpur Hospital. This reveals that nurse managers at Kuala Lumpur Hospital possess strong administrative, interpersonal, and conceptual skills, indicating a well-rounded skill set for effective leadership in healthcare settings. Their managerial competency scores confirm their expertise in their roles. The positive correlations between administrative, interpersonal, and conceptual skills with managerial competency suggest that higher proficiency

Table 2. Descriptive statistics and correlations among variables (N = 247)

No.	Variables	Mean	S.D	1	2	3	4
1	Administrative Skills	23.77	0.538	1			
2	Interpersonal Skills	22.38	0.491	0.762^{**}	1		
3	Conceptual Skills	22.92	0.514	0.898^{**}	0.731^{**}	1	
4	Managerial Competencies	75.43	0.443	0.579^{**}	0.485^{**}	0.680^{**}	1

Note: $^{**}p < 0.001$

Table 3. Predictors of Managerial Competencies (n = 247)

Criterion Variable	Predictor Variable	*F*	*R2*	*df*	Beta	*t*	*p*
Managerial Competencies	Administrative Skill	71.117**	0.467	(3.243)	-0.167	-1.471	0.142
	Interpersonal Skill				0.013	0.174	0.862
	Conceptual Skill				0.820	7.615	0.000

Note: **p < 0.001

in these areas correlates with greater managerial effectiveness. Overall, the findings suggest that nurse managers at Kuala Lumpur Hospital possess a robust set of leadership and managerial skills, enhancing their effectiveness in managing healthcare units.

Table 3 below shows the results of the multiple regression analysis used to investigate the predictors of managerial competencies. According to the findings, the combination of administrative skills, interpersonal skills, and conceptual skills accounted for 46.7% of the variance in managerial competencies. The only significant predictor of managerial competencies was discovered to be conceptual skill (beta = 0.820, $p < 0.01$). Administrative skill (beta = -0.167, $p > 0.05$) and interpersonal skill (beta = 0.013, $p > 0.05$) were found to be non-significant predictors of managerial competencies. Hypothesis H3 is thus supported, but hypotheses H1 and H2 are not.

This study reveals that administrative, interpersonal, and conceptual skills collectively account for 46.7% of managerial competencies among nurse managers. Conceptual skill was found to be the most significant predictor, with higher skills indicating greater managerial abilities. Administrative and interpersonal skills were found to be non-significant predictors. The findings suggest that, while administrative and interpersonal skills are important, conceptual thinking is more crucial for effective managerial performance.

Discussions

This study aims to determine the influence of leadership competencies (administrative skill, interpersonal skill, and conceptual skill) on the managerial competencies of nurse managers at Kuala Lumpur Hospital. The descriptive findings indicate that the leadership abilities, namely administrative skills, interpersonal skills, and conceptual skills, were all rated highly, with conceptual skills being the most prominent among the three. This study also discovered the significance of managerial competencies among nurse managers at Kuala Lumpur Hospital. The correlation analysis results show that all three leadership skills among Kuala Lumpur Hospital nurse managers, which were administrative skills, interpersonal skills, and conceptual skills in leadership competencies, had significant positive relationships with managerial competencies. However, regression analysis revealed that only conceptual skills in leadership competencies were significant in predicting managerial competencies among Kuala Lumpur Hospital nurse managers. The findings of this study emphasize the importance of leadership and managerial skills for nurse managers. The importance and instillation of these skills necessitate the support of the nurse manager and the organisation.

The three skills that comprise the leadership competencies are administrative skills (mean = 23.77), interpersonal skills (mean = 22.38), and conceptual skills (mean = 22.22). The findings of the study revealed that all of the skills were at a high level (the score ranged from 21 to 25) among nurse managers at Kuala Lumpur Hospital. As a result, nurse managers are considered leaders because they exhibit leadership qualities in their nursing roles and influence other nurses and communities to envision high-quality healthcare (Zaghini et al., 2020). In addition, this study's findings indicate that the level of managerial competencies is high (mean = 75.42). The nurse managers at Kuala Lumpur Hospital received scores ranging from 74 to 100, indicating that they were capable of fulfilling their roles as nurse managers. Some studies also found that managerial competencies are critical in an organisation, which is consistent with the findings in this study (Fanelli et al., 2020; Said & Chiang, 2020).

This study's findings indicate that conceptual leadership skill is the only predictor of managerial competencies among nurse managers at Kuala Lumpur Hospital, thus confirming hypothesis 3. Team coordination and active listening, communication to ensure a shared understanding of decisions, defining common goals, and sharing accountability are critical components that serve as the foundation for effective teamwork (Ellis, 2021). The data findings of the conceptual skills within the leadership competencies revealed all of the traits described. Furthermore, conceptual skills enable people to respond to complex ideas, concepts, and themes (Paarima et al., 2020). Critical thinking and problem-solving skills are essential to solving daily challenges faced in healthcare settings (Ahmady & Shahbazi, 2020). This allows healthcare professionals to dissect complex issues, identify underlying factors, and formulate effective strategies for resolution. The choices made in healthcare environments have a direct influence on the safety of patients and the quality of treatment provided (Molina-Mula et al., 2020). Therefore, conceptual skills empower healthcare workers to assess information, predict possible risks, and make appropriate choices that prioritize the well-being of patients. Patients' negative feedback often arises from communication and comprehension issues (Marca-Frances et al., 2020). Therefore, it is crucial to provide patients with guidance and prepare them in advance for potential outcomes in order to alleviate any uncertainties and anxieties they may have.

According to Jasim (2019), leaders' conceptual skills influence the value and degree of constructive, self-regulation, sense-making, consolidative, and innovative leadership in the public sector. These leaders use high-level conceptual abilities to drive public sector transformation, absorb conceptual skills uniquely and distinctly, and effectively lead change. Furthermore, conceptual skills are required for managers at all levels of an organization to analyze and conceptualize the actions taken as part of the organization's strategy, objectives, and policies. Conceptual thinking allows for accurate and timely feedback, which also promotes organizational agility. Visionary, inventive, values-based, and strategic leadership, on the other hand, represents the "creation of a shared vision" (Major, 2019). A nurse manager should be able to see the "bigger picture" while focusing on individuals. A leader should be able to "envision the future" and then "enlist people" to help that vision come true, in order to inspire others to share in that vision (Khan et al., 2020). As a result, leaders who inspire a shared vision take the time to solicit feedback from their team members in order to identify needs, challenges, difficulties, and triumphs, as well as to create goals. Furthermore, leaders must be educated on how to enlist employees' support in moving the organisation toward an inspiring goal by being visible, communicating with them in a timely and consistent manner, and understanding what is important to them.

Furthermore, the findings of this study support that an effective nurse leader understands resource management, has commercial and media skills, is an excellent communicator, and can influence, stimulate, and negotiate with others (Zaghini et al., 2020). This frequently requires an understanding of the system's operational flow, as well as embracing emerging variations and changes, both of which are conceptual skills in leadership competencies (Wu, 2022). In this study, nurse managers construct a declaration that defines the position and core values of an organization. Nurse managers can enhance individuals' focus and cultivate a more accurate understanding of purpose and dedication. This strengthens an organization's overarching objectives and integrates them into day-to-day choices and tasks. Values are a fundamental aspect of corporate culture, providing a reliable point of reference that remains unchanged even throughout times of transition. Examples of values in healthcare include Patient First, Integrity, Empathy, Teamwork, and Excellence.

The study's findings have important implications for organizational leadership and the development of effective leadership and managerial competency relationships. First, the study's findings can inform nurse managers at Kuala Lumpur Hospital about the critical role of conceptual skills in terms of their strengths and weaknesses, as well as what to improve, maintain, or reinforce. Second, the findings of this study suggest a link between managerial and leadership competencies, particularly conceptual skills. This is extremely important for the newly appointed nurse managers. These three leadership competency components are embedded in the training or workshop where they will be embedded as nurse managers. Nurses should also discuss potential leadership development opportunities with their line managers, such as mentorship, coaching, and action learning. Nurse managers must also be taught that conceptual skills in leadership competencies are linked to staff nurses, who are instilled by being noticeable, providing prompt and efficient interaction, and recognizing what is important to the nurses in order to enlist their participation in moving the organization toward an inspired goal. Competent leadership is one of the most important factors that positively affects organizational transformation and assists organizations in successfully adapting to a new competitive environment (Chatzoglou et al., 2017). The organization must reemphasize and promote effective leadership, as well as focus on developing the skills of potential nurse managers and assisting the nurse managers in achieving their goal. From society's perspective, nurse managers play a major role in the healthcare unit's daily operations and have a major impact on the organization's performance because they work closely with patients, families, and other healthcare team members (Goktepe et al., 2018).

Conclusion

The current study has some limitations, such as the fact that it only included nurse managers from Kuala

Lumpur Hospital. The study's findings cannot be applied uniformly to all organizational sectors. Furthermore, the sample consisted solely of females; additional research in various domains could be conducted by including male nurse managers. As a result of the findings, it may be expanded to include more nurse managers in other Malaysian public and private hospitals, where the results will be stronger, more representative, and have a significant impact on the hypothesis, as well as lead to an accurate conclusion. Aside from that, given the scarcity of research on the relationships between leadership and managerial competencies among nurse managers, more research on leadership and management in various contexts among nurse managers, particularly in Malaysia, is needed.

In conclusion, the findings of this study demonstrate the essential importance of conceptual skills in leadership for nurse managers. The cultivation and reinforcement of these skills necessitate the support of the nurse manager and the organization. Leadership competencies, administrative skills, interpersonal skills, and conceptual skills are important to be nurtured among nurse managers. These competencies undoubtedly elevate the performance of nurse managers and the organization. The goal of developing these skills in nurse managers is to project the organization's vision and mission, ultimately leading to enhanced patient care quality.

This study can be expanded to other public and private hospitals in Malaysia to include more nurse managers and larger samples, because a larger sample will be a more accurate representation of the population, implying additional accurate outcomes and having a significant impact on the hypothesis as well as reaching an accurate conclusion (Andrade, 2020). It is critical to include qualitative research in this study because it can examine how language and behavior convey information and can be used to express expressive information about ideas, values, sentiments, and motivations that support behaviors that are not expressed in quantitative data. To put it another way, qualitative research allows the researcher to ask difficult-to-answer numerical questions in order to better understand human experience. The study's results indicate that nurse managers must possess management and leadership capabilities in order to fulfil their roles. These may include nurses working in both the private and public sectors. Further investigation is required in many contexts to ascertain the significance of conceptual skills in leadership capabilities, their correlation with management capabilities, and their influence on the quality of nursing. Moreover, there is a lack of comprehensive empirical research on the influence of competences on skills. This area of study is still in its early stages and demands the attention of nursing researchers.

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ORIGINAL ARTICLE

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Navigating care: family information needs and responsibilities in the context of schizophrenia caregiving

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ABSTRACT

Introduction: : Families of schizophrenia patients need to obtain information from health services about how to care for them. Limited information and understanding of responsibilities in caring are still obstacles to becoming an empowered family in caring for patients with schizophrenia. The study aimed to explore family needs regarding information from health services and family responsibilities when caring for patients with schizophrenia.

Methods: This study used a descriptive qualitative design. The study involved families who cared for patients with schizophrenia in Surabaya, Indonesia. Twenty participants were obtained using purposive sampling techniques and the sample size was determined by data saturation. Data were collected using in-depth interviews, field notes and interview question guides. The data were processed with content analysis.

Results: The results showed eight themes. Families need information about patient conditions, medication, routine control, and counseling for patient conditions as well as for families. The family describes the responsibilities carried out for the patient as providing support for patient treatment, fulfilling daily needs, helping with social skills, and providing activities in spare time.

Conclusions: Adequate information from health services regarding both the patient's condition and family counseling can help to meet the demands of care, which stimulates families to be more empowered to carry out care responsibilities and has an impact on the ability to care better

Keywords: counseling, empowerment, family, mental disorder, responsibility, schizophrenia

Introduction

Schizophrenia is a serious mental illness characterized by incoherent thoughts, strange behavior, strange speech, and hallucinations, such as hearing voices, that cause functional disorders in carrying out daily activities (APA, 2020). Schizophrenia is a severe mental illness which continues to increase. The prevalence of serious mental disorders in Indonesia increased from 1.3 cases per mile to seven cases per mile in 2018 (Ministry of Health, 2018). The increase of prevalence rate is related to high recurrence in Indonesia, about 60% in the first year after discharge from hospital (Rahmawati, Maryanto and Apriliyani, 2022). The patient recurrence is caused by the insufficient family roles and functions, limited information, and family responsibilities during care, which have an impact on the family's powerlessness specifically in being unsure about how to treat patients at home (Fitryasari, Nursalam, Yusuf, Hargono, & Chan, 2018; Iswanti, 2023; Jessica, Fithriyah, & Ardani, 2021). Powerlessness was influenced by various things. However, fluctuations in the patient's condition, the negative stigma that is still high from society, the ability to manage burdens and stress in dealing with problems, and lacking knowledge to need information support cause helplessness in the family and have an impact on the ability to care for patients with schizophrenia every day and when a relapse occurs (Aass, Moen, Kletthagen, Lundqvist, & Schröder, 2021; Dehbozorg, Moghadam, Shahriari, & Sarani, 2022; Fitryasari, Yusuf, Dian, & Nihayati, 2018). The family requires to be empowered and able to care for them well (Sejong, 2021). Family empowerment can be done by giving the right information about schizophrenia, training the family in how to care for the patient, and showing the right attitude when accompanying the patient (Izibeloko *et al.*, 2016; Tehangga, Sunarsih and Supodo, 2021). Families need support from health workers in the form of continuous and consistent care and treatment information (Fitryasari et al., 2020; Leggatt, 2002; Tristiana, Yusuf, Fitryasari, Wahyuni, & Nihayati, 2018). Health workers, especially nurses in outpatient installations or mental health service clinics, have provided support in the form of health education to families of patients with schizophrenia.

Innovation in providing information in health education in mental health services needs to be emphasized in the aspect of empowering the potential of families (Iswanti *et al.*, 2023). Families have care demands in the form of patient care information needs that can foster a sense of responsibility in caring for and optimizing the abilities of family members to be more effective in caring for family members and maintaining their lives (Hulme, 1999). This research wants to explore in depth based on the Caregiver Empowerment Model (CEM) perspective in how to increase families' knowledge, skills and confidence in caring for patients, so that they are better able to manage the care of patients. This model defines family empowerment as increasing the family's ability to assess, influence, and manage situations by using family resources to achieve desired outcomes (Barnes *et al.*, 2020). The CEM model can be used to improve and promote families' abilities in caring for patients by considering the need of care (Sya'diyah *et al.*, 2023). Family empowerment explains that each family member has the power to meet their needs by activating the family's social support system and trying to apply skills and competencies to overcome the problems they face (Graves and Shelton, 2007). This research aims to explore the information needed to meet the demands of care and foster responsibility so that families become more empowered in caring for patients with schizophrenia.

Materials and Methods

Research design

This research uses a descriptive qualitative design by describing the family's information need from mental health services and the family's responsibilities in caring for patients with schizophrenia.

Participant and recruitment

The population was families who cared for patients with schizophrenia at the Menur Mental Hospital and the mental ward of Dr. Ramelan Naval Central Hospital Surabaya, Indonesia. This research involved 20 participants who were obtained using purposive sampling techniques, in which the number was determined based on data saturation; it means the results of the interview with the 20th participant showed data that had been told by the previous 19 participants. Inclusion criteria were family members who care for patients with a diagnosis of schizophrenia for at least 1 year, have experienced a recurrence at least once, age at least 20 years old, and live in the same house with the patient. Participants involved received an explanation of the objectives, research procedures, rights and obligations as well as the benefits of participating in the research and signed an informed consent in the consultation room.

Data collection and analysis

Data were collected using in-depth interviews and field notes. Before data collection began, the research instrument was first tested. The in-depth interview question guide and field notes were tested by conducting interviews with three participants who were not selected as research participants. The results of the pilot test were used to improve the interview questions so they were easier for participants to understand. In-depth interviews were conducted once with each participant with duration between 35 to 55 minutes. The interview location was in a consultation room at the outpatient clinic, a closed room and there were no other people in the room. Participants were asked to answer two main questions: "According to the family, what

Table 1 Participant characteristics

N	Age (Year)	Gender	Education	Occupation	Relationship	Duration of care (Year)
P1	52	Male	Senior High	Soldier	Father	7
P2	52	Male	Senior High	Self-employment	Father	10
P3	62	Male	University	Self-employment	Sibling	3
P4	44	Female	Senior High	No Work	Wife	21
P5	44	Female	Senior High	No Work	Mother	2
P6	50	Female	Junior High	No Work	Wife	22
P7	44	Female	Senior High	No Work	Child	20
P8	48	Female	University	Teacher	Wife	21
P9	28	Female	Senior High	Self-employment	Sibling	3
P10	53	Female	Junior High	Self-employment	Mother	4
P11	71	Female	Senior High	No Work	Mother	10
P12	67	Female	Junior High	No Work	Mother	23
P13	44	Female	University	No Work	Sibling	12
P14	56	Female	University	No Work	Mother	5
P15	63	Female	Elementary	Self-employment	Mother	18
P16	47	Female	Elementary	No Work	Sibling	2
P17	59	Female	Senior High	No Work	Child	3
P18	65	Male	University	Civil-government	Husband	2
P19	40	Male	University	Civil-government	Child	10
P20	46	Female	Senior High	No Work	Child	2

information is needed from mental health services when caring for patients with schizophrenia?" and "What are the family's responsibilities in caring for patients with schizophrenia at home?" The questions were open-ended and during the interview process they were recorded using a voice recorder. Interviews were conducted until the 20th participant and the researcher did not add any more participants, because the data told by the participant had already been mentioned by the previous 19 participants. Interviews were conducted by six researchers, namely RF, IM, and GAA at Menur Mental Hospital while LL, RFD and HS at Dr. Ramelan Naval Central Hospital. All interviewers had experience in conducting in-depth interviews and had previously conducted qualitative research. The recording results and notes in the field notes were then transcribed in verbatim form after each interview was completed with each participant. Discussion of interview results was carried out regularly among the four interviewers and also with other research teams to integrate research findings.

The data were analyzed and interpreted based on five steps of content analysis techniques: unitizing (data collecting), sampling (determining the sample), recording (recording and creating verbatim), reducing (select meaningful words in sentences and clustering in sub-theme), inferring (make conclusion as a theme), and narrating (describing the result) (Krippendorff, 2018). Data analysis was carried out simultaneously with data collection until data saturation was obtained. Demographic data are presented in detail in the form of a table of participant characteristics.

Rigor in this research was carried out by involving several researchers in the analysis process to check and reduce individual bias. Apart from that, member checking was also carried out, by involving research participants to read the verbatim conversations one week after the interview process to ensure that the data were correct.

Participants were recruited based on ethical principles and there was no coercion. During the recruitment, there were two potential participants who refused to be interviewed because they had to hold the patient and another had to immediately move to the pharmacy room. This research was approved by the Ethical Committee of Menur Mental Hospital with number 0009.2/5586/102.8/2023 and the Ethical Committee of Dr. Ramelan Naval Central Hospital with number 110/EC/KEP/2023.

Results

Participant characteristics

Descriptive participant characteristics are explained in Table 1. This study involved 20 family members who cared for patients with schizophrenia. The participants were aged between 28-71 years. Participants consisted of 15 women and five men with varying levels of education, from no school to university, most of them ware in senior high school. The majority, 11 participants, did not work, and the others were self-employed (n=5) or worked as civil government officer (n=2), teacher (n=1) and soldier (n=1). The relationships with the patients were as mother (6), father (2), spouse (3 as wife and 1 as husband), four children and four siblings. All participants have been involved in the process of treating the patient for at least two years and the longest was 23 years.

Table 2 Identified theme and exemplary significant statement of information needed for the family from health services for caring for the patient with a mental disorder.

Theme	Sub-theme	Significant Statement
Patient condition	type of schizophrenia signs and symptoms	"… he suddenly got angry or screaming for no reason" (P5, P11, P20)
		"...often daydreaming then talking himself, no one with him… like a hallucination?" (P2, P8)
		"… She doesn't want to talk to anyone, … stays in the bedroom all day and often smiling alone " (P7, P9, P19)
	cause of schizophrenia	"… She is sick like this (mental disorder) because she is insecure… since she was at school" (P9, P13, P15, P18)
		"… because he's quiet and doesn't want to talk about problems, he ends up getting sick (mental disorder)" (P1, P3, P9)
		"… could it be hereditary? Her uncle was also sick like this (mental disorder), the same condition" (P4, P6)
Medication for patient	accuracy of taking medication	"… we (family) want to know,.. What medicine it is? What it is for?... How long to take it?" (P1, P2, P4, P8, P10, P15)
		"… Should the medicine be taken at any time? Before or after a meal?" (P6, P17)
	how to give medicine	"… we asked the nurse, whether the medicine was oral only or perhaps some were injected" (P5, P20)
	treatment effect	" Is this medicine addictive? You know… She has to take medicine for all her life?" (P3, P15)
		" …He was sleepy after taking the medicine, his body was stiff as wood, and slept a lot" (P8, P13)
		"… She gets better talking with others after regularly taking medicine, but if she forgets to take it, she seems restless" (P10)
	medicine availability	"… medicine is very important and hospitals have complete medicine as prescribed" (P6, P16)
	persuade patients to take medication	" It's not easy to keep him from taking medicine, we have to teach (by nurses) strategies to persuade him (patient) to keep taking the medicine" (P2, P8, P15)
		" Sometimes I mix it (medicine) into food, but if he (patient) finds out, he'll be angry to me and I'll let him (P6, P11)
Routine control information	control time	" We have to know when he (patient) should brought back for next treatment here (hospital) because I have to go to work every day" (P3, P8, P14)
	equipment carried during control	"… what kind of letter must be prepared? Do we need a referral letter from the community health center or any else, we have to prepare it before the time (for routing control)" (P13, P12)
Counseling for patient condition and family	caring for patients at home	"… we are overwhelmed when he (patient) angry and out of control, what we should do?... Doctor or nurses must tell us something" (P1, P15)
		"… when he (patient) talks slurredly, we only pretend not to hear it, but it does not work and makes him angry, what should I do?" (P9, P12)
	prevent patient recurrently	"… After being treated and getting better, in less than a week he had a recurrence, why is it always like that?, we need an explanation, why?" (P5, P10)
		"...If she recurs, we (family) are confused about what to do, it's very difficult for us" (P7, P17, P20)
	stress management for caregivers	"... We (family) feel like going crazy too, We need to be checked (mental condition) too" (P15)
		"… I want to be taught, how not to be tense when caring for him… I'm stressed every day" (P8, P18)

Information that families need from mental health services when caring for patients with schizophrenia.

Based on the results, four themes were found: information about patient condition, medication for patients, information for routine control and counseling for patient conditions, and also for families (Table 2).

Patient condition

Most families want to know about the patient's condition. The information which they want to know is grouped into the type of schizophrenia, signs and symptoms and the cause of the schizophrenia. Families often report that the patient's behavior at home is abnormal and changing. According to the family, patients can become angry for no reason, talk to themselves, refuse to carry out self-care, and even stay in their room for days. Three participants (P7, P9 and P19) said that *"... She (patient) doesn't want to talk to anyone, ... stays in the bedroom all day and often smiling alone..."* The family also asked why the patient was experiencing schizophrenia. Some families think that this illness is caused by the patient's closed personality, and not discussing the problems he is facing with other people. Statements from three participants (P1, P3 and P9) describe this situation: *"... because he's quiet and doesn't want to talk about problems, he ends up getting sick (mental disorder)..."* However, some families predict that the patient's illness is decreasing. The family needs an explanation from health workers about why the patient's behavior is abnormal and what caused this to happen.

Medication for patient

Families who accompany patients during treatment at home want to know good information about medication for patients; this is divided into five groups.

Table 3 Identified theme and exemplary significant statement of family responsibility for caring for the patient with a mental disorder.

Theme	Sub-theme	Significant Statement
Giving support for patient treatment	accompany the patient for routine control	"Yes, you have to, bringing control is certain, otherwise it can be dangerous" (P1, P5, P15, P19) "The control date must be recorded, prepared the day before, someone must accompany it, me or someone" (P6, P8, P17)
	monitor patients to take medication regularly	"Every morning before going to work I wait for him to take his medicine until he swallows it, sometimes it takes time, but you know that must be" (P9, P13) " I made a schedule on my cell phone calendar, to remind him to take his medicine, he likes to forget, if he forgets it can relapse, we're all the ones in trouble" (P4, P16) "I have to check on my husband, make sure whether he has taken medicine, whether the medicine is correct or not, well, that's my obligation" (P4, P8)
Fulfill daily needs	basic need	" prepare all the food needs, every day, I also increase the amount, she needs more sometimes" (P7, P15) " I provide everything, like food, drink, snacks, it must be there" (P8, P13)
	personal hygiene	"Reminding him to shower is the most difficult, if he pees and forgets to flush, he has to be reminded" (P3, P16) " she wants to wear the same clothes, I have to change them to new ones, sometimes she looks for the clothes she wore earlier, she gets angry because of it" (P7, P11) "he doesn't want to brush his teeth, I don't give him food if his teeth aren't clean, it's not easy for me and him" (P1, P18)
	individual need	" He often cuts his clothes and tears them, I buy them new ones but he cut them again, what should I do?" (P8) "always asking for pocket money, even though I have prepared snacks, but he always asks for it or he sulks" (P19, P20)
Helps social skill	engage in interaction at home	"Take turns with his father every day to talk to him, anything about food or what he's watching on TV" (P5, P11, P12) "While eating, breakfast or dinner, we always talk to each other like normal people" (P9, P15)
	teach how to speak well to other people	"I taught him, speak well, call the name of the person you are talking to, smile, don't get angry or yell, just talk to neighbors as needed" (P10, P17) "His brother likes to shout, I told him to be patient, keep calm, just take it slow and the answer to the point, don't fight" (P7, P13) "When you speak, don't rush, think about what you want to say so that other people don't get offended" (P3, P8)
	invite interaction with the community	" I invited her to go to a social gathering at the neighbor's, she wanted to come, she liked it, she got extra snack" (P4) "When there is community service at the mosque, I bring him, ask him to help, but I monitor, so he doesn't get too tired" (P15, P17)
Provide activities in spare time	provide art activity	"I bought a guitar he liked, took lessons with a neighbor" (P8, P9, P13) "he likes painting, there is a studio near the house, he goes there diligently, so I said to the studio owner, let him join if he wants to join in" (P11)
	inviting worship activity	"Our whole family reads the Bible every morning, he wants it instead of just lying down" (P17) "pray together at the mosque, sometimes at home with us, always on time" (P6, P17, P20)
	involve in routine household activities	"I ask her to help clean the house, sweep the floor, mop, wash clothes if she's in the mood, she will do" (P1, P17, P19) "he wants and likes to wash cars, if his brother comes home when the car is dirty, he is given money and he is even happier" (P8, P12) "she likes to cook, but she feels confused but it's okay if I help because she likes to cook and clean up the kitchen" (P13, P14)
	modification of activity outside the home	"We take her to the mall, to the market, to exhibitions, out on picnics so she doesn't stay at home all the time" (P1, P3, P7) "I like gardening, he wants to help buy plants, buy fertilizer, water, so he won't keep watching TV all day" (P5, P8)
	find a job	"I once asked him to work, looking after the shop, but he still had to accompany him, because sometimes he was confused too" (P11) "He wants to be a letter delivery boy at his brother's office, and he can earn good money" (P10)

Families feel the need to know the accuracy of taking medication, how to give medication, treatment effect, medication availability, and how to persuade patients to take medication. The family has a strong desire to know the name of each drug consumed by the patient, the function of each drug, the frequency of taking the drug, and how long the patient must always take the drug. Some families also ask whether medication is given only orally and whether there are other ways to administer medication. Families often ask this because the family needs information about the treatment effect if the patient has to continue consuming it in the same way (oral administration). Some families say that the patient's condition has improved after taking medication regularly, but, on the other hand, the family is worried that the patient will become dependent if he continues to take medication orally for a long time. Families also often find it difficult because some of the patients being treated refuse to take medication orally. Families need information regarding strategies for administering medication to persuade patients to take medication regularly. Five participants expressed the situation by saying *"…It's not easy to keep him from taking medicine, we have to teach (by nurses) strategies to persuade him (patient) to keep taking the medicine…"* (P2, P8 and P15) and *"…Sometimes I mix it (medicine) into food, but if he (patient) finds out, he'll be angry to me and I'll let him…"* (P6 and P11). Knowledge about the medication that the patient must take is information that is needed by the family because medication is one way to prevent relapse in the patient.

Information for routine control

Taking patients for regular check-ups at health services is an obligation for families who care for patients with mental disorders. Families need clear and definite information regarding control time and equipment must be carried during routine control. The family said they had to set aside special time amidst their busy family schedule, so that ensuring control time would help the family to be able to take the patient to health services. Apart from that, the preparation of letters and administration that must be brought during the control must also be informed to the family. Two participants conveyed this in the following conversation, they (P13 and P12) said *"…what kind of letter must be prepared? Do we need a referral letter from the community health center or any else, we have to prepare it before the time (for routing control)…"* This will be very helpful so that the family can prepare before the control time arrives.

Counseling for patient condition and family

When families meet with health workers at health services, they need good counseling services related to how to care for patients at home, preventing recurrence as well and managing the stress experienced by the family. Some families complain of feeling overwhelmed when the patient cannot be controlled, such as when the patient becomes extremely angry, refuses to take medication, or relapses a few days after returning from the hospital. Apart from the patient's condition, the family also needs information regarding the stressful situation they are feeling. Families need counseling to manage the stress that occurs due to physical and psychological fatigue while still having to care for patients well at home. Three participants complained about the situation by saying *"…We (family) feel like going crazy too, we need to be checked (mental condition) too…"* (P15) and also *"… I want to be taught, how not to be tense when caring for him… I'm stressed every day…"* (P8 and P18). Information and special counseling services for families in health services will be very helpful in being able to survive and successfully provide good care for mental disorders patients at home.

Family responsibility for caring for the patient with a mental disorder

The results of the analysis show that there are four themes according to families related to responsibilities when caring for patients with schizophrenia, namely giving support for patient treatment, fulfilling daily needs, helping patients to have social skills, and providing patients with activities in spare time (Table 3).

Giving support for patient treatment

The family said that they always try to support the patient's treatment process because it can prevent recurrence. The support provided by the family is mainly in two ways, namely taking the patient for control to mental health services regularly and monitoring the patient to always take medication regularly. It is not uncommon for families to have to postpone activities they are going to do because they have to wait for the patient to take medication. Four participants confirmed that the control schedule was important as they said *"…Yes, you have to, bringing control is certain, otherwise it can be dangerous…"* (P1, P5, P15 and P19). For families, treatment is very important and primary because it can prevent patient recurrence.

Fulfill daily needs

The family feels that they are the ones who must be responsible for meeting the patient's needs every day because the patient is sick and needs help. Patient needs are grouped into three: basic daily needs such as eating, drinking, and snacks; patient self-care, such as bathing and changing clothes, which must be continuously reminded by the family; and personal needs such as clothing and daily pocket money. This was represented by two participants who said *"... I provide everything, like food, drink, snacks, it must be there..."* (P8 and P13). The family realizes that fulfilling the patient's daily needs is not easy, but the family must fulfill these needs so that the patient is not neglected.

Helping with social skills

To several families, mental disorder patients have difficulty socializing with other people, so the family must help gradually so that the patient can interact well with the family and neighbors. The family helps the patient to engage in interaction at home, teaches him how to speak well to other people, and invites interaction with the community. Two participants said *"...I taught him, speak well, call the name of the person you are talking to, smile, don't get angry or yell, just talk to neighbors as needed..."* (P10 and P17). The family tries to understand that the patient's socialization abilities have decreased due to the disease process so they feel they have a responsibility to help the patient by practicing their communication skills.

Provide activities in spare time

The family said they wanted to provide activities for the patient in his free time. Every day the patient must be active to avoid experiencing a recurrence. Some families try to facilitate patients who enjoy artistic activities by buying musical instruments or painting tools and taking art lessons. The family also involves the patient in doing routine household tasks such as cleaning the house, cooking, and washing clothes. The family realizes that if the patient is too bored at home it will be easy for him to relapse, so some families take the patient to the mall or market to modify the atmosphere. There are even families who find light work that the patient can do, such as tending a shop or delivering letters. Five participants stated *"...We take her to the mall, to the market, to exhibitions, out on picnics so she doesn't stay at home all the time..."* (P1, P3 and P7) and *"...I like gardening, he wants to help buy plants, buy fertilizer, water, so he won't keep watching TV all day..."* (P5 and P8). However, the family also pays attention to ensure that activities involving the patient both inside and outside the home are not too tiring so as not to result in a relapse in the patient.

Discussions

The research results are explained in the form of four themes related to the need for care information and four themes related to responsibility in caring for patients so that they become more empowered families, which will be explained in the following discussion.

Patient condition

Families when caring for patients with schizophrenia need information from health services regarding the types or symptoms and causes of schizophrenia. Types of schizophrenia based on the symptoms that appear in patients often make families confused and not knowing what to do. The symptoms can be divided into positive and negative symptoms (Hawari, 2009). Positive symptoms show an excess of normal function, such as hallucinations, delusions, and aggressive behavior (Correll and Schooler, 2021). Meanwhile, negative symptoms are explained as the absence of normal behavior, and patients have deficiencies in motivation, communication, and social functioning (Galderisi *et al.*, 2018). The families in this study had cared for the patient for at least two years; however, they were still confused about why the patient showed changing symptoms. Patients can become angry for no reason, talk to themselves, refuse to carry out self-care, and even stay in their rooms for days. The family needs continuous explanation that the symptoms displayed by the patient are a process of mental disorders experienced by the patient.

It is not easy for families to understand the causes of schizophrenia. The research results show that families need information about the causes of their family members experiencing schizophrenia. Families often ask because the patient felt insecure in the past and did not want to talk about the problems they were experiencing, and some families even still think that mental disorders are a hereditary disease. This family's thinking is in line with the opinion of Gilmore (2010) who explains that serious mental disorders, including schizophrenia, can be caused by the interaction of genetic risk factors and environmental exposure since the fetus is developing in the womb. The family is worried because they see that another family member is also experiencing schizophrenia. However, families also think that individuals who tend to hide problems and do not tell others also have a big role in causing schizophrenia. Cadge (2019) explains that personal characteristics such as a closed or introverted personality contribute to the occurrence of serious mental disorders. Each individual will try to solve their problems, but inadequate abilities and utilization of social support around them will also affect a person's mental resilience. The behavior of each patient varies greatly and requires the family to accept this condition (Fitryasari, Yusuf, et al., 2018). Family knowledge about the patient's condition, especially the type, symptoms, and causes of mental disorders, is very important because it is the basis for the family to understand that the behavior displayed by the patient is due to the disease process. The family's acceptance that the patient's condition is a demand in providing care at home will be a positive aspect that supports the family empowerment process. Sufficient information from health workers regarding the condition of patients with chronic mental disorders can increase family tolerance in dealing with the patient's symptoms, reduce family stress and negative emotional expressions, increase hope that the patient will be able to recover, and increase the family's strength to become more empowered in caring for patients at home (Suryani, Ningsih and Nur'aeni, 2019; Lohrasbi *et al.*, 2023).

Medication for patient

The research results explain that families need information about the drugs consumed by patients. Families feel the need to know the accuracy of taking medication, how to give medication, treatment effect, medication availability, and how to persuade patients to take medication. The families are concerned with the drug names, dosage, side effects, and reasons why each medication is prescribed (Izibeloko *et al.*, 2016).The family believes that patients who take medication according to the instructions of health workers will recover quickly and prevent recurrence (Haddad, Brain and Scott, 2014). The family will try to help the patient take medication regularly in various ways. The long-term treatment that patients must undergo causes a tendency to refuse to take medication or can be said to have a low level of compliance (Ngui, Vasiliadis and Tempier, 2015). The family as the closest people in the patient's life will always try to help the patient to take medication in various ways. Information on the types of drugs that can be provided by mental health services is needed by families (Hendryx, Green and Perrin, 2009). Some families ask about non-oral medication administration or using injections because. according to the family, this is easier than asking the patient to take medication every day regularly. Adequate information regarding medication will help families find solutions to ensure that the patient correctly takes medication.

Information for routine control

Research data show that families need clear and definite information regarding control time and equipment must be carried during routine control. Routine control is a systematic examination carried out in a clinic or hospital to assess the success of the therapy that has been instructed (Noorden *et al.*, 2013). All research participants stated that patients always had routine check-ups every month at the hospital. Families feel the need to prepare time and administrative requirements at least one week before the control time arrives. Insufficient information will be an obstacle when the control process arrives; on the other hand, the family has taken the time between work to accompany the patient for routine control. Families always ask health workers when they have to go back for control and whether they have to get a new referral letter. Several families said that accompanying the patient during routine check-ups is a requirement for patient care that must be carried out to maintain the patient's psychological condition and prevent recurrence.

Counseling for patient condition and family

The results showed that families when taking control patients want to have the opportunity to consult with health workers about the patient's current health condition, prevent recurrence, and also to manage the stress experienced by the family. The family plays a core role in patient care, being the main persons responsible and experiencing many challenges during care, including various tensions as a result of patient care (Ong, Fernandez and Lim, 2021). Families need to get instructions from health workers on how to care for patients at home according to the problems and symptoms of the disease that arise. Several participants expressed the difficulty of treating patients when they were experiencing an uncontrollable relapse, such as suddenly getting angry for no reason, leaving the house, or wandering around people's houses. The patient's changing behavior causes the family to feel depressed and even unable to control their emotions and the family's anger is directed at the patient. Families experience various burdens and these have an impact on the care provided to patients (Chadda, 2014).

The stressful situation faced by families is as a result of providing care to patients with schizophrenia. Families experience emotional strain and a series of changes in their family functioning (Anuradha, 2003). Families also need counseling from health workers to be able to free their thoughts and feelings from uncomfortable situations. The availability of psychological counseling for families is very useful for relieving pressure (Chen *et al.*, 2019). Professionals should assess the emotional status of the family as a caregiver, provide services on stress management, and suggest including in peer support groups to reduce the discomfort and enhance their well-being (Chang *et al.*, 2018). Several families expressed a desire to have their psychological conditions checked so that they do not develop into serious mental health problems. However, not all hospitals provide counseling facilities for families. Several health workers tried to find out what the families were feeling, but, due to time constraints, not all families received special treatment. Existing programs in hospitals still focus heavily on treating patients with schizophrenia.

Giving support for patient treatment

This research found that one of the family's responsibilities in caring is providing support for patient treatment by taking patients for routine check-ups to mental health services and monitoring patients to always take medication regularly. Patients need family support to be able to comply with treatment, as Siregar (2021) argued, which states that families who live in the same area or house need to help patients carry out treatment, such as regular control and compliance with the correct use of medication. Several families in this study always confirmed the date of the patient's return to the hospital and arranged work schedules so they could accompany and support the patient. The family views routine control as very important and must be assisted by the family.

The family is very concerned about the patient's regularity in taking medication. All research participants stated that medication was one way for patients not to relapse. The family has an understanding regarding the impact if the patient does not take medication regularly, which will cause relapse in the patient (Dirik. The consequences of a patient's recurrence require the family to provide more time, thought, energy, and even funds. The family tries to reduce this burden by maintaining the patient's condition so that it does not recur, by monitoring the patient to take medication regularly. This situation is reinforced by Kikkert and Scene (2006) that treatment compliance is influenced by positive perceptions of treatment and the family's desire to avoid the patient being readmitted to the hospital. Some research participants also used various methods to persuade patients to take medication, such as accompanying them every time they took medication, entering cell phone reminders, and monitoring by asking patients whether they had taken their medication on time.

The family's desire to help patients adhere to treatment in this study fostered high commitment among family members. Wardhani (2009) strengthens the results of this research, saying that the family agrees to accept responsibility as the main care provider with patience and continues to maintain treatment routines and adhere to treatment. Family commitment is a form of family acceptance of the patient's condition and allocating a certain amount of energy to stand tall in living life with the patients. Family involvement in the treatment process for patients can help the patient's condition improve, such as reducing relapses, increasing the duration of time between relapses, and reducing the rate of readmission to the hospital (Ong, Fernandez and Lim, 2021). A family situation that is highly committed and full of motivation makes the family stronger and more empowered and is very necessary to support treatment compliance in patients with schizophrenia.

Fulfill daily needs

The patient with schizophrenia requires the family to help meet all of their daily needs. Daily needs are basic activities related to basic human needs, such as eating and drinking, dressing, carrying out personal care (bathing and going to the toilet), and moving around (Brunner and Suddarth, 2002; Hardywinoto, 2005). The research results show that the family tries to fulfill daily needs, which include basic needs, self-care, and the patient's personal needs. Mentally disordered patients have limitations in interacting with the surrounding environment, so the family must help with all the patient's needs. The family provides food, drink, and snacks every day as the patient's basic needs. The family also tirelessly motivates and even helps patients to bathe regularly, brush their teeth, and change clothes after bathing. The families realized that this was not an easy thing because the patient's motivation to maintain personal hygiene had greatly decreased. The findings of this research are in line with Iseselo (2020), who explains that patients with chronic mental disorders experience difficulties and a reduced ability to care for themselves as before they were sick due to the influence of the drugs they consume. Several research participants stated that patients were able to shower and change clothes, but ensuring that they showered cleanly and changed into clean clothes after showering still required family help. The family must be able to provide support and assistance to the patient in carrying out self-care (Lucock *et al.*, 2011). The family's sense of responsibility to maintain the health of patients with schizophrenia creates a special motivation within the family to always remind and help the patient's hygiene every day. The family also meets the patient's personal needs such as buying new clothes and giving pocket money every day. Even though the family situation is full of tension, burdens, and busyness, the family always tries to focus on fulfilling basic needs. Several families stated that they felt relieved because they had made efforts to meet the patient's food, clothing, and personal hygiene needs.

Helping with social skills

Research data show that families help patients with schizophrenia to socialize with the environment. The family helps the patient to engage in interaction at home, teaches him how to speak well to other people, and invites interaction with the community. Patients experience problems in carrying out their social functions and tend to withdraw from interacting with the community around where they live (Hunter and Barry, 2012; Ulfseth, Josephsson and Alsaker, 2013). Several participants complained about negative symptoms experienced by patients such as not wanting to interact and communicate. Families who live with patients every day have a great opportunity to help patients improve their social skills. The family invites the patient to chat every day when doing activities at home or when eating with the family. The family also teaches how to communicate with other people in a good way, keep smiling, and not get angry when saying or asking for something. Apart from interactions at home with the nuclear family, some families try to invite patients to engage in interactions outside the home, such as with neighbors. Patient involvement in a supportive and conducive home environment will help patients improve their social function (Hunter and Barry, 2012). However, families limit their ability to invite mental disorder patients to socialize in the community, because there are still concerns that the surrounding environment does not provide enough support for patients (Harandi, Taghinasab and Nayeri, 2017). Patients who are not yet stable and interact too much with the environment outside the home will cause problems and cause the patient to relapse. However, several families who tried to take the patient out had a positive impact related to increasing the patient's communication and interaction skills. Even the neighbors want to greet him, give him food, and invite him to play at home. This situation increasingly has a positive impact on the patient's social abilities. Patients are willing to answer questions, return greetings, and begin to dare to start a conversation. However, patients must still be accompanied by a family member. A conducive environment, full of initiative and creativity to dare to make adjustments to existing problems has a positive impact on the return of the patient's function socially (Fitryasari et al., 2020).

Provide activities in spare time

The results of the analysis explained that the family looked for activities to fill the patient's free time, such as taking part in artistic activities, spiritual activities, doing household tasks, taking activities outside the home, and finding work. Efforts to prevent relapse that can be carried out by families, apart from routine and regular treatment, also need to be made to create a conducive environment by involving them in family activities and helping patients face serious life problems. Filling your free time with activities you like can improve personal relationships, happiness, and satisfaction and have an impact on increasing self-esteem (Ngamaba *et al.*, 2023). Some participants realized that the patient had an interest and talent in art, so they involved the patient in art activities and bought them musical instruments. The family also invites patients to carry out routine household activities such as preparing family meals every day for patients who like to cook. Patient involvement in family activities makes patients feel happy and appreciated and has a good impact on their emotional calm. Meanwhile, some families still consider the patient's psychological condition. If they are given heavy responsibilities, it could cause a relapse. So the family tends to limit and choose the types of activities that the patient can do. Depending on the severity of the patient's condition, some caregivers expressed a different experience (Iseselo and Ambikile, 2020).

Research data show that families also try to reduce patient boredom while at home by inviting them to do relaxing activities outside the home or finding work. Working can speed up patient recovery (Fakhrou *et al.*, 2023). The family finds light work that the patient can do, such as tending a shop or delivering letters. The family said that the patient felt happy with the work that suited his abilities and became even happier because he could earn money from his work. There is a significant relationship between the involvement of mental disorder patients in a job they like and improvements in the psychosocial symptoms they experience. The family supports the patient in doing light household work and provides praise for the patient's success as a form of motivation. The patient feels that he has increased self-esteem because he can make or earn money, and the patient even feels satisfied with life as a normal human being. Family support in finding activities for patients to fill their free time shows the family's ability to empower patients with schizophrenia.

The limitation of this research is that the interviews were conducted at the hospital outpatient clinic and not at the patient's family home, so the researchers were unable to obtain additional data related to the real situation of the patient's living environment, which could reflect the care information needed by the family. However, researchers have tried to anticipate this by asking questions that can describe the patient's home situation related to care needs.

Based on research findings, it can be identified that nurses in outpatient mental hospital units should also prepare special services that do not only focus on patients with schizophrenia but also for the families who accompany the patients, such as stress management training for families, family therapy and health education which help family to manage the burden of care.

Conclusion

This research can explain that families need information regarding the condition and treatment of patients as well as counseling for families as a demand for caring for patients with schizophrenia which fosters care responsibility as a form of family attachment so that families become more empowered and optimize the family's abilities in caring for patients well and prevent relapse in patients with schizophrenia.

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Conflicts of Interest

We declare we have no conflict of interest

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ORIGINAL ARTICLE

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Psychosocial factors affecting the adherence of chronic kidney disease patients to undergo a hemodialysis program: a cross-sectional study

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ABSTRACT

Introduction: : Chronic kidney disease (CKD) patients are often not adherent to undergoing hemodialysis programs. Psychosocial factors, such as knowledge, motivation, coping skills, support from the family and health workers, and depression are the main factors that influence hemodialysis program adherence, which has an impact on successful treatment. This study aims to analyze the effect of psychosocial factors on hemodialysis program adherence.

Methods: The study was cross-sectional, with a sample size of 90 respondents, obtained through simple random sampling. The study's dependent variable was hemodialysis program adherence and the independent variables were knowledge, motivation, coping, depression, perceived family support and health worker support. Data were collected using a questionnaire and analyzed using multiple linear regression.

Results: Most respondents adhered to the hemodialysis program (90%). The level of knowledge, motivation, coping, family support, and health worker support was in the good category (93.3%; 100%; 91.1%; 90%; 88.9%, respectively), and did not experience depression (90%). The independent variables (knowledge, motivation, coping, family support, health worker support) simultaneously significantly affected the dependent variable, namely adherence to the hemodialysis program by 94.5% (R2 = 0.945; F = 236.613; p = 0.001). Partially, the factors of knowledge, motivation, coping, family support, health workers support, and depression also had a significant effect on hemodialysis program adherence (t = 2.234, t = 5.344, t = 3.473, t = -4.190, t = 6.457, t = 4.887, t = 4.190, respectively; p = 0.001).

Conclusions: The study results showed that psychosocial factors (knowledge, motivation, coping, family support, health worker support, and depression) simultaneously or partially influenced the adherence of CKD patients to undergo a hemodialysis program, with the most dominant factor affecting adherence to hemodialysis as perceived family support. Nurses must pay attention to the psychosocial factors of CKD patients in hemodialysis services to increase their adherence to the hemodialysis program and improve the outcomes.

Keywords: Adherence, Hemodialysis, Psychosocial

Introduction

Chronic kidney disease (CKD) is an enormous global health problem, with the number of sufferers reaching 850 million people by 2022, or 10% of the world population, an increase compared to 2017, when there were only 697.5 million people. Indonesia is one of the countries in the Oceania and South East Asia-ISN region with an estimated prevalence of 10.44% (International Society of Nephrology, 2023). Based on the Indonesian Basic Health Research (RISKESDAS), in 2018, 713,783 CKD cases were reported, and East Java was ranked second nationally with 113,045 cases (Ministry of Health Republic of Indonesia, 2019). In the condition of kidney failure, which is the fifth stage or end stage of CKD, patients need kidney replacement therapy, namely transplant or dialysis (hemodialysis or peritoneal dialysis). However, many CKD patients still do not get the proper treatment, namely hemodialysis programs, especially in lower-middle-income countries such as Indonesia (International Society of Nephrology, 2023). Only 19.33% received hemodialysis treatment in Indonesia; for the province of East Java, it was higher, namely 23.14% (Ministry of Health Republic of Indonesia, 2019). However, the percentage shows that hemodialysis services in East Java province are higher than the national percentage. However, there are still 76.86% of CKD patients who have not received hemodialysis services. Limited access to hemodialysis causes enhanced mortality in CKD patients. The mortality rate was higher in lower-middle-income countries than the global mortality rate (2.6% vs. 2.4%). The mortality rate among CKD patients in Indonesia was 2.47%, which shows that the mortality rate is higher than the global mortality rate (International Society of Nephrology, 2023). The Secretary of the Directorate General of Disease Prevention and Control, Ministry of Health of the Republic of Indonesia said that the death rate in 2019 was 2.35% (1.4 million people), increasing to 3.5% (8.7 million people) in 2023 (Quality Division of PKMK FK UGM, 2024)

A hemodialysis program's success in achieving positive health outcomes in CKD patients is due to their adherence. Low adherence to undergoing a hemodialysis program causes failure to achieve the goals of the hemodialysis program, thus increasing morbidity and mortality (International Society of Nephrology, 2023). Several previous studies showed that adherence of CKD patients undergoing a hemodialysis program is still low, that is only 49.6 – 55.96% (Naalweh et al., 2017; Mukakarangwa et al., 2020; Alzahrani and Al-Khattabi, 2021; Jemali, Munyua and Atoni, 2023). Previous studies in Indonesia also showed the same results, with only 44.2 – 60% of CKD patients undergoing a hemodialysis program (Alisa and Wulandari, 2019; Agu and Tambunan, 2024). Previous studies showed that psychosocial factors were the most dominant influencing CKD patients' adherence to hemodialysis (Cardol et al., 2022; Wen et al., 2023; Yasin et al., 2024). Good knowledge enhances CKD patients' adherence to undergoing a hemodialysis program (Alisa and Wulandari, 2019; Cardol et al., 2022; Mirzaei-Alavijeh et al., 2023; Xu et al., 2023; Yasin et al., 2024). Motivation can influence the behavior of CKD patients. Higher motivation in undergoing a hemodialysis program then will increase adherence to hemodialysis program (Ok and Kutlu, 2021; Cardol et al., 2022; Mirzaei-Alavijeh et al., 2023; Agu and Tambunan, 2024). Besides that, positive coping can also improve hemodialysis adherence (Niihata et al., 2017; Hwang et al., 2018; Ulusoy and Kal, 2020; Melastuti et al., 2022). Symptoms of depression experienced by CKD patients can also worsen adherence to undergoing hemodialysis programs (Pretto et al., 2020; Cardol et al., 2022; Nielsen et al., 2023). Another factor that contributes to adherence to a hemodialysis program is social support. Previous studies stated that high family support can enhancement adherence to hemodialysis in CKD (Al Husna, Yetti and Sukmarini, 2019; Alisa and Wulandari, 2019; Mundakir et al., 2019; Mukakarangwa et al., 2020; Alhamad et al., 2023; Gebrie et al., 2023). Furthermore, previous studies mentioned that support from health workers could also increase adherence of CKD patients undergoing hemodialysis. Higher support from health workers will increase the adherence of CKD patients to undergo hemodialysis programs (Mukakarangwa et al., 2020; Alzahrani and Al-Khattabi, 2021; Sapkota et al., 2022; Gebrie et al., 2023).

However, several other previous studies have shown different results with research results stating that knowledge is unrelated to attitude when undergoing hemodialysis (Xu et al., 2023) and improved adherence in CKD patients (Alikari et al., 2019; Dsouza et al., 2023). Motivation does not always relate to treatment adherence with previous studies having mentioned that motivation is unrelated to the coping of CKD patients undergoing hemodialysis (Melastuti et al., 2022; Zher and Bahari, 2022). Moreover, neither does coping has a positive relationship with adherence to hemodialysis and positive attitude to hemodialysis did not have a significant relationship with hemodialysis adherence (Sheikh et al., 2022; Alhamad et al., 2023). Experience of depression by CKD does not influence their adherence to hemodialysis (Fotaraki et al., 2022; Zher and Bahari, 2022; Jemali, Munyua and Atoni, 2023). Previous studies also showed that social support does not always relate to adherence of CKD patients undergoing hemodialysis. High family support is not always correlated with positive adherence (Al atawi and Alaamri, 2021; Sultan, Fouad and Zaki, 2022). Likewise, support from health workers is not always correlated positively with adherence to CKD patients undergoing hemodialysis (Alhamad et al., 2023). Based on the results of several previous studies, it shows that there was inconsistency in the influence of psychosocial factors, namely knowledge, motivation, coping, depression, family support and support from health workers on the adherence of CKD patients undergoing hemodialysis. Therefore, the study aims to analyze the influence of psychosocial factors on adherence of CKD patients undergoing hemodialysis.

Materials and Methods

Design

The study was a cross-sectional design and conducted at the Hemodialysis Unit of Dr. Soebandi Hospital, Jember, from June to July 2023 to analyze the influence of psychosocial factors on the adherence of CKD patients to a hemodialysis program. The study variable is CKD patients' adherence to a hemodialysis program as the dependent variable. The independent variables are psychosocial factors, which affect adherence of CKD patients to undergo a hemodialysis program, consisting of knowledge (Alisa and Wulandari, 2019; Cardol et al., 2022; Mirzaei-Alavijeh et al., 2023; Xu et al., 2023; Yasin et al., 2024); motivation (Ok and Kutlu, 2021; Cardol et al., 2022; Mirzaei-Alavijeh et al., 2023; Agu and Tambunan, 2024); coping (Niihata et al., 2017; Hwang et al., 2018; Ulusoy and Kal, 2020; Melastuti et al., 2022); depression (Pretto et al., 2020; Cardol et al., 2022; Nielsen et al., 2023); family support (Al Husna, Yetti and Sukmarini, 2019; Alisa and Wulandari, 2019; Mundakir et al., 2019; Mukakarangwa et al., 2020; Alhamad et al., 2023; Gebrie et al., 2023); and health worker support (Mukakarangwa et al., 2020; Alzahrani and Al-Khattabi, 2021; Sapkota et al., 2022; Gebrie et al., 2023).

Sample and sampling techniques

The sample size was 90 respondents, calculated with G*Power 3.1 (α= 0.05; β= 0.8; f^2 = 0.15) and taken randomly using simple random sampling. The inclusion criteria were: (1) aged 18 – 65 years; (2) already undergoing hemodialysis ≥ 6 months; (3) compos mentis status (normal consciousness, fully aware, able to answer all questions about the surrounding conditions, with a Glasgow Coma Scale score ≥14); (4) being able to communicate. Meanwhile, the exclusion criteria included: (1) patients undergoing hospitalization; (2) unwilling to become respondents; (3) having severe conditions or multiple morbidities.

Instruments

Data were collected using a questionnaire. CKD patients' adherence to a hemodialysis program was measured using the adherence to undergo hemodialysis questionnaire adapted from The Greek Simplified Medication Adherence Questionnaire for Hemodialysis Patients (Alikari et al., 2017). The questionnaire was translated into Indonesian and was then back-translated by the researcher. The result of the validity test showed that all items were valid (r = 0.512 – 0.888 > r table = 0.361 (n = 30) and reliable (Cronbach's alpha = 0.872). This questionnaire consists of eight (8) items, namely medication adherence (4 items), presence session hemodialysis (2 items), diet and fluid management adherence (2 items), with a Guttman scale (yes/no) and Likert (0 – 2). Hemodialysis program adherence was categorized into non-adherence (<4) and adherence (≥4).

Knowledge about CKD and its management was measured with the awareness of chronic kidney disease (CKD) patients with the hemodialysis questionnaire (Utami and Dwi Susanti, 2022). This questionnaire consists of 12 items, namely awareness of the disease (5 items), CKD-related diet and exercise knowledge (3 items), examination results comprehension (2 items), understanding of medical resources (2 items) with a Likert scale (1 – 5), with a value of "not knowing at all" = 1; " know a little" = 2: "so that you know" = 3; "knows almost everything" = 4; "know very well" = 5. Results of the validity and reliability test showed that the tool is valid and reliable (r = 0.590 – 0.831 > r table = 0.361 (n=30), Cronbach's alpha = 0.865). Knowledge was categorized into poor (< 25), moderate (25 – 47), and good (≥48).

CKD patients' motivation to undergo a hemodialysis program was measured with the Motivation Questionnaire (Syamsiah, 2011). This questionnaire consists of 10 items, namely condition push act behavior (4 items), behavior in demand driven by circumstances (3 items), and goals from act behavior (3 items), with a Likert scale (1 - 5), with a value of "never" = 1; "rarely" = 2; "sometimes" = 3; "often" = 4, "always" = 5. Results of the validity and reliability test showed that the tool is valid and reliable (r = 0.390 – 0.912 > r table = 0.361 (n=30), Cronbach's alpha = 0.859). Motivation to undergo a hemodialysis program was categorized into low (≤34) and high (>34).

Coping of CKD patients undergoing hemodialysis programs was measured with the Coping Scale (Hamby et al., 2015). This questionnaire consists of 13 items, namely evaluation of problems (5 items) and behavior overcome issues (8 items) with a Likert scale (1 – 4), with a value of "untrue about me" = 1; "a bit true about me" = 2; "somewhat true about me" = 3; "mostly true about me" = 4. Results of the validity and reliability test showed that the tool is valid and reliable (r = 0.419 - 0.813 > r table = 0.361 (n = 30), Cronbach's alpha = 0.903). Coping with hemodialysis programs was categorized into poor (< 27), moderate (27 – 39), and good (> 39).

Depression in CKD patients undergoing hemodialysis programs was measured with the Hospital Anxiety and Depression Scale: Indonesian Version (Tiksnadi et al., 2023). This questionnaire consists of seven (7) items, with a Likert scale (0 = not at all to 3 = very often). Results of the validity and reliability test showed that the tool is valid and reliable (r = 0.590 – 0.774 > r table = 0.361 (n=30), Cronbach's alpha = 0.796). Depression was categorized into not depressed (< 8), mild (8 – 10), moderate (11 – 15), and severe (> 15).

Perceived family support to undergo a hemodialysis program was measured with the Family Support Questionnaire (Syamsiah, 2011). This questionnaire consists of seven (7) items, namely support and presence session hemodialysis (1 item), motivation (1 item), diet, fluid and medication management (2 items), support informational (1 item), and support emotional (2 items), with a Likert scale, with a value of "never" = 1; "rarely" = 2; "sometimes" = 4, and "always" = 5. Results of the validity and reliability test showed that the tool is valid and reliable (r = 0.661 – 0.912 > r table = 0.361 (n=30), Cronbach's alpha = 0.888). Perceived family support in the hemodialysis program was categorized into low (≤28) and high (>28).

Perceived health worker support to undergo a hemodialysis program was measured with the Health Worker Support Questionnaire (Syamsiah, 2011). This questionnaire consists of seven (7) items, namely service quality (1 item), interaction quality (1 item), performance (1 item), communication (1 item), activity counseling (1 item), motivation (1 item), health monitoring (1 item) with a Likert Scale, with a value of "never" = 1; "rarely" = 2; "sometimes" = 4, and "always" = 5. Results of the validity and reliability test showed that the tool is valid and reliable (r = 0.588 - 0.803 > r table = 0.361 (n = 30), Cronbach's alpha = 0.859). Perceived health workers' support in the hemodialysis program was categorized into low (≤28) and high (>28).

Data collection

At the data collection stage, the researcher determines candidate respondents based on criteria inclusion and exclusion study. The researcher explains to the candidate respondents a description of the general study, aims, benefits, research procedures, and data confidentiality, and there is no coercion for the following involved in the study. The researcher gives an informed consent form to the candidate respondents as a form of agreement. Assuming the candidate respondent agrees to participate in the study, the researcher asks the candidate respondent to sign the consent form as a study respondent. The data were collected once through an interview directly with the respondents (the researcher read each question in the questionnaire to the respondents). Respondents underwent the hemodialysis process, and patients stated that they were allowed to go home to home by a doctor. There was no bias in data collection; respondents were in compos mentis and not uremic conditions (normal blood urea nitrogen level: 5 to 20 mg/dl or 1.8 to 7.1 mmol/L). Respondents did not fill in the questionnaire by themselves; however, the researcher read every question to the respondents, then noted down and filled in every answer given by respondents in the questionnaire. Duration time of data collection for each respondent was ± 30 – 45 minutes.

Data analysis

The researcher analyzed the data using descriptive statistics and inferential statistics. The researcher conducted descriptive statistics to describe the respondents' sociodemographic data and study variables, categorized as frequency distributions. The researcher also performed inferential statistics with multiple linear regression tests to analyze the effect of independent variables on the dependent variable (numeric data). Thus, the researcher used categorical data for descriptive analysis, and numerical data (total score of each respondent) for statistical analysis. In addition, the researcher also conducted a chi-square test to explore differences in adherence to undergoing hemodialysis programs based on independent factors that had been categorized (categorical data) to enrich the discussion. The researcher carried out classic assumption tests, multicollinearity, heteroscedasticity, autocorrelation and normality as multiple linear regression test requirements. After testing the classic assumptions test, the researcher continued with the multiple linear regression test (α= 0.05).

Ethical consideration

The study was conducted by upholding human rights and applying ethical principles. The researcher provided direct explanations to prospective respondents about the general description, objectives, benefits, risks, right to withdraw, and rewards and compensation given to respondents. If prospective respondents agreed to participate in the research, respondents could sign the consent form. There was no coercion on respondents to participate in the study. This study has obtained ethical eligibility from the Health Research Ethics Commission

Table 1. Respondents' characteristics, psychosocial factors and adherence of CKD patients to undergo a hemodialysis program at RSD Dr. Soebandi Jember in the period June – July 2023 (n = 90)

Variables	Mean±SD (Min-Max) or Frequency (n)	%
Demographic characteristics		
Age (years)	46.82±12.976 (18 – 65)	
18 – 25	5	5.56
26 – 35	13	14.44
36 – 45	20	22.22
46 – 55	26	28.89
56 – 65	26	28.89
Gender		
Woman	57	63.33
Man	33	36.67
Education level		
No school	6	6.67
Elementary school	30	33.33
Junior high school	13	14.44
High school seniors	27	30
Diploma	2	2.22
Bachelor or higher	12	13.33
Hemodialysis history (month)	39.53±15.672 (6 – 120)	
6 – 24	30	33.33
25 – 72	50	55.56
73 – 120	10	11.11
Psychosocial factors		
Knowledge	55.92±3.339 (46 – 60)	
Poor	0	0
Moderate	6	6.67
Good	84	93.33
Motivation	46.44±3.295 (36 – 50)	
Low	0	0
High	90	100
Coping	46.14±3.683 (34 – 52)	
Poor	0	0
Moderate	8	8.89
Good	82	91.11
Depression	2.10±3.006 (0 – 12)	
Not depressed	81	90
Mild	5	5.56
Moderate	4	4.44
Severe	0	0
Perceived family support	32.52±2.437 (25 – 35)	
Low	9	10
High	81	90
Perceived health worker support	32.31±2.439 (24 – 35)	
Low	10	11.11
High	80	88.89
Hemodialysis program adherence	6.76±1.546 (2 – 8)	
Non-adherence	9	10
Adherence	81	90

(KEPK) of the Faculty of Nursing, Universitas Jember, with certificate number 246/UN25.1.14/KEPK/2023.

Results

Respondents' characteristics

Table 1 shows the average age of respondents was 46.82 years, with most respondents being in the categories of early elderly (46 – 55 years) and elderly (56 – 65 years) (28.89%), women (63.33%), primary education level, namely elementary school (33.33%), and had undergone a hemodialysis program for 25 – 72 months (55.56%). The research results also showed that most respondents had hemodialysis program adherence in the high category (90%). Psychosocial variables show that most respondents had good knowledge about hemodialysis (93.33%), good coping (91.11%), did not experience depression (90%), had perceived family support and perceived health worker support in the high category (90%; 88.89 %), and all respondents had high motivation to undergo a hemodialysis program (100%) (Table 1).

Differences in CKD patients' adherence to a hemodialysis program based on psychosocial factors (knowledge, motivation, coping, depression, perceived family support, and perceived health worker support)

The results of cross-tabulation and chi-square tests show significant differences in adherence of CKD patients to hemodialysis programs based on knowledge, motivation, coping, depression, family support and perceived health worker support (p = 0.001) (Table 2). The study results also showed that 3.33% of CKD patients had good knowledge but did not adhere to hemodialysis programs. Based on motivation, it was

Table 2. Results of cross-tabulation between adherence of CKD patients to undergo hemodialysis program with psychosocial factors at RSD Dr. Soebandi Jember in the period June – July 2023 (n= 90)

Psychosocial factors	Hemodialysis program adherence		Chi-Square Test	
	Non-adherence (n%)	Adherence n (%)	Pearson Chi-Square value	p
Knowledge				
Poor	0 (0)	0 (0)		
Moderate	6 (6.67)	0 (0)	66.667	0.001
Good	3 (3.33)	81 (90)		
Motivation				
Low	0 (0)	0 (0)	80.000	0.001
High	9 (10)	81 (90)		
Coping				
Poor	0 (0)	0 (0)	44.883	0.001
Moderate	8 (8.89)	0 (0)		
Good	1 (1.11)	81 (90)		
Depression				
Not depressed	0 (0)	81 (90)	90.000	0.001
Mild	5 (5.56)	0 (0)		
Moderate	4 (4.44)	0 (0)		
Severe	0 (0)	0 (0)		
Perceived family support				
Low	9 (10)	0 (0)	90.000	0.001
High	0 (0)	81(90)		
Perceived health worker support				
Low	9 (10)	1 (1.11)	80.000	0.001
High	0 (0)	80 (88.89)		

seen that, although 10% of CKD patients had high motivation, they did not adhere to undergo hemodialysis programs. Based on the depression variable, it showed that CKD patients who were not depressed showed adherence to undergoing hemodialysis programs (90%). Furthermore, CKD patients who had low perceived family support and health worker support showed non-adherence to undergoing hemodialysis programs (10%; 10%).

Multiple linear regression test results

The results of the classical assumption test show that all variables in this study have met the classical assumption test, namely that the data for each variable have a normal distribution (p > = 0.05), and there is no multicollinearity between independent variables (tolerance value > 0.10; VIF < 10). The autocorrelation test results showed that there was no autocorrelation (Value DW statistics = 1.940 > DW table = 1.8041 (n=90; Independent variables = 6), dL = 1.518, DW= 1.8041). There is no autocorrelation because the value of dU < DW < 4 – dU is 1.8014 < 1.940 < 2.1986. Apart from that, the data also do not show symptoms of heteroscedasticity (p > α= 0.05) (Table 3).

The results of the Fisher's test show that the estimated regression model is a fit model that is suitable for use to explain the influence of independent variables simultaneously on the dependent variable (F value = 236.631; p = 0.001 < α= 0.05) (Table 4). It means knowledge, motivation, coping, depression, perceived family support, and perceived health worker support simultaneously influence variable adherence of CKD patients to undergo a hemodialysis program. The adjusted R-square value is 0.941. It means the independent variables (knowledge, motivation, coping, depression, perceived family support, and perceived health worker support) influenced the dependent variable (adherence of CKD patients to a hemodialysis program), which amounted to 94.1%. In contrast, other variables outside the model explain the rest, 5.9 % (1 – 0.941). Successively, variable knowledge contributed to 8.3%, motivation contributed to 15.2%, coping contributed to 9.6%, depression contributed to 17.2%, perceived family support contributed to 26.7%, and perceived health worker support contributed to 13.9% on adherence of CKD patients undergoing hemodialysis program. The most dominant variable influencing CKD patients' adherence to hemodialysis programs is perceived family support (26%; t = 6.457; p = 0.001), whereas the least dominant variable is knowledge

Table 3. Results of classic assumption test

Variables	Normality	Multicollinearity		Autocorrelation	Heteroscedasticity
		Tolerance	VIF	Durbin-Watson	
Knowledge	0.225	0.104	9.651	1,940	0.066
Motivation	0.191	0.182	5.505	dL = 1.5181	0.129
Coping	0.234	0.155	6.453	dU = 1.8014	0.231
Depression	0.358	0.104	9.611		0.234
Perceived family support	0.222	0.156	6.390		0.059
Perceived health worker support	0.167	0.328	3.045		0.202

Table 4. Results of multiple regression rest

Variables	Fisher's Test		R^2	Adjusted R^2	Unstandardized Coefficients		t	p
	F	p			B	SE		
(Constant)	236.613	0.001	0.945	0.941	-22.886	2.062	-11.097	0.001
Knowledge					0.083	0.037	2.234	0.028
Motivation					0.152	0.028	5.344	0.001
Coping					0.096	0.028	3.473	0.001
Depression					-0.172	0.041	-4.190	0.001
Perceived family support					0.267	0.041	6.457	0.001
Perceived health worker support					0.139	0.029	4.887	0.001

(8.3%; t= 2.234; p = 0.001). All the independent variables positively influenced adherence of CKD patients undergoing hemodialysis programs, except depression, which has a negative influence. Higher knowledge, motivation, coping, perceived family support, and perceived health worker support will increase adherence of CKD patients undergoing hemodialysis programs. Meanwhile, if depression is higher, the adherence of CKD patients undergoing hemodialysis programs will decrease.

Discussions

The results show that most respondents aged 46 – 65 years, with an average of 46.82 years, were female, had a low education level, and had a history of undergoing a hemodialysis program of 25 – 72 months. Most respondents adhered to undergo a hemodialysis program, with most respondents having good knowledgeabout CKD disease and its management, good coping, no experience of depression, high perceived family support and perceived health worker support, and all respondents had high motivationin undergoing a hemodialysis program (Table 1 and Table 2). The study follows previous studies showing that the average age of CKD patients is 45.78 (Zher and Bahari, 2022), with most CKD patients aged over 45 – 65 years (Xu et al., 2023). Previous studies stated that the older the CKD patient, the lower the adherence to a hemodialysis program (Zher and Bahari, 2022). Younger CKD patients have a good knowledge, attitudes, and practice of hemodialysis (Xu et al., 2023). However, other studies have stated that poor coping is related to younger age, which impacts lower adherence (Hwang et al., 2018; Ulusoy and Kal, 2020). The study result aligns with previous study, which stated that female CKD patients (Zher and Bahari, 2022) have better hemodialysis adherence than men (Hwang et al., 2018; Sheikh et al., 2022; Alhamad et al., 2023). The study results align with the previous study, which stated that most CKD patients have a low level of education (Mirzaei-Alavijeh et al., 2023). Low education level causes low adherence in CKD patients undergoing hemodialysis (Hwang et al., 2018; Nielsen et al., 2023). Higher education patients adhere more to hemodialysis (Alhamad et al., 2023; Mirzaei-Alavijeh et al., 2023; Xu et al., 2023). The study aligns with a previous study that stated that most CKD patients have a hemodialysis duration of less than six years, with an average of 5.4 years (Niihata et al., 2017). DCKD patients with a long history of hemodialysis are associated with low adherence (Zher and Bahari, 2022; Alhamad et al., 2023). Patients with a more extended history of hemodialysis had lower hemodialysis practices than those with a shorter history of hemodialysis (Xu et al., 2023).

The Influence of Knowledge on Adherence of CKD Patients to Undergo a Hemodialysis Program

Results show that knowledge significantly affected CKD patients' adherence to hemodialysis programs (Table 4), with most respondents having good knowledge (Table 1). The results align with previous studies stating that knowledge determines adherence to hemodialysis programs. The better their knowledge, the adherence to hemodialysis will be (Alisa and Wulandari, 2019; Cardol et al., 2022; Mirzaei-Alavijeh et al., 2023; Xu et al., 2023; Yasin et al., 2024). Adequate hemodialysis knowledge can be the capital for determining behavior (Sousa et al., 2023; Xu et al., 2023), clarifying appropriate behavior related to hemodialysis so can they increase adherence (Mirzaei-Alavijeh et al., 2023; Mailani et al., 2024). Knowledge about hemodialysis (benefits, therapy schedule, and the impact of non-adherence, etc.) can enhance patient adherence to hemodialysis program (Alisa and Wulandari, 2019; Cardol et al., 2022; Yasin et al., 2024) to improve hemodialysis outcomes (Stømer et al., 2020). Knowledge had a significant influence, but knowledge has a minor impact on adherence to undergoing a hemodialysis program compared to other variables. It can also be seen that there were still three respondents with high knowledge but who had non-adherence to the hemodialysis program (Table 2). Sociodemographic analysis showed that the three respondents were elderly (> 56 years) with a duration of hemodialysis of more than 73 months and low perceived health worker support. Previous studies showed that age and treatment duration negatively correlate with hemodialysis adherence. The older patients with a longer duration of hemodialysis had low adherence. Older age is connected with difficulty accessing health information (Hwang et al., 2018; Mirzaei-Alavijeh et al., 2023). More specifically, even though respondents' overall level of knowledge is high, the knowledge component analysis shows that understanding and awareness of medical resources is of low value. Therefore, it is essential to pay attention to efforts to comprehensively increase patient knowledge by increasing understanding of the results of laboratory tests that have been carried out and their impact on health, as well as increasing CKD patients' knowledge of medical resources, such as access to information and education from health workers so that they can increase positive perceptions of health workers thereby increasing compliance and better outcomes. Health literacy can increase positive perception, adherence, and quality of life (Alzahrani and Al-Khattabi, 2021; Mailani et al., 2024).

The Influence of Motivation on Adherence of CKD Patients to Undergo a Hemodialysis Program

The results show that motivation significantly affected CKD patients' adherence to hemodialysis programs (Table 4), with all respondents having high motivation (Table 1). The study follows previous studies, which stated that motivation can influence the behavior of CKD patients so that it can determine adherence to a hemodialysis program (Ok and Kutlu, 2021; Cardol et al., 2022; Mirzaei-Alavijeh et al., 2023; Agu and Tambunan, 2024). Motivation is the strongest predictor of hemodialysis adherence (Mirzaei-Alavijeh et al., 2023). Enhancement motivation for undergoing treatment facilitates behavior change through positive and supportive treatment (Ok and Kutlu, 2021; Cardol et al., 2022) to achieve positive clinical outcomes (Mukakarangwa et al., 2020). Study results show that, although all respondents have high motivation, nine (9) still did not adhere to a hemodialysis program (Table 2). Sociodemographic analysis showed that non-adherence respondents were CKD patients who were older and male. A previous study stated younger CKD patients have better adherence than older (Sheikh et al., 2022). Besides that, women adhere more than men (Hwang et al., 2018; Alzahrani and Al-Khattabi, 2021; Alhamad et al., 2023). More specifically, although the overall motivation of all respondents is in the high category, based on the components, it was found, however, that some components still need to be improved, namely the goal behavior component. Therefore, more intensive efforts are required from health workers to educate CKD patients about the benefits of hemodialysis for their health. Health workers should continuously improve the quality of service for CKD patients undergoing hemodialysis therapy to increase patient motivation in undergoing hemodialysis (Agu and Tambunan, 2024). Besides that, the nurse's caring behavior must continually improve to increase patient motivation in undergoing hemodialysis therapy. Enhancement motivation can become positive energy and increase adherence to hemodialysis (Cardol et al., 2022) and outcomes (Naalweh et al., 2017; Mukakarangwa et al., 2020).

The Influence of Coping on Adherence of CKD Patients to Undergo a Hemodialysis Program

The results show that coping has significantly affected CKD patients' adherence to hemodialysis programs (Table 4), with most respondents having high coping (Table 1). This study's results align with previous studies stating that coping affects hemodialysis adherence (Niihata et al., 2017; Hwang et al., 2018; Ulusoy and Kal, 2020; Melastuti et al., 2022). Positive coping increases perceived behavioral control, reduces negative stressors, and enhances disease self-management (Niihata et al., 2017; Sheikh et al., 2022). Good coping can reduce symptom depression connection with burden management disease, increase obedience to treatment that impacts positive outcomes, and improve the quality of life of CKD patients (Ulusoy and Kal, 2020). The study result shows that one respondent still has positive coping but does not adhere to the hemodialysis program (Table 2). Sociodemographic analysis shows that respondents have a hemodialysis duration of more than 73 months, namely 120 months. Patients with a history of longer duration of the hemodialysis program and poor clinical results can cause non-adherence (Mirzaei-Alavijeh et al., 2023). The use of emotion-focused coping is associated with a reduced risk of depressive disorders. However, longer duration of hemodialysis had a negative correlation with emotion-focused coping strategies (Ulusoy and Kal, 2020). The study shows all the respondents' coping is in the moderate-good category, and none is in the poor category. However, coping components need to be improved, especially problem-solving behavior. Therefore, it is necessary to develop an appropriate strategy to enhance the proper behavior of CKD patients to overcome problems related to hemodialysis (Hwang et al., 2018; Ulusoy and Kal, 2020), reducing mortality and increasing quality of life (Niihata et al., 2017). One of the efforts made is education and counseling to improve disease management motivation (Ok and Kutlu, 2021) or involving the family in disease management so that the burden of disease management can be distributed to other family members, ultimately increasing adherence to undergo a hemodialysis program (Sousa et al., 2023).

The Influence of Depression on Adherence of CKD Patients to Undergo a Hemodialysis Program

The results show that depression significantly affected CKD patients' adherence to hemodialysis programs (Table 4), with most respondents having no depression and respondents who experience depression having non-adherence to undergoing hemodialysis program (Table 1; Table 2). Respondents who experienced severe depression also experienced increased non-compliance (Table 4). This study's results align with previous studies that stated that depression experienced by CKD patients could also worsen adherence to hemodialysis (Pretto et al., 2020; Cardol et al., 2022; Nielsen et al., 2023). An increase in the burden associated with managing a disease that cannot be managed well can cause depression, which can reduce hemodialysis adherence (Nielsen et al., 2023). The results of the further analysis show that CKD patients who experience depression are younger CKD patients of the male gender, thus increasing non-adherence (Hwang et al., 2018). Younger age is linked with poor coping and increasing non-adherence (Ulusoy and Kal, 2020). It may be related to their role as heads of families obliged to earn a living for their families. Failure to play the role can worsen coping, resulting in non-adherence. Previous study explains that poor coping is related to low resilience and high cognitive distortions, giving rise to depression (González-Flores et al., 2021). Emotional well-being and psychological stress that can be managed well can increase CKD patient' adherence to controlling their disease. Symptoms of depression experienced by CKD patients, as well as the lack of social support, cause non-adherence to undergo hemodialysis (Pretto et al., 2020; Cardol et al., 2022) and decrease quality of life (Ulusoy and Kal, 2020).

The Influence of Family Support on Adherence of CKD Patients to Undergo a Hemodialysis Program

The results show that family support significantly affected CKD patients' adherence to undergoing hemodialysis programs. Perceived family support is the most dominant factor influencing CKD patients' adherence to undergoing hemodialysis program (Table 4). The result aligns with previous studies, which stated that family support had a positive influence on the adherence of CKD patients in hemodialysis (Al Husna, Yetti and Sukmarini, 2019; Alisa and Wulandari, 2019; Mundakir et al., 2019; Mukakarangwa et al., 2020; Alhamad et al., 2023; Gebrie et al., 2023). Families who participate in disease management, fulfilling the physical, emotional and social needs of CKD patients undergoing hemodialysis, can increase perceived family support (Gebrie et al., 2023), so it can increase adherence to hemodialysis (Sousa et al., 2023). Most respondents perceived family support to be in the high category (Table 1). However, nine (9) respondents still perceived family support in the low category (Table 2). More specifically, the components of family support that are still low are the components of support for managing diet, fluids and medicines, and informational support.

Moreover, support for attendance at hemodialysis sessions, motivation and emotional support is high. Efforts to increase health literacy in families must be improved so that families can understand the problem and how to manage it well. In the end, the family can appraise the issues faced by the patient and provide accurate information. Apart from that, families can also be actively involved in managing disease, especially in managing diet, fluids and medication needed by the patient. A previous study stated that good family support is essential for helping CKD patients overcome problems connected with the disease (Mukakarangwa et al., 2020), especially from a spouse, can reduce low interdialytic weight gain in hemodialysis patients (Mundakir et al., 2019). Family involvement in disease management can balance the disease management burden among family members, thereby increasing adherence to hemodialysis (Kerr et al., 2024). Therefore, family-focused interventions for CKD patients with an interdisciplinary approach combining psychosocial support can increase family involvement through providing emotional support in overcoming problems that arise in connection with disease management as well as providing instrumental support (Alhamad et al., 2023), so can increase adherence (Sousa et al., 2023), and improve the quality of life of CKD patients (Isdiarti and Ardian, 2020).

The Influence of Health Worker Support on Adherence of CKD Patients to Undergo a Hemodialysis Program

The results show that health worker support significantly affected the adherence of CKD patients in hemodialysis programs (Table 4). The study results align with previous studies, which stated that social support from health workers could increase adherence to hemodialysis programs (Mukakarangwa et al., 2020; Alzahrani and Al-Khattabi, 2021; Sapkota et al., 2022; Gebrie et al., 2023). Most respondents perceived health worker support to be in a high category (Table 1). However, nine (9) respondents stated that support of health workers was still low, which impacted hemodialysis adherence (Table 2). The item analysis results show that components are still low in health worker support, including communication, counseling/education, and health monitoring. A previous study stated that health workers are responsible for assessing and managing individual symptoms of CKD patients based on existing needs and resources (Mehrotra et al., 2023). Health workers must be aware of and consider the factors that can be facilitators and barriers in providing effective hemodialysis therapy for better health outcomes (Mukakarangwa et al., 2020). Health workers should create tailored and customized health information plans to inform patients of the critical components they need to manage chronic kidney disease (Mailani et al., 2024). As much as possible, health workers provide interventions tailored to CKD patients' sociodemographic and psychological factors to increase their understanding of the disease and how to manage it (Alhamad et al., 2023). A supportive social environment, where family and health workers constantly interact with patients, can increase CKD patients' adherence. Good relationships with dialysis center staff and the fact that they receive good care, which makes them comfortable when they come for routine care, can increase adherence to the hemodialysis program (Gebrie et al., 2023). Discussions with patients about their adherence with a focus on managing the patient-health worker relationship need to be carried out by assessing the patient's experience of symptoms so they can participate in finding solutions to overcome existing problems (Nielsen et al., 2023). Health worker support through motivation and counseling can increase adherence to undergo hemodialysis with dialysis (Sapkota et al., 2022). Development of a multidisciplinary team with family involvement to better meet the physical, emotional and social needs of patients while undergoing hemodialysis to increase patient adherence is needed (Gebrie et al., 2023; Sousa et al., 2023; Yasin et al., 2024)

The strength of this study is that it is one of the few studies that analyze how psychosocial factors influence CKD patient compliance to undergo hemodialysis using a multiple regression model. This study method allows researchers to simultaneously investigate the influence of independent variables on the dependent variable. In addition, the method used can also partially analyze the influence of each independent variable on the dependent variable. The use of this method can confirm the inconsistency of the results of previous studies, namely, on the one hand, stating that psychosocial factors influence CKD patient compliance to undergo hemodialysis. However, it states that there is no influence. The results of this study confirm that psychosocial factors, such as knowledge, motivation, coping, depression, family support and health worker support have a significant influence on CKD patient compliance to undergo hemodialysis both simultaneously and partially. The variable that has the most considerable influence on compliance to undergo hemodialysis is perceived family support, while the factor that has the smallest influence is knowledge. However, this study has several limitations. This study was conducted with a small sample size and only in Jember. Variations in CKD patient compliance to undergo hemodialysis programs between regions in Indonesia may occur. Further studies using large sample sizes and multi-centers are needed. In our study, we did not exclude other comorbidities such as diabetes, cardiovascular disease, and other comorbidities that are usually present in CKD patients.

Conclusion

The study results show that the psychosocial factors of CKD patients, namely knowledge, motivation, coping, depression, perceived family support, and perceived support from health workers, had a significant effect on their adherence to the hemodialysis program. The most dominant variable influencing hemodialysis compliance is perceived family support. To improve services for CKD patients undergoing hemodialysis, nurses should pay attention to psychosocial factors, especially perceived family support. Family involvement in managing CKD disease can increase CKD patient compliance in undergoing hemodialysis programs to improve the quality of hemodialysis services.

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Conflicts of Interest

The authors declare that they have no competing interests.

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ORIGINAL ARTICLE

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Spiritual needs throughout childbirth: a cross-sectional study among working women at the largest university in Brunei

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ABSTRACT

Introduction: : Healthcare professionals have fundamental roles in ensuring the spiritual needs of women throughout childbirth are met. This concurs with the World Health Organization's definition of health that holistically comprises of physical/biological, psychological/mental, social and spiritual aspects. This study evaluates spiritual needs throughout childbirth of women who are working in higher education setting.

Methods: Healthcare professionals have fundamental roles in ensuring the spiritual needs of women throughout childbirth are met. This concurs with the World Health Organization's definition of health that holistically comprises of physical/biological, psychological/mental, social and spiritual aspects. This study evaluates spiritual needs throughout childbirth of women who are working in higher education setting.

Results: A total 80 female staff participated in the study. Three out of the five domains of the spiritual needs scale were found to be the most frequently addressed as interpreted from the mean score. These are: "Finding meaning and purpose" 4.2 (0.6) followed by "Religious needs" 4.1 (0.7) and "Seeking peace" 4.0 (0.6). Those aged 40 and above scored 4.3 (0.8), which is significantly higher (P = 0.048) for "Finding meaning and purpose" compared to other age groups. Those who had four or more children had significantly higher spiritual needs for "Finding meaning and purpose" 4.2 (0.6) and "Seeking peace" 4.4 (0.7) compared to those having one to three children.

Conclusions: The findings of this study suggest that spiritual needs are essential during childbirth. "Finding meaning and purpose" and "Seeking peace" were identified to be the most common spiritual needs during childbirth. As women age and have more children, their spiritual needs increase. This study contributes positively toward the improvement of care, particularly spiritual aspects where evidence is scarce. This study findings may be used by healthcare professionals for developing interventions or strategies to provide a better and more holistic care to women facing childbirth.

Keywords: Assessment, Brunei, Childbirth, Women, Spiritual

Introduction

Spirituality is a complex discussion matter that has been subjected to contentious debate in the last two decades (Pargament et al., 2013). To date, the meaning and scope of spiritual needs are yet to be explicitly understood, and the importance of accomplishing the spiritual needs must be acknowledged. Substantial research evidence on spirituality, spiritual needs and spiritual care has centrally focused on chronic illnesses, terminal illness and end of life, but that concerning the childbearing year and start of life yet remains scarce (Crowther & Hall, 2015). Childbirth is comprised of antenatal, birth and postnatal periods: this includes the beginning of life (Mahiti et al., 2015). It is a significant event, and considered as the normal life process of a woman; this period would take about 38 - 42 weeks of gestation and will continue up to six weeks or more postnatal (McKelvin et al, 2021). The overall health of woman is crucial during childbirth for it to be a fulfilling and satisfying experience (Akhtaria et al., 2023). The World Health Organisation (WHO) definition of health is not merely the absence of diseases and infirmity, but also includes holistic aspects: physical/biological, psychological/mental, social and spiritual (World Health Organization, 2006). All these aspects are interlinked and contribute to the health of mothers and the developing fetus which later contributes to the birth of a healthy baby.

Although childbirth is a normal physiologic process in a woman's life, it is a life-changing event. It involves various physical, physiological and mental changes to a woman which may require social adaptation of the women to her family and friends. The experiences of childbirth are commonly illustrated as an intense experience and deeply meaningful to the women (Aziato et al., 2016). Childbirth carries significant spiritual meaning to women, family and community. The experiences of childbirth often bring fear to women, which is often unknown to or taken for granted by the healthcare professionals (da Costa Silveira de Camargo et al., 2023). This fear differs for different women and different pregnancies of the same woman (Saisto & Halmesmäki, 2003). The fear mainly centers on not knowing what to expect throughout childbirth, which is obscured by the expectation for a normal childbirth and the birth of a normal baby (Bélanger-Lévesque et al, 2016). Women often turn to spirituality to deal with the fear and expectations of childbirth; and fulfilling their needs for a gratifying childbirth experience (Crowther & Hall, 2017).

Most of the previous studies on spirituality and childbirth are qualitative in nature and provide in-depth accounts of the convoluted relationship of childbirth as spiritual experiences. This provides insights into the importance of spirituality in and around childbirth (Crowther et. al, 2020). Spirituality is viewed as the way in which an individual organizes his or her life in relationship to making his or her life meaningful and purposeful (Aziato et al., 2016). However, the spiritual needs of women throughout childbirth remain unclear, hence, studies surrounding this topic are still an area of interest to date.

Spiritual needs may be defined as the need for humanity to search for meaning and purpose (Backes et al., 2022). Religious needs have been commonly addressed in the existing literature and closely linked as a component of the spiritual needs. However, both these needs may well be independent of each other. During childbirth, women attempt to undertake actions which are believed to be meaningful and purposeful to the maternal and fetal health (Crowther et al., 2020). For example, there are beliefs that childbirth is a gift from god or a higher being and that childbirth experiences are influenced by the power of a higher being (Heidari et al., 2014a). The women draw the higher being closer to them, and this impacts the coping mechanism throughout childbirth (Attard, 2022). The belief in a higher being and power is consistent with the religious component and has been linked to spiritual needs (Aziato et al., 2016). Provision of a faith-tolerant healthcare has been emphasized to ensure the spiritual needs of women throughout childbirth are met (Adanikin et al., 2014).

Spiritual needs are more than just that concerned with religiosity. Spiritual needs may be observed as the belief of specific actions, or specific things, or a specific being/ beings that contribute to the outcome of childbirth (Abdul-Mumin, 2015). With this in mind, spiritual needs may be viewed as a core aspect in a women's support system throughout childbirth. In particular, spiritual needs strengthen women's psychological/mental health which is transformed into the women's ability to cope with outcomes of childbirth, regardless of whether it is positive or negative. In these instances, spiritual needs are often associated with complementary alternative therapy, aligned with traditional and cultural beliefs (Abdul-Mumin, 2016). A study has reported that yoga can reduce stress of pregnancy and ensure a strong mental well-being, hence supporting their spirituality (Kusaka et al., 2016). Traditional and cultural practices include such as coconut oil (mixed with roots and herbs) added with recitation of the verses from the Qur'an. This oil is applied to the women's abdomen and around the hip area and is believed to ease the birth of the baby (Abdul-Mumin, 2015). Similarly, aromatherapy using essential oils for massage during the postnatal period was also reported to help relax the women's body (Abdul-Mumin, 2016). Often, women do not require that their spiritual needs be validated and scientifically proven. Simply addressing and respecting their spiritual needs is more than adequate to them. Their spiritual needs are unique, and perceived as meaningful and purposeful in contributing to satisfying childbirth experiences (Crowther et al., 2020).

Spiritual needs play a crucial role in enhancing women's resolve and confidence throughout the entire childbirth process, spanning from pregnancy to the postnatal phase, a concept reinforced by their deep-seated beliefs and faith (Aziato et al., 2016). Recognizing women's spiritual requirements during childbirth is imperative for comprehensive healthcare, a fundamental aspect that all healthcare professionals, including doctors, nurses, and midwives, should prioritize (da Costa Silveira de Camargo et al., 2023). However, existing literature often relies on healthcare providers' viewpoints rather than directly seeking input from women themselves, potentially neglecting significant aspects of their spiritual journey through childbirth. This oversight risks obscuring the profound spiritual dimensions inherent in women's childbirth experiences, highlighting the need for further exploration (Bélanger-Lévesque et al., 2016). This study aims to explore women's specific spiritual needs, thereby facilitating a more comprehensive and holistic approach to care.

Materials and Methods

Ethics

Ethical approval was obtained from the Institutional Research Ethics Committee (Reference number: UBD/PAPRSBIHSREC/2019/04) on February 7, 2019. Permission to conduct the study was also given by the Registrar and Secretary of the university. Participants' personal information was kept anonymous and confidential throughout the study period to protect their identity and dignity (World Medical Association, 2013). No names or participants are mentioned in the report, and the questionnaires were kept safely in cabinet and data saved in a computer were password protected and only accessible to the researchers.

Study design and setting

A cross-sectional quantitative study was conducted from February to May 2019 which targeted female staff members of the largest university in Brunei.

Population, eligibility and recruitment

Inclusion criteria for this study were any female who had experienced childbirth, both normal and instrumental delivery, from 2013- 2019 at least once, and who was currently working at the university including academic and administrative staff. The reason for this inclusion is to determine the variations in spiritual needs of women throughout childbirth with different mode of birth. Women who had complications during birth, had still birth and neonatal death as well as chronic conditions (for example, hypertension, diabetes, anemia), were excluded. All female staff were invited to participate, eligibility criteria were clearly stated in the participation sheet and confirmed with a question on the consent page of the questionnaire. If women were not eligible but still answered the questionnaire their data were excluded. Only questionnaires from eligible and consenting women were included in the analysis.

Invitations were sent to the faculties' Assistant Registrars (ARs) via electronic mail from the AR of the research team faculty. The faculties ARs extended the invitations to their respective eligible female staff (n=373). A follow up meeting was also set with each AR to distribute the hard copy of the questionnaire. This prevented coercion due to direct contact of the research team with the participants (Manandhar & Joshi, 2020). The study participants were given one week to answer the questionnaire. The answered questionnaires were returned to the faculties' ARs in a designated box. The research team then collected the box from the faculties' ARs. The exact number of study population cannot be determined due to confidentiality of data related to marital status and pregnancy information. To ensure that the cross-sectional design achieves its purpose, communication was made with all faculties' ARs to invite all eligible participants in the study. The participation in the study, however, depended on those who consented to the study.

Data collection

Data was collected using a self-administered questionnaire for four months. The questionnaire is divided into three parts. Part one consist of questions related to demographic data; part two comprises open-ended question requiring participants to elaborate on their specific spiritual needs; and part three contains "Spiritual Needs Assessment Scale Questionnaire" (SpNQ) used with permission from the developer (Hatamipour et al., 2018a). Permission for translation, modification and validation to Brunei context was also given by the developer. The questionnaire was first piloted amongst eight female staff to check the comprehensibility and reliability of the questionnaire; data from pilot study were not used in the main study. Cronbach's alpha was also calculated on the data obtained from the main study and all domains scored

>0.67, indicating high reliability of the scales within this sample.

The SpNQ was originally developed to assess spiritual needs of cancer patients. To the best of our knowledge at the time of our study, SpNQ was the only available published questionnaire that assessed spiritual needs quantitatively. The research team was interested in using the questionnaire as most of the questions were relevant and adaptable for use in normal condition such as childbirth. Modifications were made so that irrelevant questions were either excluded or amended to better reflect on childbirth spiritual needs rather than the original version of spiritual needs of cancer patients.

The original SpNQ was in the English language. The English version of the SpNQ was translated to the Farsi version of the SpNQ and validated with good content, face, and construct validity; and internal reliability and consistency (Hatamipour et al., 2018b). The SpNQ was developed based on the conceptual framework of Bussing et al. (2010). The SpNQ questions were 38 items categorized into five domains:

Religious needs

Religious needs, if brought to attention, help an individual to adapt to their conditions through strong belief in his or her faith.

Finding meaning and purpose

Finding meaning and purpose is composed in the existential dimension of life. This is concerned with self-actualization through understanding and doing actions which are considered to be purposeful and meaningful (Hatamipour et al., 2018a).

Seeking peace

Seeking peace focuses on being free from anxiousness, having hope, strength and courage to face the given situation as well as satisfying others and achieving self-satisfaction while in the given situation.

The need to communicate

The need to communicate with friends and families is believed to be part of spirituality (Hatamipour et al., 2018b).

Support and independence

Support and independence, getting support from family members and healthcare providers throughout childbirth.

The SpNQ was translated into the Malay language by two members of the research team and another member of the research team checked with the accuracy of the translations. The Malay translations of the questions were inserted above each question asked in the English language. Content and face validity was done by requesting feedback from an expert panel (Kisut et al., 2022). Opinion was sought from a member of the research team who is a content expert in childbirth on the final Brunei version of the SpNQ. Aside from this, the Institutional Research Ethics Committee also gave suggestions and feedback on questions within the questionnaire so that they could be easily understood by lay people. As a result, one question from the domain of seeking peace was excluded: "To try to live despite my illness;" this is because childbirth experience is not an illness. The rest of the questions were kept but modified to better suit childbirth aspects, which is a normal event, instead of an illness focus. The modifications also consider languages that take into consideration sociocultural aspects of Brunei which may be different from that of Iran.

Data analysis

After data collection, the questionnaire was assessed for internal consistency and reliability. Descriptive statistics of sociodemographic data and spiritual needs was calculated. Mean scores and estimation of prevalence of spiritual needs were calculated using 95% confidence interval by normal approximation method. Subgroup analysis was conducted to compare these scores with sociodemographic factors using independent t test and one-way ANOVA or Mann-Whitney test and Kruskal-Wallis test, respectively, when assumptions were not met. All statistical tests were two-sided and p value of less than 0.05 was considered statistically significant. All analysis was computed in R-Studio v.4.3.3. Cronbach's alpha was also calculated to test the reliability of each domain.

Results

A total of 100 questionnaires was confirmed for eligibility and consent. However, only a final total of 80 was included as study samples in view of completeness of the questions answered. Faculty ARs notified that non-response to the questionnaires was either due to not eligible, non-willingness to participate in the study or staff were on leave during the data collection period.

Table 1 describes that internal consistency and reliability of SpNQ for childbirth was adequate to good where Cronbach's alpha value was 0.83, 0.81, 0.88, 0.76 and 0.67 for "Religious needs," "Finding meaning and purpose," "Seeking peace," "Need to communicate" and "Support and independence," respectively. This indicates that Cronbach's alpha of the whole

Table 1: Internal consistency and reliability of Spiritual Needs Questionnaire (SpNQ) for childbirth (n=80)

	Alpha
Religious needs	0.83
Finding meaning and purpose	0.81
Seeking peace	0.88
Need to communicate	0.76
Support and independence	0.67

Alpha = Cronbach's Alpha

questionnaire, the Brunei version of the SpNQ for women throughout childbirth, is close to the values obtained in the original English and Farsi version of the SpNQ for Cancer patients. The Cronbach's alpha value indicates that the instrument has good reliability and validity.

Table 2 displays the descriptive characteristics of the participants. The majority of the women were between the age of 40 and above (51.2%). Out of the 80 participants, 90.0% of them were Malay (95%CI: 80.7, 95.3), 55.0% of them experienced one to three pregnancies (95%CI: 43.5, 66.0) and 63.8% of them had one to three children (95%CI: 52.3, 74.0). Since all the participants are either academic or administrative staff of the university, documentations of participants with no formal schooling were not obtained.

Table 3 illustrates the levels of spiritual needs among the women throughout childbirth. It was estimated that "Finding meaning and purpose" was the most prevalent spiritual need among women throughout childbirth (Mean score = 4.2; 95%CI: 4.1, 4.3), followed by "Religious needs" (Mean score = 4.1; 95%CI:3.9, 4.2) and then "Seeking peace" (Mean score = 4.0; 95%CI: 3.9, 4.1). The least prevalent was "Support and independence" (Mean score = 3.6; 95%CI: 3.4, 3.7). Table 4 shows scores according to different levels of age.

The independent variable of female staff members was significantly higher for "Finding meaning and purpose" compared to other age groups (P = 0.048). No further significant association was detected. However, it was observed that those aged 40 to 49 also had the highest mean scores for all other domains.

It was observed that, in terms of spiritual needs in seeking peace (Mean score = 4.2) and the need to communicate (Mean score = 3.7), Malay ethnicity had the highest score compared to Chinese and other ethnicities. Despite these differences, there was no statistically significant difference detected between ethnicity and spiritual needs of the participants.

Table 2: Descriptive statistics of participants (n= 80)

	n	**%**	**95%CI**
Age			
20 – 29	11	13.8	(7.4, 23.7)
30 – 39	28	35.0	(24.9, 46.6)
40 & above	41	51.2	(39.9, 62.5)
Ethnic			
Malay	72	90.0	(80.7, 95.3)
Chinese	5	6.2	(2.3, 14.6)
Others	3	3.8	(1.0, 11.3)
No. of pregnancy			
1– 3	44	55.0	(43.5, 66.0)
4– 6	30	37.5	(27.1, 49.0)
7 – 9	6	7.5	(3.1, 16.2)
No. of children			
1 – 3	51	63.8	(52.3, 74.0)
4 – 6	29	35.2	(26.0, 47.8)
Education			
Secondary school	43	53.8	(42.3, 64.8)
University	37	46.2	(35.2, 57.7)

n = frequency, CI = Confidence interval

In terms of religious needs, women having experienced seven to nine pregnancies' had the highest perceived religious needs compared to those women experiencing four to six and one to three pregnancies (Mean score = 4.5). In terms of the need to communicate, women experiencing four to six pregnancies had the highest spiritual needs to communicate compared to the other groups (Mean score = 3.8). Despite these differences, there was no statistically significant difference detected between number of pregnancy and spiritual needs of the participants.

Women with secondary school education (Mean score = 4.2) had the highest spiritual needs of the religious needs domain as compared to those women educated at the university level. Women educated at the university level also scored significantly high for spiritual needs of seeking for peace compared to the other group (Mean score = 3.7). Despite these differences, there was no statistically significant difference detected between different educational level and spiritual needs of the participants.

Table 5 illustrates spiritual needs scores according to the different number of children the women have to date. There were statistically significant differences detected between different number of children and

Table 3: Mean scores, standard deviation and 95% confidence interval of spiritual needs assessment (n= 80)

N = 80	**Mean**	**(SD)**	**(95% CI)**
Support and independence	3.6	0.6	(3.4, 3.7)
The need to communicate	3.7	0.7	(3.5, 3.8)
Seeking peace	4.0	0.6	(3.9, 4.1)
Religious needs	4.1	0.7	(3.9, 4.2)
Finding meaning and purpose	4.2	0.6	(4.1, 4.3)

SD = Standard deviation, CI = Confidence interval

Table 4: Spiritual needs assessment scores according to participants' different age groups (n = 80)

Age	**20 - 29**		**30 – 39**		**40 & above**		***P*-value a**
Spiritual needs	**Mean**	**(SD)**	**Mean**	**(SD)**	**Mean**	**(SD)**	
Religious needs	4.0	1.0	4.1	0.7	4.1	0.6	0.477
Finding meaning and purpose	3.9	1.3	3.8	0.6	4.3	0.8	0.048^{b}
Seeking peace	3.9	0.7	4.2	0.6	4.3	0.6	0.088
The need to communicate	3.5	0.8	3.7	0.7	3.7	0.6	0.511
Support and independence	3.4	0.5	3.7	0.5	3.6	0.7	0.792

a = one-way ANOVA, b = Kruskal-Wallis test
Scoring:
1.00 = Very little
1.01 - 2.00 = Little
2.01 - 3.00 = Average
3.01 - 4.00 = Much
4.01 - 5.00 = Very much

spiritual needs. The significant associations between mean score of spiritual needs and number of children observed that those women who had four to six children had significantly higher spiritual needs in "Seeking peace" compared to women having one to three children (P = 0.032). It was also observed that women having four to six children have significantly higher mean score in spiritual needs of "Finding meaning and purpose" compared to women having one to three children (P = 0.011). No further significant association was detected. Moreover, it was observed that those having four to six children had the highest mean scores for all constructs.

Discussions

Our study is the first adapted, amended and modified version of the Spiritual Needs Assessment Scale questionnaire (SpNQ) for women throughout childbirth. The SpNQ is produced in two versions: Malay and English. Our questionnaire is both reliable and has validity which is confirmed with the acceptable value of between 0.67 and the highest Cronbach's alpha value of 0.88.

This study contributes toward understanding spiritual needs of women throughout childbirth where evidence is still scarce, particularly, in Brunei. Spiritual needs are an important aspect in caregiving to improve health consequences and respect toward patients' dignity (Javedanpour et al., 2017). The meaningfulness of childbirth spirituality is repeatedly proven as it is used as a coping mechanism throughout childbirth, especially when it is accompanied by childbirth complications (Bélanger-Lévesque, 2016).

The present study demonstrated significant association between age and spiritual needs of participant. Specifically, women over 40 years old significantly required the spiritual needs associated with "Finding meaning and purpose" of childbirth. Although this study contrasts with the result in a Nigerian multi-center cross-sectional study done in 2014, where women aged 15 to 24 (68.6%) required more spiritual care, the result is similar to those aged 35 years old and above (67.7%) as compared to women of age 25 to 34 years old (59.9%) (Adanikin et al., 2014). Our study is congruent with a Nigerian study that indicates spiritual needs are different between different age groups and highly significant as the women become mature in age. Finding meaning and purpose is considered to be an essential and central component of spirituality (Crowther et al, 2020). Spiritual needs may be evaded by healthcare providers due to their complicated nature (Oboyle & Brady, 2019). In Brunei, the dominant religion is Islam, which may influence the spiritual needs on finding meaning and purpose throughout childbirth. This could be the reason behind the significant association.

There was also significant association between number of children the women have and spiritual needs of "Finding meaning and purpose" and "Seeking peace,"

Table 5: Scores according to different number of children of the participants (n = 80)

Number of children	**1-3**		**4-6**		**P-value** ^{a}
Spiritual needs	**Mean**	**(SD)**	**Mean**	**(SD)**	
Religious needs	4.0	0.7	4.2	0.7	0.321
Finding meaning and purpose	3.9	0.6	4.2	0.6	0.011
Seeking peace	4.1	0.6	4.4	0.7	0.032
The need to communicate	3.6	0.7	3.8	0.6	0.079
Support and independence	3.6	0.6	3.7	0.6	0.467

a = Independent *t* test
Scoring:
1.00 = Very little
1.01 - 2.00 = Little
2.01 - 3.00 = Average
3.01 - 4.00 = Much
4.01 - 5.00 = Very much

which were detected as significantly higher in women with four to six children. This result is similar with a qualitative study finding conducted in Iran in 2014, which indicates the significance of the relationship could be due to having a greater risk of developing a high-risk pregnancy in multiparous pregnancies (Heidari et al., 2014b). Moreover, differences from the previous study were shown in a preceding study where there was improved outcome of childbirth among multiparous pregnancies when their spiritual needs were addressed whereby, there was less likelihood of caesarean section and complicated vaginal labor (Nicholson et al., 2009). Another possible reason is that it is likely that, as women have more children, their spiritual needs in “Finding meaning and purpose” and “Seeking peace” of their childbirth experiences become more higher due to the need to cope with the increasing number of children.

Ethnic backgrounds did not significantly affect spiritual needs in this study, which may be due to limited ethnic variation in the recruited participants where 90% of them were Malay. This result is different to a comparative study done in America in 2009, in which some ethnic backgrounds received less spiritual attention (Hamilton, 2009). A study done in Tehran City, Iran, concluded that some women implement spiritual aspects in childbirth to overcome mental adversity, avoiding the use of verbal abusive words and refraining from damaging behaviors (Heidari et al., 2015). Consequently, the lack of disparity in terms of ethnic backgrounds could be due to different composition of religions within each ethnicity. Having said the above, it should be acknowledged that spiritual needs are essential to all women throughout their childbirth experience, although these spiritual needs may be unique to each individual woman in consideration of their demographic background.

In this study, no statistically significant difference between education level and spiritual needs was observed. There are few research studies investigating the relationship between different educational backgrounds and spiritual needs throughout childbirth. Our study pointed out that women with university education level have a higher mean score in terms of spiritual needs of “Support and independence” compared to the women with secondary education level. The reason for this might be due to the provision of in-depth education influencing spirituality from the primary to the university level (da Costa Silveira de Camargo et al., 2023). In our earlier study, it is evident in Brunei that religious education, in particular, Islam, is considered as the way of life that governs the daily life of the people of Brunei (Abdul-Mumin, 2015). Religious studies are also commenced as early as the kindergarten and pre-school. In addition, Brunei people undertake a dual education system comprising of the mainstream education which is assumed in the morning and religious education which is implemented in the afternoon. It is compulsory for Muslim children to attend religious school as early as seven years old. The educational system in Brunei could be the other reason for the significant statistical difference observed where spiritual importance awareness increases more as education status increase further (Abdul-Mumin 2016).

In previous studies, several other important factors were explored, which were not measured in this study. A study done in Nigeria reported that, among 397 women, spiritual guidance throughout pregnancy and childbirth was essentially needed by a majority of women, 301 (75.8%) (Adanikin et al., 2014). In the same study, statistical significant difference could be observed between spiritual needs and monthly income of the womens’ family. Higher monthly family income (> $1000) required fewer spiritual needs than those families receiving lower monthly income of less than $1000. In another study done in Canada, the spiritual needs of fathers throughout childbirth were also assessed and the results showed that spiritual needs are also of great importance for the father (Bélanger-Lévesque et al., 2016). In our study, the paternal aspects of spiritual needs throughout childbirth were not estimated.

Since data collection only took place in a university, the study findings may not be adequately representing all women in Brunei. Due to the cross-sectional nature of this study, prospective implications are limited. In addition, the use of self-administered questionnaire may be subjected to recall bias and reporting bias. Future studies may consider assessing more of the sociodemographics which were not evaluated or lacking in the sample of this study, such as religions, complications in delivery, and maternal and foetal complications. Our study was the first to produce two versions (Malay and English) of the SpNQ for women throughout childbirth. The dual language ensured that individuals who are not proficient in one language could still participate in the study. This promotes inclusivity and allows a broader range of participants to contribute their perspectives. This also minimizes language bias, which can occur when individuals respond differently to questions due to variations in language proficiency or cultural interpretation. This reduces the risk of systematic errors in data collection and analysis. Our study confirmed that not only is the SpNQ a cross-culturally adaptable research instrument, it is also equally valid for patients with terminal illness: cancer patients and normal condition: including women throughout childbirth. This of course took into consideration the adaptation, amendments and modification of questions within the SpNQ to better suit the condition: women throughout childbirth; language used; and sociocultural aspects of Brunei.

Conclusion

In conclusion, the modified and Malay translated SpNQ for childbirth is a cross-culturally reliable research instrument as applied in this study. The findings of this study suggest that spiritual needs are essential during childbirth where “Finding meaning and purpose” and “Seeking peace” were identified to be the common spiritual needs during childbirth. Higher spiritual needs were observed for women aged 40 years old or more and having four to six children. To our knowledge, this is the first study that quantitatively evaluates spiritual needs of women throughout childbirth using a Spiritual Needs Assessment Scale, specifically in Brunei. This study findings may be used by healthcare professionals for developing interventions or strategies to fulfill clients’ spiritual needs throughout childbirth. Baseline data from this study could guide future studies to further explore in-depth spiritual aspects of childbirth. Research and practice in this area continue to emphasize the importance of integrating spiritual care into maternity services to support women throughout the childbirth process effectively.

This study focus was on working mothers in one of the largest universities in Brunei, hence, is limited to this population. Future study should embrace women in Brunei as a nationwide study. Since this study is quantitative and cross-sectional in nature, we were not able to gauge in-depth data. However, this study serves as a baseline for future study on the needs of spirituality throughout childbirth. A qualitative study is suggested to delve into women’s experiences of spiritual needs during childbirth. Like any study requiring recall, our study may be affected by potential recall bias. Future inclusion criterion may include those with a year or two years of childbirth experiences.

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Conflicts of Interest

We have no conflicts of interest to declare.

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ORIGINAL ARTICLE

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Experience of transcultural nursing for migrant workers in covid-19 field hospitals: a qualitative study in Samut Sakhon Province, Thailand

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ABSTRACT

Introduction: The rapid spread of COVID-19 among many migrant workers has led to the establishment of field hospitals in Samut Sakhon Province, Thailand. Nurses were among the healthcare professionals crucial in controlling the pandemic. They used knowledge and nursing skills to care for quarantined patients from diverse cultures. Transcultural nursing competence among migrant workers is essential for nurses' practice. This study aimed to explore Thai nurses' experiences of caring for migrant workers with COVID-19 in a field hospital.

Methods: This is a qualitative study. An in-depth interview was used to collect data from nine nurses between May and September 2022. The data were transcribed verbatim and content analysis was performed to analyze the data. Interviews with interpreters and co-workers of participants in the field hospital were used to examine data triangulation.

Results: Three themes described the transcultural nursing experiences of nurses caring for COVID-19 migrant patients: 1) the role of nurses in a field hospital caring for migrant patients with COVID-19, 2) care delivery through the nursing process, and 3) cultural competence and transcultural nursing approach under mask and personal protective equipment for migrants with COVID-19 in the field hospital.

Conclusions: Nurses' experiences highlighted the crucial role of managing patient care resources, coordinating with other healthcare professionals, and providing direct patient care in various situations in a field hospital. Despite mental and cultural care challenges, nurses still embrace transcultural nursing for migrant patients, addressing cross-cultural communication and basic needs and respecting beliefs related to religion to provide optimal care.

Keywords: transcultural nursing, covid-19 field hospital, migrant workers, migrant patients

Introduction

In late December 2020, an outbreak of COVID-19 emerged in Thailand, originating from Myanmar migrant workers in the shrimp market in Samut Sakhon province. This outbreak had catastrophic effects throughout Thailand, where a range of provinces were under lockdown restrictions. During the peak of confirmed cases, there were insufficient hospital beds for all the patients in need. As a result, home isolation has become an alternative treatment option for mildly symptomatic COVID-19 patients. However, many migrant workers, particularly those living in congested areas, find it difficult to isolate themselves at home. Furthermore, migrant workers who lack work-permitted documentation feared the local authorities, discouraging them from seeking treatment at official health facilities. (Uansri et al, 2023). Consequently, a field hospital was established to accommodate several infected migrant workers, including those from Myanmar, Cambodia, and Laos. (Emergency Operations

Center, 2020). To improve the quality of nursing services, nurses who provide healthcare to migrants must understand their cultures and contexts as well as have a positive attitude toward them. (Wichaikhum et al., 2024). Even though nurses have studied or experienced disaster management, the COVID-19 pandemic might be the first time that nurses have provided transcultural care to migrant workers. Developing transcultural nursing competence in migrant workers should be one of the nurses' performances, as they deal with the spread of COVID-19 by caring for hundreds of patients with various cultural backgrounds. This was in addition to the development of nursing knowledge and abilities.

The majority of studies during the COVID-19 pandemic have focused more on the effects or adaptation of different groups of people. For example, a study of the effects and adaptation during the first wave of the pandemic among different ethnicities in North Thailand. The population of hill tribes in several villages would worry about and fear the pandemic. This population used herbs for self-care and required knowledge of the characteristics and prevention of the pandemic as well as healthcare accessibility support from healthcare professionals (Suratana et al., 2021). Miconi et al. (2021) studied sociocultural factors and found that preventing the transmission of COVID-19 in multicultural diverse communities in Canada was related to stigmatization or discrimination in marginalized groups, especially the East Asian population. Culture and belief in the causes of disease and cure and health care in different ethnicities affected access to health care. In addition, searching for and monitoring infected and at-risk people, such as the homeless, migrant workers, immigrants, and quarantines, has been stigmatized and negatively perceived. (Bruns et al, 2020; Romem et al, 2021).

From the literature review, the studies of nurses' performance in field hospitals focus on sharing experiences in multidisciplinary collaboration, stress coping, and many challenges, such as solving problems in field hospital establishment, accepting new concepts of caring by concerning non-discrimination, and respecting the belief and culture of the patients (Nielsen et al., 2020; Almieda, 2021; He et al., 2021; Miconi, 2021; Romen et al., 2021; Song et al., 2021). However, studies on cultural competence in vulnerable nursing groups in field hospitals are lacking. Hence, healthcare professionals should respect and be aware of patients' cultural differences by integrating patients' beliefs and culture with the nursing care plan, because most people behave involuntarily and powerfully. This may influence health and illness (Purnell, 2019).

As mentioned above, this research focused on the core experiences of Thai nurses caring for COVID-19 patients, particularly groups of migrant workers. The lessons learned from this pandemic have led to increased preparedness for new emerging infectious diseases and improved nursing services for migrants in the post-COVID-19 era. This study aimed to explore the experiences of nurses caring for COVID-19 patients among migrant workers, including describing transcultural nursing for migrant workers and explaining their cultural competence. The research results will help nurses work with patients from diverse cultures. The knowledge obtained from this research can be developed as a nursing student learning outcome and a plan for enhancing cultural competence.

Materials and Methods

Study design

This is a qualitative study. The methodology applied a descriptive case study to explore the experiences of nurses who had worked in the COVID-19 field hospital and transcultural nursing related to migrant worker patients.

Participants

The research participants were nine registered nurses, consisting of five nurses from the Ministry of Public Health located in Samut Sakhon province and four military nurses from the Ministry of Defence. Nine nurses were selected using the snowball sampling technique, met the inclusion criteria, and were fully qualified. Nurses who were rich in information were included in the study. They worked in the Wattana Factory Field Hospital established by the Ministry of Defense and the Ministry of Public Health during the outbreak from January 2021 to September 30, 2021. In addition, they had experienced caring for migrant worker patients with COVID-19 in the field hospital for at least five weeks or 200 hours or more. This period of practice in the field hospital has enough experience to apply transcultural knowledge and skills (Caffrey et al., 2005; Tosun, 2021).

Data Collection

The data collection used a semi-structured instrument to guide in-depth interviews with nurses who had worked in Wattana Factory Field Hospital. The instrument was prepared by researchers based on the research objectives, which consisted of the performance characteristics of transcultural nursing in COVID-19 patients who were migrant workers and the competency of professional nurses providing care for migrant workers in field hospitals, including the knowledge and experiences learned to practice in field hospitals in Samut Sakhon province.

The snowball sampling technique was used for the qualitative data collection of nine participants. The data collection process was as follows (Moser et al. 2018): 1) The researcher asked for the manager nurses' advice of Wattana Factory to recommend qualified for in-depth interviews. 2) The researcher contacted the participants, informing them of the research objectives, methodology, and approval of the research ethics numbers that were considered by the Institutional Review Board of the Royal Thai Army Medical Department. 3) Protecting the rights of participants: The researcher interviewed participants who were willing to give information and arranged them with the informant for a convenient date. 4) An in-depth interview with each participant took approximately 45-60 minutes. 4) Then, the participant was asked to recommend the next qualified interviewee. Information was saturated until no new information was added to the interviews. It took five months to correct the data (May-September, 2022).

Data Analysis

The data from the participants were organized and analyzed using manifest qualitative content analysis (Moser et al., 2018) to interpret the meaning of the content of transcultural caring for migrant worker patients with COVID-19 and operating management in the field hospital. Additionally, observations and other recordings during data collection were analyzed and performed as follows: reading all data and finding general ideas and supporting information about transcultural care and transcultural competency; determining coding from general ideas and supporting information; subcategories were identified and grouped related to codes and the purpose of this research; and finally, several subcategories were combined into one category. The analysis process was divided into three main themes.

Trustworthiness

Credibility was achieved through member checking; the researchers conducted verbatim interviews with the participants for verification. All participants were given a chance to review the descriptions when no one disagreed. The data were analyzed for classifications and themes, and the information was returned to the participants. All participants agreed with the analysis results, and no new data were added during validation.

The validity of the results was confirmed using data triangulation. Participants' data were confirmed using the same questions to interview nurses and interpreters working with participants in this field hospital at different times.

The research team thoroughly reviewed and approved each stage of the research process. Detailed field notes and a reflective journal were kept documenting the entire process and the role of the researcher. Team researchers verified the coding accuracy in the data analysis and ensured consistency of the inferences.

Ethical considerations

This research was approved for the research methodology and ethics by the Institutional Review Board Royal Thai Army Medical Department on March

Table 1: Characteristics of the participants

Characteristics	**Participants**								
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
Nursing experiences (year)									
Novice (0-2 years)				•	•				
Advanced beginner (3 - 4 years)									
Competent (5 - 7 years)									
Proficient (8 - 10 years)			•						
Expert (> 10 years)	•	•				•	•	•	•
Original affiliation									
Public Hospital from Samut Sakhon Province	•	•	•	•	•				
The Royal Thai Army						•	•	•	
The Royal Thai Armed Forces									•
Areas of expertise in nursing									
Pediatric	•								
Medical		•	•						
Surgical						•	•		
Emergency								•	
Psychiatric									•
Nurse Internship				•	•				

Table 2: The role of nurses in a field hospital caring for migrant patients with Covid-19.

Meaning Units	Codes	Sub-theme
Theme: The role of nurses in a field hospital caring for migrant patients with COVID-19		
- Allocate staff roles and rotations. - Identify and respond to critical incidents. - Handle and manage clinical service delivery and unit coordinators. - Arrange stock levels of medical supplies and medication. - report for resupply requirements including allocating food donations	- Daily operate service delivery planning and management - Use clinical leadership skills to solve problems in the field hospital. - Manage resources in the field hospital	- Management role
- Coordinate patients' needs with other personnel. - Do pre-discharge planning and collaborate with agencies. - Collaborate and refer patients	- Organize clinical flow and patient referrals. - Support clinical operations and collaborate with the healthcare team.	- Coordination role
- Assess personal data on patients' admission. - Deliver medications in accordance with the treatment plan. - Assess and evaluate the patient's signs and symptoms for proper care. - Follow-up consultation for occurring physical and psychological signs and symptoms. - Provide going-home instructions for prevention and recurrence.	- Monitor and identify clinical presentations with special needs. - Identify and facilitate nursing care for special needs patients. - Daily inpatient ward round	- Clinical role

28, 2022, with Code N001q/65. Informed consent was obtained from all participants after the researcher explained the purpose and study process and confirmed no conflict of interest in their job duties.

Results

Seven participants had experience in nursing for more than eight years; and two were nurse internships. None of the participants had previously experienced a disaster field or military medical shelters before. The details are presented in Table 1.

Three themes and ten subthemes were identified to describe the transcultural nursing experiences of nurses with COVID-19 migrant patients in a field hospital in Samut Sakhon Province.

Theme 1: The role of nurses in a field hospital caring for migrant patients with COVID-19.

Theme 2: Care delivery through the nursing process.

Theme 3: Cultural competence and transcultural nursing approach under masks and personal protective equipment (PPE) for migrant patients with COVID-19 in a field hospital.

Table 3: Nurses deliver nursing care for migrant patients with Covid-19 through the nursing process.

Meaning Units	Codes	Sub-theme
Theme: Care delivery through the nursing process (NP)		
- Perform health assessment when the patients first came into the field hospital - Arrange an area/zone for patients staying in the field hospital - Take the patient's vital signs every morning	- Gather information of the patient's individual physiological and psycho-social	Nursing assessment
- Detect the warning signs of abnormal respiratory signs & symptoms - Detect psychosocial problems in patients whose member's family died. - Find out that the patient lacks knowledge of COVID-19 and other underlying complications of diseases.	- Identify the patients' basic needs and health problems	Nursing diagnosis
- Manage the caring process such as food, medicine, Chest X-Ray, and patient consulting. - Provide information about behavior while in the hospital to reduce anxiety. - Listen to the patients and evaluate depression from the loss of a family member. - Consult psychologists for mental health screening to assess the risk of depression	- Nursing care during patients' admitting in the field hospital	Nursing Intervention
- Assess the patients' symptoms of change and psycho-social needs through the front of the CCTV cameras 24 hours a day	- Assess and monitor changes in the patient's vital signs and mental status	Nursing evaluation

Table 4: Cultural Competence and transcultural nursing approach under Mask and Personal Protective Equipment (PPE)

Meaning Units	Codes	Sub-theme
Theme: Cultural Competence and transcultural nursing approach under Mask and Personal Protective Equipment (PPE) for migrant patients with COVID-19 in the field hospital.		
- Nurses understood the cultural characteristics, history, values, beliefs, and behaviors of the ethnic or cultural group	- Nurses must have cultural knowledge about each ethnic group to enhance their care of migrant workers.	Cultural knowledge
- The patients' culture, beliefs, and habits were respected by nurses. Additionally, nurses didn't evaluate whether the patient's beliefs related to supernatural events (such as ghosts or seeing ghosts) were correct or incorrect.	- Nursing care was unbiased and respectful, encompassing equal treatment and a patient-centered approach.	Cultural awareness
- Nurses respected and accepted their patient's cultures. Nurses try to learn the language to communicate with foreign patients.	- Being aware of cultural communication differences.	
- Volunteer interpreters communicated with patients who could not speak Thai. They needed to speak Thai.	- Culturally sensitive communication, learning migrant patients' language, and utilizing interpreters	Cultural skills: Cross-cultural communication
- Nurses shared the information with migrant patients as they did with Thais through the interpreter. - A large number of patients, communication was also a challenge. - "Or Sor Tor" was abbreviated for volunteer interpreter who was a patient infected with COVID-19 coming to the field hospital and assisted in communicating with nurses.	- Patients who volunteer to be interpreters helped nurses communicate with patients. - Adjusting and choosing a variety of interactive methods for the individual. - Listening attentively to needs/problems	

The Analysis process of the in-depth interviews about the experiences of transcultural nursing for migrant workers in COVID-19 field hospitals is presented in Table 2 - Table 4

Table 2 demonstrates the analysis process of the in-depth interview results regarding the experiences of transcultural nursing of migrant workers with COVID-19. This theme was derived from the researcher’s question about the informant’s experience of working in the field hospital. The data indicated that Their experiences emphasized clinical leadership, which included management, coordination, and clinical roles. In the management role, nurses planned daily operational service delivery and used clinical leadership skills to solve problems in the field hospital, which was explained as follows:

P1: *“I arranged an area to keep patients in the field hospital. According to care needs, the area near the camera was for patients who needed meticulous nursing care and closed observation, such as patients who had congenital diseases, high blood pressure, and heart disease.”*

P2: *“Patients were divided amongst themselves on the first day, and the beds were sorted by number. Whoever came first went to Bed No. 1 and so on, but the patients preferred to stay in a group. As a result, nurses placed patients of the same culture/ethnicity in the same area to minimize conflict.”*

For the coordination role, nurses liaised with the medical doctor and healthcare teams for the proper treatment of patients and to facilitate discharge planning. Nurses coordinated with the patients’ relatives to provide information and prepare for patient discharge. In addition, nurses contacted the Subdistrict Administrative Organization and other local authorities for help with food and facilities during the patients’ stay in the field hospital.

P1: *“When the patient's symptoms become more severe, with high fever, tiredness, and difficulty breathing, they will contact Samut Sakhon Hospital to refer patients for treatment.”*

P2: *“Getting in touch with state organizations was a new experience and it was a matter of systematizing the coordination work to make as few mistakes as possible. Nurses must have good relationships with the sub-district administrative organizations and the various sectors.”*

P3: *“Nurses thought relatives should be allowed to visit the patient once a week. Some Burmese people came to donate food to Burmese patients. Therefore, nurses required coordination by relatives’ individuals, and external entities to make it successful management.”*

In the clinical role, nurses provided nursing care for patients, focusing on rapid triage, evaluation, stabilization, and referral of patients as appropriate rather than definitive evaluation.

P1: *“Nurses received cases from the originating unit. Before admitting the patient to the field hospital, nurses* *assessed the patient's signs and symptoms, COVID test results, name, age, gender, and nationality."*

P2: *"Screening patients. When screening patients, if the patient was found to be very tired, with oxygen saturation less than 95%, and a temperature more than 38 degrees Celsius, first aid would be provided."*

P3: *"The nurse dispensed medicine to the patient and gave advice on taking medication. For patients taking Favipiravir, body temperature, blood pressure, and respiratory system abnormalities must be assessed."*

While working in the field hospital, nurses encountered immigrant patients from Myanmar, Cambodia, Vietnam, and other countries. Even though most patients were Burmese and some nurses were familiar with them, nurses were still faced with stressful situations. Moreover, the study described how nurses dealt with cultural sensitivity while providing care for migrant patients at the field hospital, as shown in Table 3.

Table 3 presents the results of the analysis of Theme 2: Care delivery through the nursing process. This theme was formed from the researcher's question regarding nurses' care activities in a field hospital. This assessment is explained as follows:

P1: *"A nurse took on the nursing clinical handover from the previous hospital before accepting the patient's admission to the field hospital. We checked personal information and history of illness including COVID-19 and medication history."*

P2: *"A nurse wearing PPE went to the field to assess the signs and symptoms. Body temperature above 38 oC, oxygen saturation less than 95%, did not qualify for admission and in routine care."*

P3: *"Patients could talk to nurses in front of the CCTV camera 24 hours a day. Nurses monitored and answered patients' questions. When patients had serious problems, nurses wearing PPE assessed the patient's clinical changes in the field if necessary."*

Other statements expressed by participants related to nursing interventions focused on the mental health of patients as follows:

P1: *"We had Burmese patients who could speak Thai and were willing to be volunteers. The nurse manager authorized them to assist the nurse in bringing patients who required consultation to communicate with the nurse through CCTV monitors. There was a case in which the nurses assessed that the patient was anxious about the illness and the severe symptoms of his wife. We gave him mental support and monitored for more psychological problems."*

P2: *"There was a male patient who had no children or relatives in Thailand. His wife died from COVID-19 at Samut Sakhon Hospital. Our nursing team coordinated with various departments of the hospital and local authorities to manage the funeral proceedings following the patient's religion."*

In addition, nurses must assess patient problems or needs, diagnose them, manage clinical risk issues, and respond to emergencies and crises. The participants addressed this issue as follows:

P1: *"Two Elderly Indian patients... one who could speak Thai, but the other who could not communicate in Thai. He was unable to consume the Thai food provided by the hospital. The patient in the adjacent bed informed the nurse that he had been lying down without getting up to eat. So…the nursing team had to adjust the CCTV camera for observation. We quickly put on PPE and went in to check on him and indeed, he had hypoglycemia. This case served as a lesson for us to be concerned about patients' food intake."*

P2: *"For patients prescribed Favipiravir medication, nurses must assess body temperature, O2 saturation, and any abnormal respiratory symptoms, and prepare patients for the chest X-ray after one day of admission in the field hospital."*

P3: *"Nurses performed triage on patients at admission who initially presented as a yellow case but then the condition changed to red. The patient was experiencing dyspnea and loss of consciousness. We used to perform CPR while awaiting a referral. In situations like this, preparedness was crucial."*

In summary, nurses have used the nursing process to care for migrant patients. The nursing process involved collecting data for triage and classifying patients according to the severity of the disease, as well as providing nursing care that aligns with patients' problems or needs. The nursing diagnosis for COVID-19 patients at the field hospital included hyperthermia, which was caused by an increase in the body's metabolic rate and the viral infection process; ineffective airway clearance, associated with excessive coughing and secretion; and the infectious process, gas exchange disorder; COVID-19knowledge deficit; risk of insufficient nutrient intake to meet metabolic demands or comorbidity-induced hypoglycemia caused by cultural dietary needs and preferences; and anxiety, depression, fear, and ineffective coping due to COVID-19. Nurses performed care planning and executed nursing care related to patients' daily needs and provided necessary observations for early warning signs to ensure patients' safety and support their mental health.

From the interviews, the researcher analyzed the data and concluded that nurses employed in COVID-19 field hospitals had cultural competency. Cultural competencies consisted of recognizing different cultures, having knowledge of cultures that were different from oneself, and having the ability to communicate across cultures; examples were the following:

Cultural knowledge: Nurses must have cultural knowledge of each ethnic group to enhance their care of migrant workers.

P2: *"I thought that nurses needed to know the culture of each ethnicity. To be honest, when I first worked in the field hospital, it was very fast, and I couldn't. No... didn't study. But I was getting used to a bit of Burmese."*

P4: *"At times, individuals offered food donations. We informed them that stir-fried basil was not suitable for Cambodian patients as they were unfamiliar with it. On the other hand, Burmese patients preferred sour, salty, and oily food. They specifically requested Burmese-style."*

P3: *"Patients belonging to ethnic minorities in Myanmar did not call themselves Burmese. They called themselves Tai Yai, Thai Lue, and Karen, people who lived next to the Kanchanaburi border. The nurses understood that they were also Burmese. We called the patients Burmese. The patients would not come to see us. It was important to recognize and respect the unique identities of different ethnic groups."*

Cultural awareness: Nurses in the field hospital exhibited exemplary behavior by providing equitable care without prejudice or stigma, upholding individual rights, respecting diverse beliefs, and demonstrating awareness of cultural communication differences.

P8: *"We offer equal nursing care to all patients, regardless of their nationality. It should be noted that some patients follow specific dietary restrictions. Our nurses would accommodate each patient's way of life, beliefs, and cultural background when providing meals, as this was an essential aspect to consider."*

P6: *"Although we had limited knowledge about the backgrounds of Cambodian patients, we provided equal care and treatment to all patients regardless of their race. However, Cambodian patients may feel that we favored Burmese patients over them when we were not even aware of anyone's nationality."*

P7: *"Burmese and Cambodian individuals tended to engage in acts of merit. The Burmese placed a high value on Buddhist holy days and, as a result, we decided to offer a prayer for prosperity before bedtime. However, due to the presence of patients from other countries, the prayer did not last very long. Nonetheless, this activity had the potential to alleviate stress."*

P9: *"The patient had a history of alcohol withdrawal. The patient's wife reported a change in his behavior and expressed concern that he may attempt to leave the hospital. She believed that he was possessed by a ghost. She believed a sarong belonging to her mother-in-law was necessary for an exorcism ritual and asked the nurse to obtain one. Nurses utilized what was available and allowed them to perform the ritual. The nurse was present at the ceremony and assessed her husband's condition."*

P5: *"The nurse called the patient's name as written in their passport. The patient claimed that the nurse had called their names incorrectly. Additionally, patients generally preferred to be referred to as Cambodian instead of Khmer."*

Cultural skills: Nurses learned cross-cultural communication by imitating the pronunciation of calling patients' names and simple words in daily life and collaborating with interpreters to engage effectively with patients from diverse backgrounds. Nurses used patient volunteers as interpreters for new patients and COVID-19 communication, interacted with individuals from various cultures, and skillfully selected appropriate interactive methods while attentively listening to patients' needs and concerns through CCTV cameras or interpreters.

P2: *"Burmese liked us to call men "Ah..." Ah.... What did women call? It's called "Ma" which means sister. We always called the name Burmese people incorrectly, with false accents (smiles), even if it was an English name. Since the accent was strange, you could not pronounce it properly."*

P6: *"This language issue was really a problem we encountered. Initially, we would have translators from both Samut Sakhon Hospital and the army's translator."*

P3: *"Patients at the field hospital could communicate with staff because many of them spoke Thai. These patients are going to help us. The nurse who was the manager of the field hospital, together with the team, thought that a patient who spoke Thai could be used as a medium to communicate with other patients. If there* *is any problem, tell the patient, who acts as an interpreter, to help the nurse. Patients would reduce their anxiety'."*

P8: *"Many patients were easy to deal with, while others made daily fuss. We attempted to make the participants feel as comfortable as possible. We understood that everyone was bored with quarantine'."*

In summary, the ability to communicate across cultures was the cultural competence that nurses in this COVID-19 field hospital practice most clearly demonstrated. Learning to pronounce words and call names correctly, being sensitive to sensitive topics, and being aware of nonverbal messages are important communication skills. Additionally, nurses communicated their genuineness to the patients through their voices and looks. Cross-cultural communication skills make communication effective, avoid conflict, and receive cooperation from patients and other personnel in the care team.

Discussions

The study's results supported the research objective on the experiences of nurses working under the Ministry of Public Health and the Ministry of Defence, who were mobilized to care for migrant workers from various cultural backgrounds, such as Burmese, Cambodia, Vietnam, and others, at the Wattana Factory Field Hospital in Samut Sakhon Province. This was the epicenter of Thailand's initial COVID-19 outbreak. The findings revealed that nurses play a crucial role in various situations within hospitals. These roles include managing nursing personnel and patient care resources, coordinating with other healthcare professionals at the field hospital, and providing direct patient care. Their roles align with the nursing practices at Boston Hope Field Hospital in the United States and the pandemic in Wuhan, China, where a military command structure is implemented and a medical support system of the state is in place. The nurse's roles include chief nursing officer, nursing director, and operations team leader. In this context, the chief nursing officer and director are responsible for managing the workforce in the clinical setting and making structural and policy decisions. The unit resource nurse is responsible for resource allocation to support clinical operations and work closely with medical team leaders. (Baughman et al., 2020; He et al., 2020). This finding is consistent with Martin et al. (2020), who discussed the nursing role in a field hospital, emphasizing the crucial role of the nursing team leader in operational management and close collaboration with the medical team leader in providing optimal care. These responsibilities require nursing team leaders to be highly flexible and adaptable to their leadership approach.

Another important finding from our study supported the research objective of the transcultural nursing approach to migrant workers in field hospitals and highlighted the importance of the care team in providing direct care to migrant worker patients. Nurses used their clinical abilities to assess their physical condition and to determine their nursing diagnoses. Therefore, they provide care to meet basic needs, detect abnormal vital signs, and identify warning signs of hypoxia due to respiratory infections. They also performed surveillance and provided care for mental health problems of patients affected by quarantine measures. These findings are in accordance with the study by Hidayati et al. (2022), who explained that nurses can perform complete nursing assessments and diagnoses during the pandemic. However, it was difficult to complete the implementation of some nursing diagnoses, especially mental care, owing to the lack of complete data collected during the evaluation.

In addition to the nursing process applied in providing care for migrant worker patients in field hospitals, the ACCESS model of transcultural nursing, developed by Aru Narayanasamy in 1999, may also represent the concept of the nursing approach (Doody, 2012; Romem, 2020). Nurses gathered comprehensive information about the patients' physiological and psychosocial health during the assessment process (A), considering their cultural needs. They paid particular attention to the patient's lifestyle, food preferences, and beliefs related to supernatural occurrences. The study found that communication barriers were significant. The nurses learned how to communicate (C) with immigrant worker patients, both verbal and non-verbal, and collaborate with interpreters. In addition to non-verbal communication, such as gestures and facial expressions; the nursing team initiated "Or Sor Tor (Volunteer Interpreter)" a COVID-19 infected patient assigned as an interpreter at the field hospital assisted communication with nurses to accommodate the increasing number of patients needing translators.

In addition to providing nursing care directly to assess the patient's condition remotely via CCTV cameras and VDO calls, patients could have cross-cultural communication with nurses through interpreters. These findings align with the International Council of Nurses (ICN) determination of disaster nursing practice, which includes performing basic nursing care in emergency and trauma settings, monitoring and identifying clinical presentations, and facilitating care for highly dependent, vulnerable, or specialized-needs patients (Martin et al., 2020; Baughman, 2020). Additionally, the research results emphasized the importance of cultural assessment and tailored approaches in nursing care, respecting patients' beliefs and understanding their cultural lifestyles. These findings are consistent with the application of Giger and Davidhizar's Transcultural Assessment Model, particularly in the assessment phase of the nursing process, which focuses on communication and social organization (Merritt, 2013; Gieger, 2013). They also align with the findings of utilizing the ACCESS model for transcultural nursing to control the spread of the COVID-19 outbreak in Beit Shemesh, highlighting effective communication, cultural negotiation, respect, rapport, sensitivity, and safety in addressing the specific needs of the community. Nursing services emphasize cultural assessments, the significance of tailored approaches to people, and collaborative efforts to address the Ultraorthodox community. These components shaped healthcare providers' utilization of culturally appropriate language and communication methods, leveraging traditional communication channels, and participation of community leaders to ensure that measures were accepted by the community (Romem et al., 2021).

The findings of this study support the research objective of the cross-cultural nursing competencies of professional nurses. These were partially similar to the cultural competence of Campinha-Bacote, which demonstrated nurses' adherence to applying cultural knowledge, cultural awareness, and cultural skill, especially in cross-cultural communication with diverse cultural and ethnic backgrounds patients to care in the COVID-19 field hospital effectively. However, cultural encounters and cultural desire competencies were not evident in the nurses' practices. This was probably because, during this pandemic, nurses had to directly care for patients only as necessary and for a short period, wearing masks and personal protective equipment. Therefore, the opportunity for nurses to engage in an open mind, actively listen to, and understand cultural backgrounds, health beliefs, values, and lifestyles could not be deeply explored. Cultural desire motivates nurses to "want to" engage in becoming culturally aware, culturally knowledgeable, culturally skillful, and seeking cultural encounters rather than feeling "obligated to do." Thus, nurses who possess cultural encounters and cultural desire competencies must have a starting point for cultural competence development and progress from cultural awareness to cultural knowledge and skills through the personal effort to actively encounter cultural challenges when interacting with patients (Campinha-Bacote, 2019; Slobodin, 2020; Songwathana et al., 2021; Narayan, 2022).

Cultural competence is a process that must continually evolve in order to care for patients' diverse cultures. Therefore, it should be developed for nursing students and continuously promoted after graduation. Students' cultural awareness can be developed in the first year by evaluating their own and their family's culture to understand beliefs, lifestyles, values, customs, and cultures. (Nur'ainun et al., 2019; Gragdellini 2021). Direct patient care experience enables nurses to develop cross-cultural communication skills to understand clients' needs, learn to satisfy the needs of other cultures, and ultimately provide holistic care. As a result, teaching and learning activities must provide an experience for students to learn by doing. The ability to collect data, communicate across cultures, and practice nursing with compassion and respect for individuality will be a talent that students can acquire (Arayathanitkul et al., 2017; Gragdellini 2021; Tosun, 2021). Additionally, culturally different field experiences should be organized in hospitals and communities, which will help students develop cultural assessment skills and learn more about the attitudes of individuals and groups (Prosen, 2015; Dotevall et al., 2018; Ho et al., 2022).

There are data limitations to this study because it was conducted in a field hospital in central Thailand that exclusively cared for migrant worker patients. Future studies may need to promote the vital role of nurses in addressing health inequities and ensuring that migrant workers have access to necessary healthcare services. However, the results of this study provide important nursing approaches for nurses who serve as frontline health care providers. In addition, healthcare policymakers can use the results to plan the management of new emerging infectious diseases in the post COVID-19 era.

Conclusion

Nurses' experience working at the Wattana Factory Field Hospital in Thailand during the initial COVID-19 outbreak highlighted the crucial role of nurses in managing various situations within the hospital. Nurses managed personnel and patient care resources, coordinated with other healthcare professionals, and provided direct patient care. Additionally, nurses emphasized the importance of transcultural care for migrant workers from diverse cultural backgrounds. They applied the nursing process and gathered patient information during the pandemic, even though some aspects of nursing care, particularly mental and cultural care, were challenging to implement. Nurses still put efforts into demonstrating cultural competence to emphasize the importance of incorporating transcultural nursing approaches in providing optimal care to diverse patients.

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Conflict of Interest

There is no conflict of interest.

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ORIGINAL ARTICLE

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Changes in paternal perinatal depression and its predictors from third trimester of pregnancy to one-year post-partum: a longitudinal study

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ABSTRACT

Introduction: Paternal depression is not as widely recognized as maternal depression. Studies in Japan have examined the factors associated with paternal depression, but these have been limited to specific regions rather than conducted on a nationwide scale. This study aimed to examine changes in paternal perinatal depression from the last trimester of pregnancy to one year postpartum. Additionally, we explored the relationship between paternal perinatal depression and fathers' feelings toward their infants.

Methods: This study used a longitudinal design. We initially planned to collect data from over 384 cases based on sample size calculations, and successfully collected data from 494 men in the first survey. However, more than half of the participants dropped out in the second and subsequent surveys, resulting in 201 men completing the longitudinal survey over a one-year period.

Results: The mean Edinburgh Postnatal Depression Scale, Japanese version (EPDS-J) score in the last trimester of pregnancy was 9.274 (95% confidence interval [CI] 8.413-10.134), which was the highest throughout the study period. The mean EPDS-J score was lowest at 3-5 months postpartum, with a score of 7.682 (95% CI 6.816-8.547). At all time points, occupational stress and partner relationships were associated with EPDS-J scores.

Conclusions: Reducing paternal perinatal depression requires controlling for occupational stress and maintaining good marital relationships. The findings suggest that addressing work-life balance is crucial for Japanese fathers to enhance their whole-family well-being.

Keywords: fathers, marital relationship, occupational stress, perinatal depression

Introduction

Japanese society is now transitioning from a traditional division of roles, with fathers supporting the family economically and mothers doing housework and raising children, to fathers becoming more involved in parenting. Japan has amended the "Act on Childcare Leave, Caregiver Leave, and Other Measures for the Welfare of Workers Caring for Children or Other Family Members" and launched the *Ikumen Project* to eliminate traditional gender role divisions to promote the idea of parents sharing childcare responsibilities (Japan Ministry of Health, Labour and Welfare, 2020; Tatsumi, 2022). These efforts have been underpinned by the idea that increasing fathers' role in parenting could reduce the childcare burden borne by mothers, improve mothers' mental well-being, and create the best possible childcare environment. However, while the active involvement of fathers in parenting has helped stabilize mothers' mental health (Ikeda & Saeki, 2018), it is now being addressed that fathers, in a supportive position, also suffer from depression (Nishimura et al., 2015; Nishimura & Ohashi, 2010; Suto et al., 2016;

Takehara et al., 2017, 2020). However, screening and intervention for paternal depression have been insufficient (Kido et al., 2022), although screening and intervention for maternal depression have been conducted by municipalities and medical facilities since the 2000s (Suzumiya et al., 2008).

It is common for fathers to be involved proactively in childcare. However, similar to working women, working men have a greater childcare burden, which negatively affects their health (Glasser & Lerner-Geva, 2019). In particular, in the period between their partner's pregnancy and the year after birth, men struggle to reconcile their personal and work needs with the demands of their new families (Genesoni & Tallandini, 2009). Consequently, fathers might experience depression during the perinatal period. This depression in fathers is referred to as paternal depression. Chen et al (2023) conducted a conceptual analysis of paternal perinatal depression and defined it as depression in fathers whose partner is pregnant or in the first year postpartum, lasting at least two weeks and including 'masked' symptoms such as emotional symptoms, physical symptoms, negative parenting behavior, risk-taking behavior, substance abuse, irritability and emotional rigidity.

Currently, men face a struggle to balance work and raise children in Japan. This can cause stress, hamper mental health, and increase the risk of depression among fathers. Several studies have examined the effects of paternal perinatal depression on children's subsequent development and mental health (Fletcher et al., 2011; Ip et al., 2018; Pietikäinen et al., 2020; Tichovolsky et al., 2018). Although the prevalence of paternal perinatal depression is lower than maternal depression rates, a focus on fathers' mental health during the perinatal period is crucial not only for their spouses and children, but also because of the negative impact on the fathers themselves (Chen et al., 2023). For example, the effect of paternal depression on fathers themselves includes loss of working and short-term memory (Pio de Almeida et al., 2012) and an impact on their ability to perform tasks at their place of work (Melrose, 2010).

Perinatal paternal depression is the tendency of fathers to show depressive symptoms during their partner's pregnancy and postpartum period, with a reported worldwide prevalence of 8.4 % (95% confidence interval, 7.2–9.6 %)(Cameron et al., 2016). In Japan, the prevalence of prenatal depression in fathers is 8.5%;the prevalence of postpartum depression in fathers is 9.7% in the first month after delivery, 8.6% in the first-3 months after delivery, 13.2% in the 3-6 months after delivery, and 8.2% in the 6-12 months after delivery (Tokumitsu et al., 2020). This meta-analysis analyzed articles published from 2006-2017, with no reports from the last five years; the included longitudinal studies are from a limited region and there are no recent reports from the last five years. The symptoms of depression specific to men include alcohol and drug misuse, risk-taking, and decreased impulse control (Hyde & Mezulis, 2020). There are no reported symptoms of perinatal paternal depression specific to male depression (Kido et al., 2022). The Gotland Male Depression Scale was developed; however, its ability to detect perinatal depression is questionable (Carlberg et al., 2018).Therefore, the EPDS is often used to examine fathers' risk of perinatal depression (Shafian et al., 2022).

Perinatal paternal depression is related to perinatal paternal depression and includes a history of psychiatric illnesses (Matthey et al., 2003; Skari, 2002; Zelkowitz & Milet, 2001). Furthermore, relationships with partners have been identified as an important risk factor for perinatal paternal depression(Chhabra et al., 2020; Gawlik et al., 2014). In addition, we hypothesized that work stress might be related to perinatal paternal depression in Japanese fathers because of their history of a strong belief in the role of men in working hard after having a child and supporting the family financially. However, there are no studies that have found an association with work stress as a factor related to perinatal paternal depression. In summary, the results of previous studies indicate that perinatal paternal depression is an important adverse occurrence that negatively affects fathers, as well as their children and mothers. However, updated data are needed to determine at what point and how support should be provided to fathers.

This study aimed to examine changes in paternal perinatal depression from the last trimester of pregnancy to one year after childbirth. To do this, we monitored paternal perinatal depression from before childbirth (the final trimester of pregnancy or gestational age of 32–40 weeks) to one year after childbirth. The goal was to determine when mental health declines, and whether work stress and relationships with partners affect mental health.

Materials and Methods

Study design

This longitudinal study with a predictive design aimed to examine changes in paternal perinatal depression from the last trimester of pregnancy to one year postpartum and to identify its predictors from the last trimester of pregnancy to one year postpartum. In the present study, paternal perinatal depression was repeatedly examined five times, starting in the last trimester of pregnancy and continuing for one year postpartum.

Operational definition

Paternal perinatal depression was defined as depression in fathers when their partner is pregnant or in the first year postpartum, lasting at least two weeks and including 'masked' symptoms such as emotional symptoms, physical symptoms, negative parenting behavior, risk-taking behavior, substance abuse, irritability and emotional rigidity (Chen et al., 2023).

This study was initiated before this definition was presented. In this study, we did not strictly follow the definition proposed by Chen et al. (2023). In this study, paternal perinatal depression was defined as a state of deteriorating mental health in the father from his partner's pregnancy to one year postpartum. No specific scale has been dedicated to measuring paternal perinatal depression. Therefore, the Edinburgh Postnatal Depression Scale (EPDS), a scale measuring maternal postpartum depression, was used in the present study to measure paternal perinatal depression. The EPDS was developed to screen for maternal depression, but it is also a reliable measure for detecting paternal depression (Rigmor Cet al., 2022). Furthermore, referring to previous studies (Nishigori et al., 2020; Nishimura et al., 2015; Nishimura & Ohashi, 2010), the present study hypothesized that paternal perinatal depression is also associated with work stress and relationships with partners.

Participants and data collection

Data were collected by conducting a nationwide web-based survey via Macromill, a marketing research company with monitors across Japan. The target population comprised men whose partners were pregnant and registered as macromill monitors. Participants were informed that participation was voluntary, that the survey would be anonymous, and that it would take approximately 15 minutes to complete the survey. They were asked to complete a web-based survey if they agreed to its purpose. Furthermore, they explained that by answering the questionnaire, they would receive points that could be used for online shopping. Foreigners residing in Japan were excluded because they might not have been able to fully understand the questions owing to their language ability. As this was a longitudinal study, the survey was conducted five times: at the gestational age of 32–40 weeks, 0–2 months after birth, 3–5 months after birth, 6–9 months after birth, and 10–13 months after birth. These surveys were conducted between June 2019 and August 2020.

Sample size

In 2019, there were 864,000 births in Japan in 2019 (Japan Ministry of Health, Labour and Welfare,2019). Based on these births, to have an accuracy of 5% and a confidence rate of 95% for the number of births per year, it was necessary to have at least 384 cases for each study period (five times: at a gestational age of 32–40 weeks, 0–2 months after birth, 3–5 months after birth, 6–9 months after birth, and 10–13 months after birth). However, the number of dropouts increased after the third survey, resulting in fewer than 384 dropouts.

Measurement of perinatal depression

There is no appropriate tool for assessing depression in men with a perinatal partner. The Japanese version of the Edinburgh Postnatal Depression Scale (EPDS-J) is used to assess maternal depression during the postpartum period (Kubota et al., 2014) and pregnancy period (Usuda et al., 2017); and has also been administered to fathers (Nishimura et al., 2015; Suto et al., 2016; Takehara et al., 2017). Therefore, we used the EPDS-J to assess paternal perinatal depression in this study. The EPDS-J consists of 10 items, each rated on a 4-point Likert scale ranging from 0 to 3. The maximum score on the scale was 30. The cut-off score for fathers varied among the studies. Three studies suggested a cutoff score of 13 points (Ballard et al., 1994; Lane et al., 1997; Pio de Almeida et al., 2012), two suggested eight points (Nishigori et al., 2020; Nishimura et al.2015), while one study each suggested 10 (Da Costa et al., 2019),11 (Dudley et al., 2001), and 12 points (Clavenna et al., 2017). The cut-off values for using the EPDS for fathers have not been determined, and researchers have used different cut-off values. We decided to calculate prevalence rates using cutoff scores from 8 to 13, which have been reported so far.

Factors related to paternal perinatal depression

The sociodemographic characteristics and other factors related to postpartum depression among fathers identified in previous studies were as follows: whether it was the first child, whether it was an unexpected

Tabel 1 Basic attributes of the fathers (during pregnancy of their partners through one year after birth)

	Pre birth	After birth (months)				longitudinal
	The final trimester	0-2	3-5	6-9	10-13	study case
parameter	N=494	N=385	N=352	N=300	N=224	N=201
Area						
Hokkaidō	21(4.3)	15(3.7)	15(4.3)	11(3.7)	7(3.1)	6(3.0)
Tōhoku	19(3.8)	16(3.9)	12(3.4)	12(4.0)	8(3.6)	4(2.0)
Kantō	179(36.2)	152(37.1)	131(37.2)	115(38.3)	84(37.5)	79(39.3)
Chūbu	91(18.4)	74(18.0)	65(18.5)	59(19.7)	45(20.1)	44(21.9)
Kinki	91(18.4)	75(18.3)	65(18.5)	53(17.7)	40(17.9)	34(16.9)
Chūgoku	24(4.9)	17(4.1)	12(3.4)	10(3.3)	10(4.5)	9(4.5)
Shikoku	17(3.4)	12(2.9)	10(2.8)	8(2.7)	5(2.2)	3(1.5)
Kyūshū	52(10.5)	49(12.0)	42(11.9)	32(10.7)	25(11.2)	22(10.9)
Age of father						
20 to 24 years	8(1.6)	3(0.8)	3(0.9)	2(0.7)	2(0.9)	1(0.5)
25 to 29	83(16.8)	58(15.1)	44(12.5)	34(11.3)	24(10.7)	31(15.4)
30 to 34	128(25.9)	98(25.5)	85(24.1)	75(25.0)	50(22.3)	55(27.4)
35 to 39	122(24.7)	98(25.5)	85(24.1)	68(22.7)	53(23.7)	49(24.4)
40 to 44	90(18.2)	83(21.6)	87(24.7)	79(26.3)	60(26.8)	42(20.9)
45 to 49	63(12.8)	43(11.2)	41(11.6)	34(11.3)	29(12.9)	23(11.4)
50 to 54	0(0.0)	2(0.5)	7(2.0)	8(2.7)	6(2.7)	0(0.0)
Family structure	428(86.6)	332(86.2)	287(81.5)	238(79.3)	190(84.8)	173(86.1)
Nuclear families(lives with his wife and child(ren))	57(11.5)	47(12.2)	36(10.2)	36(12.0)	25(11.2)	24(11.9)
Extended families(with his/her parents and others)	9(1.8)	4(1.0)	6(1.7)	7(2.3)	9(4.0)	3(1.5)
Alone(lives away from his wife and(or) child(ren))	0(0.0)	2(0.5)	23(6.5)	19(6.3)	0(0.0)	1(0.5)
No answer	428(86.6)	332(86.2)	287(81.5)	238(79.3)	190(84.8)	173(86.1)
Income						
<2,000,000yen	6(1.2)	5(1.3)	4(1.1)	3(1.0)	3(1.3)	1(0.5)
2,000,000<4,000,000	57(11.5)	49(12.7)	44(12.5)	38(12.7)	34(15.2)	22(10.9)
4,000,000<6,000,000	110(22.3)	105(27.3)	77(21.9)	74(24.7)	58(25.9)	37(18.4)
6000000<8000000	94(19.0)	89(23.1)	71(20.2)	66(22.0)	47(21.0)	35(17.4)
8000000-10000000	47(9.5)	46(11.9)	33(9.4)	30(10.0)	26(11.6)	22(10.9)
>10000000	57(11.5)	65(16.9)	54(15.3)	49(16.3)	40(17.9)	22(10.9)
No answer	123(25.0)	26(6.8)	69(19.6)	40(13.3)	16(7.1)	62(30.8)
Birth experience /Number of children						
First time baby	236(47.8)	181(47.0)	166(47.2)	145(48.3)	113(50.4)	101(50.2)
Second and more	258(52.2)	204(53.0)	186(52.8)	155(51.7)	111(49.6)	100(49.8)
Marriage						
Yes	481(97.4)	374(97.1)	322(91.5)	271(90.3)	212(94.6)	199(99.0)
No	13(2.6)	11(2.9)	7(2.0)	11(3.7)	12(5.3)	2(1.0)
No answer	0(0.0)	0(0.0)	23(6.5)	18(6.0)	0(0.0)	0(0.0)
Live together with partner(and child)						
Yes	451(91.3)	369(95.8)	320(90.9)	271(90.3)	211(94.2)	184(91.5)
No	43(8.7)	16(4.2)	9(2.6)	11(3.7)	13(5.8)	17(8.5)
No answer	0(0.0)	0(0.0)	23(6.5)	18(6.0)	0(0.0)	0(0.0)
Unexpected pregnancy						
No	396(80.2)	308(80.0)	279(79.3)	235(78.3)	214(95.5)	157(78.1)
Yes	98(19.8)	77(20.0)	73(20.7)	65(21.7)	10(4.5)	44(21.9)
Children health						
Good	447(90.5)	369(90.0)	315(89.5)	265(88.3)	214(95.5)	176(87.6)
Poor	47(9.5)	16(3.9)	14(4.0)	17(5.7)	10(4.5)	25(12.4)
No answer	0(0.0)	0(0.0)	23(6.5)	18(6.0)	0(0.0)	0(0.0)
Family bereavement						
No	362(73.3)	291(75.6)	252(71.6)	219(73.0)	173(77.2)	141(70.1)
Yes	132(26.7)	94(24.4)	77(21.9)	63(21.0)	51(22.8)	60(29.9)
No answer	0(0.0)	0(0.0)	23(6.5)	18(6.0)	0(0.0)	0(0.0)
History of mental health problems(himself)						
No	427(86.4)	340(88.3)	291(82.7)	248(82.7)	202(90.2)	176(87.6)
Yes	67(13.6)	45(11.7)	38(10.8)	34(11.3)	22(9.8)	25(12.4)
No answer	0(0.0)	0(0.0)	23(6.5)	18(6.0)	0(0.0)	0(0.0)
History of mental helath problems(partner)						
No	444(89.9)	350(90.9)	300(85.2)	252(84.0)	206(92.0)	185(92.0)
Yes	50(10.1)	35(9.1)	29(8.2)	30(10.0)	18(8.0)	16(8.0)
No answer	0(0.0)	0(0.0)	23(6.5)	18(6.0)	0(0.0)	0(0.0)
Anxiety about economic status(subjective)						
No	188(38.1)	256(66.5)	206(58.5)	185(61.7)	79(35.3)	75(37.3)
Yes	306(61.9)	129(33.5)	123(34.9)	97(32.3)	145(64.7)	126(62.7)
No answer	0(0.0)	0(0.0)	23(6.5)	18(6.0)	0(0.0)	0(0.0)

Note. *32-40 weeks of pregnancy

Note. **A total of 201 cases could be followed through the final trimester of pregnancy until one year postpartum.

pregnancy, whether one lived with their partner, whether one had experienced the death of a family member, whether one was anxious about one's economic condition, the mental health history of the father, the mental health history of the partner, the family as a life event (e.g., death in the family member), and the health status of the child (Nishigori et al., 2020;

Tabel 2 Changes in the prevalence of paternal perinatal depression during pregnancy through one year after birth-percentage by the EPDS-J cut-off level-

N=201*		EPDS≥8	EPDS≥9	EPDS≥10	EPDS≥11	EPDS≥12	EPDS≥13
*longitudinal study case		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
The final trimester (32-40 weeks of pregnancy)		108(53.7)	99(49.3)	91(45.3)	87(43.3)	77(38.3)	67(33.3)
	0-2	97(48.3)	87(43.3)	79(39.3)	70(34.8)	63(31.3)	54(26.9)
	3-5	60(29.9)	52(25.9)	81(40.3)	70(34.8)	59(29.4)	54(26.9)
After birth (months)	6-9	54(26.9)	52(25.9)	78(38.8)	71(35.3)	58(28.9)	65(32.3)
	10-13	45(22.4)	43(21.4)	79(39.3)	75(37.3)	66(32.8)	59(29.4)

Nishimura et al., 2015; Kido et al., 2020). All these items were used in this study.

The survey items for marital relationships (6 items) and work stress (11 items), which have been reported to be related to men's mental health, were based on the Survey on the Current Status of Working Styles and Attitudes (Japan Ministry of Health, Labour and Welfare, 2015). The survey can be used for research purposes without permission. The items for work stress were about "heavy responsibility" "having no one talking with me at workplace" "working long hours" "not fit for the job" "difficulty responding to informatization and technological innovation" "anxiety of the company's future" "anxiety of being fired/going bankrupt" "too many expectations on work performance" "heavy workload" "Uncomfortable working environment" "distressing relationships at work place." The items were rated on a 4-point Likert scale, with 3 denoting "strongly," 2 = "slightly," 1 = "not so much, " and 0 = "not at all." The total score ranged from 0 to 30, with higher scores indicating higher stress at work.

The items for marital relationship were about "my wife (partner) can count on me," "my wife (partner) understands me," "I have enough time for my wife (partner)," "I often talk to my wife," "my wife (partner) respects my hobbies and behavior," and "I try to be good at housework and parenting." The items were rated on a 4-point Likert scale, with 3 denoting "strongly agree," 2 denoting "slightly agree," 1 denoting "slightly disagree," and 0 denoting "strongly disagree." The total score ranges from 0 to 24, with higher scores indicating better marital relationships.

The items for work stress and satisfaction were about "having heavy responsibilities," "having no one to talk to at the workplace," "working long hours," "not being fit for the job," "having difficulty adapting to informatization and technological innovations," "being anxious about the company's future," "being anxious about getting fired or going bankrupt," "experiencing extreme stress regarding work performance," "having a heavy workload," "having an uncomfortable working environment," and "having distressing relationships at the workplace." All items were rated on a 4-point Likert scale ranging from "completely disagree" to "completely agree."

Data analysis

The 201 cases used for analysis in the longitudinal study had complete data, excluding missing data. First, we calculated descriptive statistics. We then performed repeated one-way analysis of variance to investigate changes in the EPDS-J scores from the last trimester of pregnancy to one year after childbirth. Multiple comparisons were performed when the changes were statistically significant. Next, we calculated the prevalence of paternal perinatal depression using different cutoff scores of the EPDS-J. Finally, we performed general linear and multiple regression analyses to determine the factors predicting paternal perinatal depression. All statistical analyses were performed using IBM SPSS Statistics version 28.0. Statistical significance was set at $p < 0.05$.

Ethical considerations

The rationale, aims, and methods of the study were explained to all the participants through the Macromill webpage. Participants were also informed that there would be no negative consequences if they refused to

Tabel 3 Multiple regression analysis of paternal perinatal depression (EPDS-J) and the sociodemographics of participants - 201 cases followed during the final trimester of pregnancy through one year postpartum-

		A	B	C	D	E	F	G	H	I	J
		First time:1 Second or more:0		Yes:1 No:0	Yes:1 No:0	Yes:1 No:0	Poor:1 Good: 0	Yes:1 No:0	Poor:1 Good:0	Poor:1 Good:0	Yes:1 No:0
The final trimester**		-0.244*	-0.047	0.060	-0.283*	0.021	-0.053	0.159*	0.107	-0.003	0.107
After birth	0-2	-0.151*	0.015	0.055	-0.281*	0.033	-0.040	0.121	-0.015	0.112	0.150*
(months)	3-5	-0.070	0.090	0.059	0.071	0.085	0.005	0.002	0.081	-0.014	0.075
	6-9	-0.182*	0.093	0.101	-0.195*	0.044	-0.107	0.193*	-0.024	0.150	0.061
	10-13	-0.174*	-0.028	0.053	-0.257*	0.052	-0.032	0.136	0.035	0.067	0.049

Note. All numbers in the table indicate the standardized partial regression coefficient. B: standardized partial regression coefficient *<0.05;**32-40 weeks of pregnancy; Variables; A: birth experience; B: age; C: marriage; D: living together with partner; E: unexpected pregnancy; F: children's health; G: family bereavement; H: history of mental health problems (himself); I: history of mental health problems (partner); J: anxiety about economic status (subjective).

Tabel 4 Linear regression analysis between Paternal perinatal depression and work stress and marital relationship-201 cases followed during the final trimester of pregnancy through one year postpartum

	N=201	Occupational stress	Marital relationship
		Standardized partial regression coefficient (B)	
The final trimester (32-40 weeks of pregnancy)		0.483*	-0.254*
After birth (months)	0-2	0.435*	-0.332*
	3-5	0.421*	-0.263*
	6-9	0.465*	-0.332*
	10-13	0.429*	-0.295*

Note. Dependent variable: Edinburgh Postnatal Depression Scale (EPDS); independent variable:work stress, marital relationship * p <0.05

participate in the survey. Consent was then obtained, and the survey was administered. The survey was completed anonymously. This study was approved by the ethics committee of Kagawa Prefectural University of Health Sciences (approval number 279, Approval Date: July 8, 2019).

Results

Characteristics of the participants

Table 1 present the characteristics of the participants. The largest number of participants were from the Kanto area, followed by the Chubu and Kinki areas. There were only a few participants from the Shikoku, Tohoku, and Hokkaido areas. Most participants were in their 30s and had a nuclear family. The number of participants having their first child at the time was approximately the same as the number of participants having their second or more babies. Most participants were married and lived with their partners.

Changes in paternal perinatal depression from the final trimester of pregnancy to one year after childbirth

Table 2 presents the results of analyzing changes in the prevalence of perinatal depression in fathers from the last trimester of pregnancy to one year after birth using different cut-off scores on the EPDS-J. Changes in the mean values of paternal perinatal depression (EPDS-J) over a one-year period are shown in Figure 1. The mean scores for the five survey periods differed significantly (F = 6.253, p < 0.001). Bonferroni's multiple comparison test showed significant differences in the mean scores in the last trimester of pregnancy, 0–2 months postpartum, and 3–5 months postpartum. The mean score on the EPDS-J was 9.274 (95% CI = 8.413–10.134) during the final trimester of pregnancy. The mean score was the highest among all survey periods. The lowest mean score was 7.682 (95% CI] = 6.816–8.547) at 3–5 months postpartum. After this, The mean score was 8.284 (95% CI] = 7.355–9.212) at 6–9 months after birth. At 10–13 months postpartum, the mean score increased to 8.373 (95% CI] = 7.473–9.273) and remained unchanged.

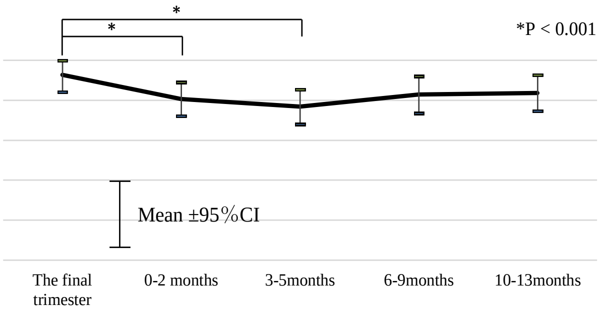

Figure 1. Changes in paternal perinatal depression measured by EPDS-J

Multiple regression analysis of EPDS-J scores and participants' sociodemographic characteristics

Multiple regression analysis was conducted with EPDS-J scores in the five survey periods as dependent variables and participants' sociodemographic characteristics as independent variables. The results are presented in Table 3. Birth experience and whether one lived with their partner were significantly associated with EPDS-J scores at all time points, except for the score at 3–5 months postpartum. Family bereavement was significantly associated with EPDS-J scores in the last trimester of pregnancy and 6–9 months postpartum. Anxiety regarding economic status was significantly associated with the EPDS-J score at 0–2 months after birth.

Linear regression analyses of EPDS-J scores, work stress, marital relationship

We conducted a linear regression analysis with EPDS-J scores as dependent variables, and all items of work stress were independent variables. The results showed significant correlations in all survey periods (Table 4). Then, a linear regression analysis was performed with EPDS-J scores as the dependent variable and all items measuring marital relationships as the independent variable. A significant correlation was found for all survey periods (Table 4).

Discussions

Changes in paternal perinatal depression scores among fathers from the last trimester of pregnancy to one year postpartum

The EPDS-J scores of fathers in Japan were highest in the last trimester of pregnancy and lowest at 3–5 months postpartum. According to a meta-analysis conducted by Paulson and Bazemore (2010), the prevalence of depression among fathers was 11% in the first and second trimesters of pregnancy, 12% in the third trimester, 7.7% in the first three months after childbirth, 25.6% (and the highest) in the first three–six months postpartum, 9% in the first six–twelve months postpartum, and 10.4% from gestation to one year postpartum. Our results were quite different from those of Paulson and Bazemore (2010), but their meta-analysis was more than a decade old and was possibly affected by different social conditions today. Moreover, it examined paternal depression in Western countries but did not include Japanese cases. Suto et al. (2016) conducted a survey in Japan and found that 17% of fathers exhibited depressive symptoms at three months postpartum, but our results showed a higher prevalence of depression. The reason for this discrepancy could be that we conducted an online nationwide survey and the participants may have made exaggerated declarations. Nonetheless, it is important to identify other reasons for the highest prevalence of paternal depression in the third trimester of pregnancy. In this study, fathers were most depressed in the last trimester of pregnancy and the first year after childbirth. The characteristics associated with EPDS-J scores in the last trimester of pregnancy were whether it was the first child, whether the father lived with their partner, and whether the father had experienced the death of a family member. Work stress and relationship with the partner were also related to the EPDS-J scores. Although the number of children did not increase physically because of gestational stage, fathers may have experienced an emotional burden. Overlapping emotional burdens such as work stress and family misfortune can exacerbate mental health problems. Furthermore, the findings of the present study show that fathers' mental health changed during their partner's last trimester of pregnancy and in the first year postpartum. Mental health levels were the lowest in the last trimester of pregnancy and recovered thereafter. However, they did not recover dramatically and remained stable. Paternal mental health status possibly suffered the most in the last trimester of pregnancy due to expectations anxiety about the increased burden of raising a child. Although the situation has somewhat recovered, the level of the situation has remained unchanged. This may be partly related to the constant exposure to work stress that fathers continue to experience throughout their child-rearing phase. However, there is no conclusive data to support these findings, and further studies are required.

Factors influencing fathers' scores on the Paternal perinatal depression

A large Italian study reported that an EPDS-J cutoff score of 12 or higher increases the risk of maternal perinatal depression to 6.4% during pregnancy and 19.9% postpartum (Cena et al., 2021). Economic status was also found to be associated with depression during pregnancy and the postpartum period (Cena et al., 2021). The incidence of depression in mothers is higher during the postpartum period than during the gestational period. This result differs from our findings, which show that the incidence of depression in fathers is higher during the gestational period and lower during the postpartum period. Fathers' mental health during the parenting period may be affected by work stress and their relationship with their partner, which may differ from the background of mothers' depression. In this study, work stress was identified as a risk factor for depression among fathers. Similarly observed for mothers, a German study showed that precarious working conditions and psychosocial work stress increase the risk of perinatal depression (Karl et al., 2020). We also found that marital relationships were associated with depression in fathers. When couples have poor relationships, they are unable to work collaboratively to raise their children (Schoppe-Sullivan et al., 2007; Van Egeren, 2004). This may cause stress and negatively impact mental health, although there is insufficient evidence. Regarding marital relationships, studies have shown an association between marital satisfaction and depression among fathers during childrearing (Wang et al., 2021). Similar results have been obtained in a previous study. Japanese society is currently experiencing a very low fertility rate, and it may be argued that having a good marital relationship not only maintains good mental health for both spouses, but also influences their hopes for the next pregnancy and childbirth. Mothers who have reported greater involvement and indirect care from their child's father have been found to be more likely to have another child from the same father and less likely to have another child from a different father. In other words, if the father is heavily involved in childcare, their partner is likely to be willing to have another child with them (Kotila & Kamp Dush, 2012). In contrast, if the father is not involved in childcare, their partner is likely to choose not to have another child with them. Therefore, it is necessary to emphasize the maintenance of a good marital relationship, not only to improve mental health but also to combat declining birth rates.

Paternal perinatal depression and the risk of maltreatment

Our results revealed that father–infant bonding can be predicted using the EPDS-J. Paternal perinatal depression of fathers has been shown to be directly related to father–infant bonding (Wells & Jeon, 2023). Symptoms of postpartum blues in fathers are associated with impaired father–infant bonding (Baldy et al., 2023). Parent–child bonding promotes cognitive neurodevelopment in children (Winston & Chicot, 2016). Improving the mental health of fathers during the child-rearing period is extremely critical, as the formation of the father–child bond influences the child's development. The questionnaire we used to assess the father–child bond is a simple 10-item scale that Japanese healthcare institutions use to assess the risk of abuse. Thus, it can be inferred that fathers' mental health can predict the risk of abuse. Although the focus tends to be on the mother–child bond, it is necessary to examine the mental health of fathers to form a good father–child bond (Nakić Radoš, 2021).

The study design was longitudinal, and the changes in paternal perinatal depression and relevant factors were examined. However, this study has several limitations. First, the number of dropouts increased after the third study, and the number of cases was less than 384. Only 201 patients were included in the longitudinal study. It is difficult to obtain a sufficient sample size in longitudinal studies. Owing to the insufficient sample size required for this study, it is possible that it was difficult to obtain significant differences as an effect on the results, and we cannot generalize our results. Second, we did not examine the mothers' mental status; thus, we could not determine the impact of their partners. The next survey should be conducted with the fathers and mothers. Third, diagnostic interviews were not used to assess depression. The possibility of perinatal depression in fathers should be rigorously assessed. Nonetheless, there are no recent studies in Japan examining changes in fathers' mental health status during the one-year prenatal and postpartum periods, and the present study provides important data for supporting fathers during the perinatal period.

Conclusion

Measuring paternal perinatal depression, the mean score on the EPDS-J was the highest during the final trimester of pregnancy and the lowest at 3–5 months postpartum. Subsequently, it increased slightly in the first 6–9 months postpartum and remained unchanged at 10–13 months. Whether one lived with their partner and whether it was the first child was associated with EPDS-J scores in all survey periods, except for the scores at 3–5 months postpartum. Anxiety about economic status was associated with EPDS-J scores at 0–2 months after birth. Whether one had experienced The death of a family member was associated with EPDS-J scores in the last trimester of pregnancy and at 6–9 months after birth. Work stress and relationship with the partner were associated with EPDS-J scores in all survey periods. These results suggest that reducing paternal depression requires controlling for work stress and maintaining a good marital relationship. Screening mothers for maternal perinatal depression should include questions about the fathers' mental health status. Additionally, this study suggests that to reduce paternal perinatal depression, healthcare providers need to identify specific factors associated with paternal perinatal depression at each time point between the last trimester of the partner's pregnancy and the first year postpartum and provide individualized interventions for fathers.

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Author contribution statement

KK conceived the study and performed the statistical analysis. AM and YU supervised the study design and performed the statistical analyses. KK, AM, and YU contributed to writing the manuscript, and all authors read and approved the submitted version of the manuscript.

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Conflicts of Interest

We have no conflicts of interest to declare.

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ORIGINAL ARTICLE

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Determinants of parents’ readiness for face-to-face learning among elementary school children during the new normal

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ABSTRACT

Introduction: The education field has undergone major changes as a result of the COVID-19 outbreak. Schools have had to quickly modify the way they teach, moving away from traditional face-to-face learning and toward a variety of models, such as fully online and hybrid courses. As things change, many schools are now thinking about going back to face-to-face learning. However, there are difficulties with this shift, particularly for parents of elementary school-aged children. This study aimed to determine the factors related to the readiness of parents who have elementary school-age children in regard to face-to-face learning using the Health Promotion Model (HPM) theoretical approach.

Methods: This was a cross-sectional study. The study population consisted of parents of elementary school students in Surabaya. A purposive sampling method was used to select 395 respondents. The independent variables included motivation, parental knowledge, perceived benefits, perceptions of barriers, self-efficacy, interpersonal factors, situational factors, and commitment, while the dependent variable was parental behavior in face-to-face learning readiness. Data were collected using a validated and reliable questionnaire. Data analysis was conducted using a logistic regression test, with a significance level of $\alpha \leq 0.05$.

Results: Most parents were 37 years old, and children in the 5th grade of elementary school. Most of the parents' motivation was in the sufficient category (57%). The parents’ knowledge of COVID-19 was good (66.8%). Most parents had a good perception of benefits (68.4%), and the perception of barriers was sufficient (59.7%). Good self-efficacy was observed in only 49% of cases, and interpersonal and situational factors accounted for 99.7% and 100%, respectively. Meanwhile, regarding parental readiness for face-to-face learning, the majority exhibited good behavior (96.2%). The factors that influenced parental behavior in face-to-face learning readiness were parental knowledge (0.010), perceived benefits (0.019), and commitment (0.029).

Conclusions: Good knowledge, perceived benefits, and parental commitment are factors that influence parents' readiness to participate in face-to-face learning. To ensure children's safe return to school, parents must stay up-to-date on safety measures and learning options, and each parent must be prepared to adapt to changes if necessary, while also encouraging vaccination to protect against COVID-19

Keywords: COVID-19, face-to-face learning, good health and well-being, Health promotion model (HPM), parents

Introduction

The coronavirus disease 2019 (COVID-19) pandemic has impacted all sectors worldwide, including education (Sharma & Alvi, 2021). The pandemic prompted a sudden shift in the teaching and learning model in schools from offline to fully online, then to hybrid, and eventually back to offline learning as the situation improved. This transition from online to offline learning necessitates parents' readiness to ensure their children can return to school safely and comfortably (Sholikhah, 2021). Previous studies have demonstrated that prolonged online learning negatively affects children's mental health, social welfare, academic performance, and exacerbates educational disparities (Hoffman, & Miller, 2020; Masonbrink & Hurley, 2020; UNICEF, 2020). Face-to-face learning during a pandemic is not easy and requires adaptation from educators, students, parents, and adequate facilities to support the learning process. The key is implementing new habits by applying methods and strict health protocols, leading to the improvement of life (Prabawati, 2020). Parental readiness has become more challenging over the past year due to the COVID-19 outbreak, which has restricted many offline activities initially designed to promote school readiness (e.g., site visits). To the best of our knowledge, few studies have examined children's school readiness and parents' involvement in preparing their children for school during the COVID-19 pandemic. A timely understanding of this topic is essential for explaining how to support children's school readiness during this unique time (Lau and Li, 2021).

Based on the Health Promotion Model (HPM) theory, independent variables can be categorized into individual characteristics, perceived benefits and barriers (e.g., perceived benefits of face-to-face learning, perceived barriers such as concerns about COVID-19), and self-efficacy (e.g., confidence in the ability to ensure their child's safety during face-to-face learning) (Ostrognaj *et al.*, 2023). This research is suitable for the HPM theory because it focuses on understanding and predicting health-related behaviors, which aligns with the decision-making process of parents regarding their children's education, particularly in the context of face-to-face learning during the transition to the new normal. Based on the HPM theory, researchers can develop hypotheses about how these factors interact and influence parental readiness for face-to-face learning. For example, higher levels of parental knowledge and perceived benefits may lead to greater readiness for face-to-face learning, while perceived barriers and low self-efficacy may decrease readiness (Haller and Novita, 2021).

Parents have the primary responsibility for the education of their children (Wulan Sari, 2018). Parental readiness is closely related to parental participation, which improves the quality of educational programs (Sholikhah, 2021). In other words, the readiness of parents encompasses both material and nonmaterial aspects. The readiness of parents to send their children to face-to-face learning is an important factor to consider when promoting such learning. Parents provided mixed responses to the limited face-to-face learning plan (Xie and Li, 2022). School readiness is also an important issue that challenges children's ability to return to school, especially during the COVID-19 pandemic when coronavirus cases remain volatile (Van Lancker & Parolin, 2020). Although many studies have examined the effects of COVID-19 on children's education, to the best of our knowledge the topic of parental readiness for the transition from online to offline learning in elementary schools has never been studied.

Materials and Methods

Study Design

A correlation analysis was conducted as part of the cross-sectional study design. This study aimed to analyze the factors influencing parents' readiness for face-to-face learning among elementary school children during the pandemic. Purposive sampling was used. The independent variables in this study were motivation, parental knowledge, perceived benefits of face-to-face learning, perceptions of barriers to face-to-face learning implementation, self-efficacy in face-to-face learning implementation, interpersonal factors, situational factors, and commitment. The dependent variable in this study was parental behavior in face-to-face learning readiness

The population in this study consisted of parents of school-age children in the Surabaya area, totaling 227,805 individuals, using the Slovin formula to obtain the sample size. The sample was selected based on the following inclusion criteria: (1) parents of primary school children aged 6–12 years, (2) parents who could complete online questionnaires, and (3) parents who were willing to participate in this study. The researchers distributed online questionnaires for three months, from March to May 2022, and obtained 395 responses

Procedure

The initial action involved conducting an online questionnaire using Google Forms. The Google Form was created by the researcher and used as a data collection tool. The form was designed to be user-friendly and easily understandable for parents whose children are in school. Once created, the Google Form was released. The recruitment process involved disseminating information through the social media platforms of both the researchers and the schools, as

Table 1. Demographic characteristics of respondents (n = 395)

Characteristics	n	%
Parent Age		
36	18	4.56%
37	175	44.30%
38	76	19.24%
39	122	30.88%
40	4	1.02%
Child's Age		
6–7	87	22.02%
8–9	117	29.60%
10–11	161	40.79
12	30	7.56%
Grade		
1	46	11.65%
2	50	12.66%
3	67	16.96%
4	70	17.72%1
5	111	28.10%
6	51	12.91%

well as directly providing information to parents of school-age children across various cities in Surabaya. The questionnaire distribution was facilitated by friends, colleagues, and teachers.

The Google Form included explanations about the research's purpose, benefits, risks, confidentiality principles, and voluntary participation. Parents who agreed after reading the informed consent could provide their consent by clicking the consent button. As a token of appreciation, every respondent who completed the questionnaire received compensation.

Data collected via Google Forms were calculated and updated regularly. The researcher checked for duplicate data using mobile numbers to ensure no duplicates. Any duplicate data were removed from the data tabulation. In Indonesia, every cellular card holder is legally required to register their phone numbers centrally, which helps reduce the use of multiple numbers. The data collection targeted parents of school-aged children in the Surabaya region.

Instrument

The independent variables in this study are factors aligned with the Health Promotion Model (HPM) theory, namely motivation, knowledge, perception of the benefits of face-to-face learning, perception of barriers, self-efficacy, interpersonal factors, situational factors, and commitment. The questionnaire used for these variables refers to The Health Promotion Model Manual (Pender, 1995). The dependent variable in this research is parents' readiness for face-to-face learning, measured using the "Learning Readiness Survey during the COVID-19 Pandemic" instrument developed by the Center for Policy Research, Balitbang, Ministry of Education and Culture, which has been tested for validity and reliability.

Table 2. Data characteristic variable

Variable	n	%
Motivation		
Low	1	.3
Moderate	225	57.0
High	169	42.8
Knowledge		
Low	15	3.8
Moderate	116	29.4
High	264	66.8
Benefit Perception		
Low	0	0
Moderate	125	31.6
High	270	68.4
Perception of Barriers		
Low	69	17.5
Moderate	236	59.7
High	90	22.8
Self-Efficacy		
Low	3	.8
Moderate	195	49.4
High	197	49.9
Interpersonal Factors		
No	1	.3
Yes	394	99.7
Situational Factor		
Yes	395	100.0
Commitment		
Low	4	1.0
High	391	99.0
Face-to-face Learning Readiness Behavior		
Low	15	3.8
High	380	96.2

Responses were recorded on a scale of 1-4 to describe situations ranging from 1 (never), 2 (sometimes), 3 (often), to 4 (always), and were then categorized as high (76-100%), fair (56-75%), and low (≤ 55%). Parental face-to-face learning readiness behavior was categorized into two groups: high (> 65%) and low (< 65%).

Data Analysis

The collected data were analyzed using a logistic regression statistical test with a significance level of α = 0.05. This test was chosen because the dependent variable is binary or categorical. Logistic regression helps

Table 3. Bivariate test relationship between variables

	Motivation	Knowledge	Perception of Benefit	Perception of barriers	Self-Efficacy	Interpersonal Influence	Situational Influence	Commitment	Behavior
Correlation Coefficient	.260**	.087	.454**	.023	.387**	.145**	.277**	.471**	1.000
Sig. (2-tailed)	.000	.008	.000	.645	.000	.004	.000	.000	.
Behavior (N)	395	395	395	395	395	395	395	395	395

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Table 4. Logistic regression statistical test

Variable	B	S.E	Wald	df	Sig.	OR	95% CI	
							Lower	Upper
Knowledge	.047	.018	6.553	1	.010	1.048	1.011	1.086
Benefit Perception	.119	.051	5.526	1	.019	1.127	1.020	1.245
Commitment	.076	.035	4.746	1	.029	1.079	1.008	1.156

explain which factors influence the likelihood of parents' readiness for face-to-face learning during the new normal COVID-19 period. It provides coefficient estimates that can be interpreted as a measure of the relative influence of the independent variables on the dependent variable.

Results

The results showed that most parents were 37 years old, most of the respondents' children were in the 5th grade of elementary school, and many of the children were 11 years old (Table 1).

Based on the study's results, most parents' motivation was in the sufficient category (57%), with only one respondent having low motivation. Parents' knowledge about COVID-19 was good in more than half of the cases (66.8%). Most parents had a good perception of benefits (68.4%), and the perception of barriers was sufficient (59.7%). Good self-efficacy was observed in only 49% of the cases, whereas interpersonal and situational factors accounted for 99.7% and 100%, respectively. Meanwhile, regarding parental readiness for face-to-face learning, the majority exhibited good behavior (96.2%), with only 3.8% not showing good readiness (Table 2).

The results of the bivariate test using Spearman's Rho to determine the relationship between variables revealed that six variables were related to parental readiness for face-to-face learning: knowledge, perceived benefits, self-efficacy, interpersonal factors, situational factors, and commitment (Table 3).

The logistic regression analysis reveals that knowledge, perceived benefits, and commitment are significant predictors of parental readiness for face-to-face learning during the new normal period. Specifically, each unit increase in knowledge increases the odds of parental readiness by approximately 4.8% (OR = 1.048, 95% CI: 1.011-1.086, p = 0.010), each unit increase in perceived benefits increases the odds by approximately 12.7% (OR = 1.127, 95% CI: 1.020-1.245, p = 0.019), and each unit increase in commitment increases the odds by approximately 7.9% (OR = 1.079, 95% CI: 1.008-1.156, p = 0.029). These findings indicate that improving parents' knowledge, enhancing their perception of the benefits of face-to-face learning, and strengthening their commitment are essential for increasing their readiness to support their children's return to school (Table 4).

Discussions

Factors influencing parental behavior in face-to-face learning readiness are parental knowledge, perceived benefits, and commitment. The better the parents' knowledge, the higher the chance of having good readiness behavior compared to less knowledgeable parents. Parents who have a high perception of benefits are 1.020 times more likely to exhibit good face-to-face learning behavior readiness than those with low perceived benefits. Similarly, parents who have high commitment are 1.008 times more likely to show good face-to-face learning readiness behavior than parents with low commitment. Parents with good knowledge also exhibited good face-to-face learning readiness for elementary school children (Hariati, 2023). This knowledge provides the basis for allowing their children to engage in limited face-to-face learning activities, carefully considering the positive and negative impacts. Parents and stakeholders function as the school's COVID-19 task force team (Sholikhah, 2021). Parents with good knowledge understand that COVID-19 can weaken the immune system, making the body more susceptible to secondary infections, which motivates them to prepare well (Rahmawati, Pinastika and Wicaksono, 2022).

The knowledge parents possess includes understanding the transmission methods, symptoms, prevention measures, and severity of COVID-19. They are aware that washing hands with soap or using hand sanitizers, wearing masks correctly, and maintaining overall health through exercise, rest, and nutrition are crucial (Septiani, 2020). This aligns with previous research on COVID-19 prevention, including using masks, hand washing, covering the mouth when coughing or sneezing, maintaining distance, getting enough rest, and eating nutritious food (Menap & Sismulyanto, 2023). Children are not significant sources of SARS-CoV-2 transmission compared to adults (Hariati, 2023; Shintya Oftaviana, Wahyuningrum and Daramatasia, 2023). Previous studies have defined face-to-face learning readiness as involving children's cognition, self-care, psychomotor skills, and preventive actions (Altun, 2018). During the COVID-19 pandemic, elementary school students need to return to offline school settings to acquire competencies that may have been missed during online learning. This requires parental involvement in preparing their children for school and continuing health protocols (Lau and Li, 2021). Parents prefer offline learning as it fosters children's abstract operational thinking, aiding in rational decision-making and better understanding health protocols (Malik, 2020). Online learning lacks the academic atmosphere and social interactions that engage students, leading to poorer outcomes (Dong, 2021). The return to face-to-face learning is beneficial due to the decreased spread of COVID-19 and the need for an unstructured, play-based learning method for young (Stephen, 2017).

Parents with a high perception of benefits are more likely to be ready for face-to-face learning. During the pandemic lockdown, the shift to online learning impacted educational standards, and parents believe that offline learning should resume as COVID-19 cases decrease. Parental perception of the school's quality is a key indicator of satisfaction, reflecting the school's ability to adapt to rapid changes (Andresen *et al.*, 2020). A high perception of benefits regarding offline learning is crucial for preparing children to return to school (Coroiu, 2021). Parental satisfaction with the school's measures against COVID-19 is an important criterion for assessing school performance (Valiente *et al.*, 2021). Research suggests that parental perception of benefit is also influenced by their children's vaccination status (Efendi *et al.*, 2023). This perception is supported by the availability of school infrastructure, such as hand sanitizers, multivitamins, sinks with soap and running water, masks, and a COVID task force (Dong, 2021). A UNICEF-IRC study highlighted the impact of COVID-19 on education and the role of parents in learning and school readiness (Andrew *et al.*, 2020). Parents believe that learning outcomes are more effective in school settings, aligning with previous research on parental satisfaction and school quality (Haller and Novita, 2021).

Parents with high commitment had better readiness for children's limited face-to-face schooling during the pandemic. According to the UNESCO IIEP Learning Portal, parents are the first educators of their children, and the support they provide affects their children's development, learning, and subsequent educational outcomes (Bubb and Jones, 2020). Commitment is the act of binding oneself to do something and can affect one's consistency and motivation to change one's behavior. Parents who have a high commitment to preparing their children to return to school will be followed by good behavior in readiness to return to school, such as providing masks, vitamins, and hand sanitizers (Andresen *et al.*, 2020). A study by Mahuro and Hungi in Uganda found that parental participation in the form of time and resource commitments for their children's education plays a vital role in motivating children to prepare for school so that academic scores can improve again (Dietrich, Patzina and Lerche, 2021). The Program for International Student Assessment and the Organization for Economic Co-operation and Development both state that parental commitment to a child's school readiness is crucial. By showing their children how to prepare, plan, monitor, and be aware of the learning process, highly committed parents can help children avoid contracting or transmitting COVID-19 to others during the learning process (Damiati *et al.*, 2023). In addition, research has shown how children's literacy and skills improve when their parents are involved in school preparation (Garbe *et al.*, 2020). Parental commitment can be related to children's readiness in school during the pandemic by providing support for safe and comfortable learning, as well as facilitating factors such as nutrition, health, and infrastructure such as hand sanitizers, provision of masks, vitamins, and indirect hygiene.

The strength of this study lies in its use of a comprehensive Health Promotion Model theory, a large sample size, a valid questionnaire, and appropriate statistical analysis, which offers valuable insight into the factors influencing parental readiness for face-to-face learning. This research can encourage greater parental involvement in school activities and decision-making processes, as well as foster stronger school-parent partnerships. However, there are several limitations in this research, namely that this research focuses on parents of elementary school students in Surabaya, as such these findings may not be applicable to parents in other locations or with children in different age groups.

Conclusion

Good knowledge, perceived benefits, and commitment from parents influence parents' readiness for face-to-face learning. To ensure children's safe return to school, parents must stay up-to-date on safety measures and each parent must be prepared to adapt to changes if necessary, while also encouraging vaccination to protect against COVID-19. The implications of this study are multi-faceted. First, it underscores the importance of providing parents with accurate information and resources to enhance their knowledge of the benefits and safety measures associated with face-to-face learning. Schools can develop educational programs and communication strategies tailored to address parental concerns and misconceptions, thereby fostering a supportive environment for students' return to school. Additionally, the findings emphasize the need for schools to engage parents as partners in the education process. By involving parents in decision-making and planning, schools can build trust and collaboration, ultimately enhancing the quality of education and student outcomes. We recommend long-term monitoring and evaluation of the transition to face-to-face learning, including continuous assessment of parental attitudes and behaviors. This approach will identify emerging issues and inform future strategies. Additionally, there is a need to supplement quantitative findings with qualitative research to explore the underlying reasons behind parental attitudes and behaviors toward face-to-face learning more thoroughly.

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Conflicts of Interest

We declare that there is no conflict of interest in this study.

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ORIGINAL ARTICLE

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Factors influencing modern contraceptive usage among women aged 15-49 years: a cross-sectional study

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ABSTRACT

Introduction: Modern contraceptives are hormonal or non-hormonal medicines and medical procedures that prevent sexual reproduction. However, millions of reproductive-aged women globally cannot afford modern contraception, leading to unwanted pregnancies and unsafe abortions. This study aimed to examine the factors that influence modern contraceptive use among married women of reproductive age in Kirkuk City, Iraq.

Methods: A cross-sectional study was conducted to gather data from a convenience sample of 500 married women of reproductive age attending family planning units at 10 healthcare facilities, Azadi, Kirkuk Teaching Hospital, and private gynecological and obstetric clinics. Data were collected using a structured questionnaire from October 1st, 2023, to February 1st, 2024. The statistical analysis involved descriptive and inferential techniques.

Results: The prevalence of contraceptive use among participants was 74.6%, with about (21%) reporting condom use and (16.0%) withdrawal usage. However, intrauterine devices were reported in (12.6%). Side effects were significantly ($p<0.001$) associated with contraceptive method choices, with 52% of the users experiencing adverse effects. External pressures to have additional children or become pregnant significantly ($p=0.037$) influenced contraceptive method choices. There were fewer modern contraceptive methods due to unsafety (30.9%), discomfort (23.6%), and side effects, such as headache (18%), weight gain (16%), and irregular bleeding (14%).

Conclusions: Modern contraceptive use is affected by healthcare, safety, side effects, reproductive health, and personal choices. Providing complete knowledge and access to modern contraceptives helps couples make informed reproductive health decisions, empowers women to regulate their fertility, supports their personal and reproductive objectives, and promotes their health and well-being.

Keywords: birth control, childbearing age, Iraq, modern contraceptive, side effects

Introduction

Family planning enhances self-fulfillment, empowerment, and general wellness, thereby decreasing mother and infant mortality rates through the prevention of unintended pregnancies and unsafe abortions (World Health Organization, 2022). Contraceptive use reduces the health risks associated with pregnancy in both women and children. Contraceptive prevalence, as defined by the (WHO), refers to the proportion of married or cohabiting women who use any form or technique of contraception (WHO, 2022). Previous research has shown that if the interval between births is fewer than two years, the rate of mortality in infants would be 45% higher than that in births that are spaced 2-3 years apart and 60% higher compared to births that are spaced four or more years apart (United Nation Population Division, 2019; Kantorová *et al.*, 2020). The WHO provides a wide variety of birth control methods on a global scale. These methods include oral contraceptive pills, implants, patches, intrauterine devices (IUDs), injectables, condoms, male and female sterilization, vaginal rings as modern methods, lactational amenorrhea methods (LAM), withdrawal, rhythm methods, and fertility awareness-based approaches as traditional methods (WHO, 2023).

The global family planning unit or department provides a wide variety of interventions, including preconception counseling, infertility management, and sexually transmitted disease therapy (WHO 2023). The provision of family planning services has demonstrated consistent and continuous growth in many nations worldwide (WHO 2022). Additional advantages of family planning, other than the purpose of spacing or prolonging pregnancy, encompass the reduction of infant mortality, avoidance of HIV/AIDS and acquired immune deficiency syndrome, promotion of individual empowerment and educational progress, prevention of adolescent pregnancies, and control of population growth (Bongaarts and Hardee, 2019). Despite the availability of free or high-cost contraceptives from various healthcare institutions, both public and private, some women may choose not to utilize them because of constraints related to societal norms, cultural factors, financial limits, or inadequate access to healthcare services (Alrawi, 2021).

A study conducted in 2019 in Kirkuk reported that the prevailing contraceptive methods among married women were male condoms (50%), IUDs (28.7%), injections (14.9%), and oral contraceptive tablets (6.4%) (Ahmed et al., 2019). In Iraq, fertility rates remain elevated, and as of 2021, over 58% of married women in their childbearing years have utilized family planning methods (Alrawi, 2021). In Kirkuk City, contraceptive use is limited, as only 51.3% of married women with children make use of any form of contraception. Furthermore, among those who used contraception, only 36.5% chose modern techniques. Nevertheless, the proportion of individuals in Kirkuk City who had their family planning needs fulfilled using modern techniques remained at a higher rate of 59.7% in 2018 (UNICEF, 2018). This research contributes to the existing knowledge on contraceptive dynamics among married populations, focusing on improving contraceptive literacy and promoting modern methods, which can positively impact women's reproductive health, decision-making, and overall quality of life. This research also explores the side effects of modern contraceptives, guiding the development of effective family planning programs. Thus, this study aimed to examine the factors that impact the use of modern contraceptive methods among married women of childbearing age residing in Kirkuk City.

Materials and Methods

Study design and participants

A cross-sectional study was conducted to gather data from a convenience sample, using convenience sampling as a non-probability method to select participants based on their accessibility. Convenience sampling offers several advantages, including simplicity, cost-effectiveness, ability to gather participants at a specific point in time, and suitability for exploratory research. In this study, a sample of 500 married women of reproductive age attending family planning units at 10

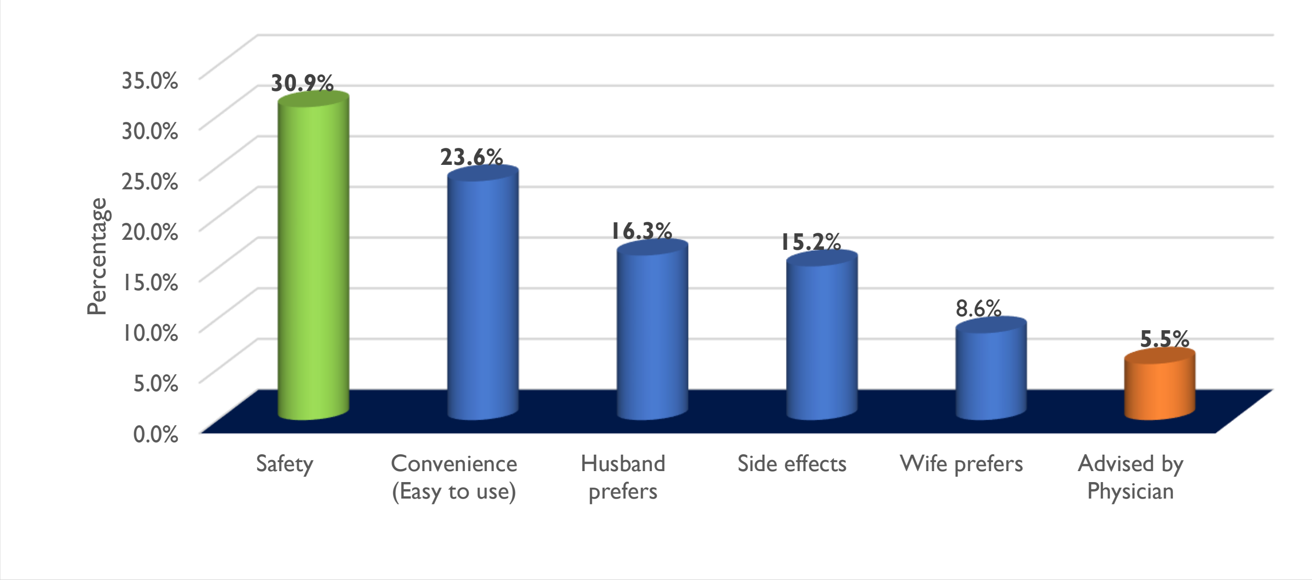

Figure 1 : Reasons for utilizing specific family planning methods among study participants n=373

primary healthcare facilities, Azadi Teaching Hospital, Kirkuk Teaching Hospital, and Private Gynecological and Obstetric Clinics were selected using convenience sampling (Figure 1). The data were collected using a structured questionnaire. As this study was designed as a cross-sectional study, the estimations for sample size calculation incorporated the following notations. The confidence level (Z) was set at 95% and was equal to 1.96. The prevalence of contraceptive use in Kirkuk City (P) is 51.3% (0.513) (UNICEF, 2018). The level of accuracy or sampling error (D) was set at 5% (0.05). The sample size was calculated using the following formula: sample size = (Z^2 × P × (1-P))/D^2 (Daniel and Cross, 2018). Therefore, the sample size was determined as 384 for an infinite population. However, a larger sample size enhances the generalizability and credibility of study findings and helps mitigate the potential for unrepresentativeness associated with convenience sampling (Littler, 2015; Memon et al., 2020). Hence, we recruited 500 women to enhance the generalizability of the findings. However, only 373 of the 500 currently used contraceptive techniques have been used. Therefore, the association was computed for 373 participants currently using contraceptive methods. The study included married women aged 15 to 49 years, while excluding those who expressed unwillingness to participate, pregnant women, and women who had undergone a hysterectomy.

Data Collection Tools and Techniques

Data for this study were gathered using a structured questionnaire administered through face-to-face interviews. The interviews were conducted from October the 1st 2023 to January the 1st 2024 in a confidential and comfortable environment. Anonymity and encouragement of participants' willingness to provide accurate and truthful responses were carefully considered.

The duration of each interview ranged from 15 to 20 min. After obtaining verbal consent from the participants, the questions were asked in their native language. The questionnaire design was influenced by a comprehensive investigation of the available literature on contraceptive use. The study covered a range of factors such as sociodemographic variables, reproductive health indicators, and data on contraceptive use. Sociodemographic factors included age, place of residence, religion, educational attainment of women and their spouses, monthly family income, and occupation. Reproductive health-related parameters included variables such as gravida, parity, history of miscarriage, number of children, age at marriage, interpregnancy interval, menstrual cycle regularity, and method of last delivery. The inclusion of these characteristics aimed to evaluate the reproductive health condition of the participants and offer a framework for understanding their contraceptive preferences.

Table 1: Demographic and reproductive characteristics of the study participants (n=500)

Items		**n**	**%**
age	<20	5	1.0
	20 - 24	61	12.2
	25 - 29	120	24.0
	30 - 34	128	25.6
	35 - 39	110	22.0
	40 or more	76	15.2
Women Educational level	Illiterate	68	13.6
	Primary Graduated	95	19.0
	Secondary Graduated	87	17.4
	Institute Graduated	89	17.8
	College Graduated	161	32.2
Monthly Family Income (Iraqi Dinar)	< 500,000	61	12.2
	500,000-749,000	146	29.2
	750,001-1 million	153	30.6
	>1 million	140	28.0
Occupation	Employed	159	31.8
	Housewife	266	53.2
	Student	4	0.8
	Private work	71	14.2
Gravida	0	37	7.4
	1 - 2	175	35.0
	3 - 4	200	40.0
	5+	88	17.6
Para	0	37	7.4
	1 - 2	238	47.6
	3 - 4	178	35.6
	5+	47	9.4
Miscarriage	0	307	61.4
	1 - 2	183	36.6
	≥ 3	10	2.0
Number of children	0	51	10.2
	1 - 2	232	46.4
	3 - 4	174	34.8
	5+	43	8.6
Women age at marriage(year)	13 -17	12	2.4
	18 - 22	231	46.2
	23 - 27	169	33.8
	28 - 32	85	17.0
	33 - 39	3	0.6
Interpregnancy interval(year)	Non	84	16.8
	1 - 2	324	64.8
	3 - 4	77	15.4
	5+	15	3.0
Menstrual cycle	Regular	304	60.8
	Irregular	196	39.2
Method of last delivery	ND	280	56.0
	C/S	183	36.6
	Nullipara	37	7.4

n = Frequency, %=Percentage, ND= Normal Delivery, C/S= Cesarean section

Statistical analysis

Data processing and analysis were performed using a statistical program SPSS, Version 27. Descriptive statistical analysis approaches, such as frequency and percentage, were used to summarize the samples and measurements. The study utilized inferential statistical techniques, namely the Fisher-Freeman-Halton Exact

Table 2: Contraceptive methods using currently among study participants (n=373)

Contraceptive methods currently using	n	%
Male Condom	105	21.0
Natural (withdrawal)	80	16.0
Intrauterine device (IUD)	63	12.6
Oral pill (COCP)	51	10.2
Injection(DMPA)	27	5.4
Oral pill (POP)	20	4.0
Skin patch (Implanon)	19	3.8
LAM (breastfeeding)	6	1.2
Rhythm method	2	0.4
Total	373	74.6

n = Frequency , %=Percentage

Test, to examine the relationships between categorical variables. This test was chosen because it is appropriate when the predicted count is less than 5 and exceeds 20% of the total count. Each test was considered significant at a p-value less than 0.05.

Ethics approval and consent to participate

The Kirkuk Nursing College Ethical Committee approved and granted data collection permits (Number 3 / 7 / 2340 on 19 / 10 / 2023). The authors received formal consent from Azadi and Kirkuk Teaching Hospitals (Number 713 on 31 / 10 / 2023). The researcher protected the privacy and ethics of the subjects. The researcher introduced herself and described the study's goal before involving participants, ensuring that the data would be safeguarded and used for research.

Results

Data of 500 married women of childbearing age (15-49) years who were attending the Family Planning Unit at 10 Primary Health Care Centers, Azadi Teaching Hospital, Kirkuk Teaching Hospital, and Private Gynecological and Obstetric Clinics were analyzed. One hundred twenty-eight women (25.6%) were aged 30 to under 35 years, and 153 (30.6) belongs to 750000-1 million (Iraqi Dinar) equivalent to (500 to 700 USD) monthly income. College graduates had the highest

Table 3: Factors influencing the choice of modern contraceptive methods among study participants. n=373

Items	Types of contraceptive methods currently used Frequency (%)									Total(%)	Fisher Freman-Halton Exact Test	P-Value (Sig.)
	Oral pill (COCP)	Oral pill (POP)	IUD	Injection	Skin patch (Implanon)	Condom	Natural (withdrawal)	LAM (breastfeeding)	Rhythm method			
Side effects experiencing while using Contraceptive methods												
No	-	-	-	-	-	94 (25)	77 (21)	6 (2)	2 (1)	179(48)		
Yes	51 (14)	20 (5)	63 (17)	27 (7)	19 (5)	11 (3)	3 (1)	-	-	194(52)		
If (Yes): (n=194)												
Headache	11 (6)	8 (4)	-	4 (2)	7 (4)	5 (3)	-	-	-	35(18)		
Irregular bleeding	1 (1)	-	24 (12)	-	2 (1)	-	-	-	-	27(14)		
Weight gain	17 (9)	2 (1)	-	10 (5)	2 (1)	1 (1)	-	-	-	32(16)		
Fatigue	1 (1)	1 (1)	7 (4)	2 (1)	2 (1)	-	-	-	-	13(7)		
Backache	3 (2)	-	17 (9)	1 (1)	-	-	1 (1)	-	-	22(11)		
Nausea	8 (4)	7 (4)	1 (1)	2 (1)	2 (1)	-	-	-	-	20(10)		
Abdominal pain	2 (1)	-	-	2 (1)	-	3 (2)	-	-	-	7(4)		
Vertigo	-	-	-	1 (1)	-	-	-	-	-	1(0)	920.863	
Increase heartbeat	1 (1)	-	1 (1)	-	3 (2)	-	-	-	-	5(3)		<0.001(HS) ☐
Pains in whole body	2 (1)	-	-	2 (1)	1 (1)	-	-	-	-	5(3)		
Depression	3 (2)	-	-	3 (2)	-	-	-	-	-	6(3)		
Nervous & Anxiety	2 (1)	2 (1)	-	-	-	-	-	-	-	4(2)		
Infection	-	-	6 (3)	-	-	2 (1)	2 (1)	-	-	10(5)		
Heavy menstrual bleeding	-	-	7 (4)	-	-	-	-	-	-	7(4)		
The final decision-maker in choosing reproductive decisions, such as the timing of the next birth and the number of children in the family												
Wife	6 (2)	5 (1)	4 (1)	4 (1)	1 (0)	15 (4)	13 (3)	-	-	48(13)		
Husband	9 (2)	7 (2)	12 (3)	6 (2)	4 (1)	13 (3)	10 (3)	1 (0)	-	62(17)	17.455	
Both	36 (10)	8 (2)	47 (13)	17 (5)	14 (4)	77 (21)	57 (15)	5 (1)	2 (1)	263(70)		0.295(NS) ☐
Experiencing any pressure from spouse or family to have additional children or to become pregnant if haven't given birth yet												
Yes	16 (4)	11 (3)	17 (5)	9 (2)	8 (2)	29 (8)	16 (4)	2 (1)	2 (1)	110(29)	15.692	0.037(S)
No	35 (9)	9 (2)	46 (12)	18 (5)	11 (3)	76 (20)	64 (17)	4 (1)	0 (0)	263(71)		☐

F.= Frequency , %=Percentage, ☐=Fisher-Freeman-Halton Exact Test, N.S = Non-Significant at P >0.05 , S = Significant at P ≤ 0.05 , H.S = Highly Significant at P ≤ 0.01.

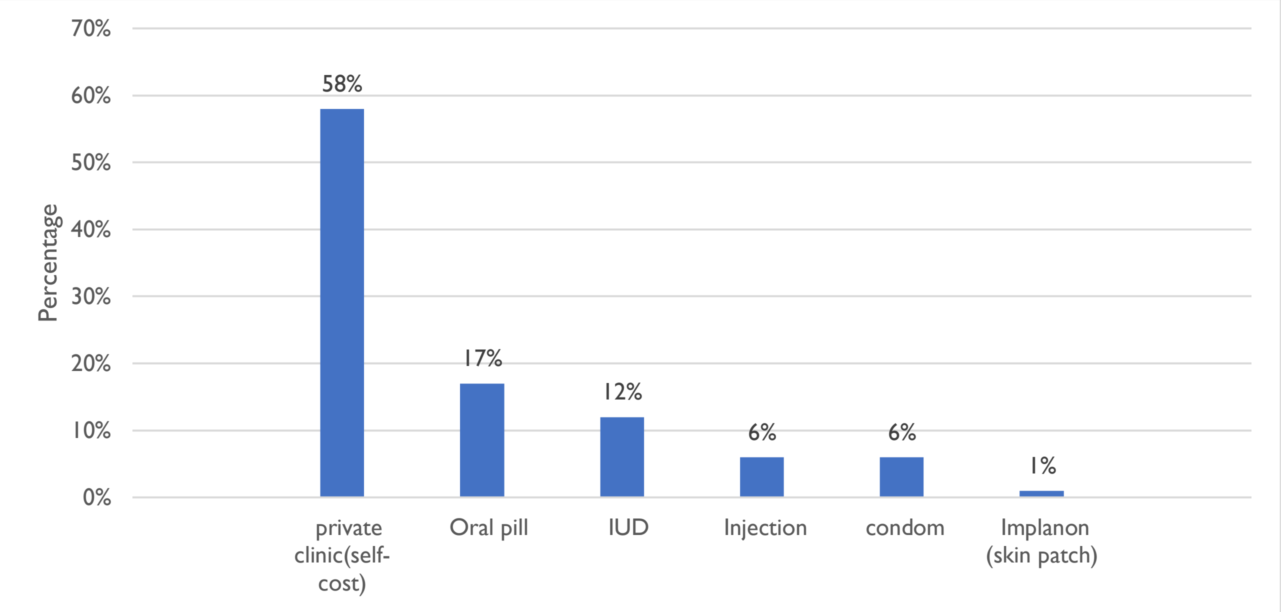

Figure 2: Contraceptive methods offered by FP units in primary health care centers and Hospitals n=373

education level (32.2%). Reproductive features showed that 200 women (40%) had 3-4 pregnancies and two handered thirty-two of women (46.4%) had 1-2 children. Three handered twenty-four women (64.8%) had a median interpregnancy interval of 1-2 years. The majority of the women (60.8%) experienced a regular menstrual cycle (Table 1). Of the 500 respondents, 373 (74.6%) reported using contraceptive methods, while 127 (25.4%) did not. Of the 373 participants who currently used contraceptive methods, condoms were the most popular, chosen by 21.0% (n=105) of the participants. Subsequently, natural withdrawal was observed in 16.0% (n=80), IUD in 12.6% (n=63), oral contraceptive pills containing COCP 10.2% (n=51), injections of 5.04% (n=27), progestin-only pills (POP) 4.0% (n=20), and skin patches (Implanon**)** (Table 2). The association between the nine contraceptive methods and side effects, as well as decision-making authority and pressure to become pregnant by the surroundings, are presented in (Table 3). The results revealed a strong significant association (Fisher-Freman-Halton Exact Test= 920.863, p<0.001) between side effects and participants' choices of contraceptive methods. Among the 373 respondents currently using contraceptive methods, 52% reported experiencing adverse effects, whereas 48% did not. Most of the reported side effects were associated with modern contraceptive techniques, with headache (18%), weight increase (16%), and irregular bleeding (14%) being the most common side effects. The results also showed a significant association between the presence of external pressures from spouses or family members to have additional children or become pregnant and participants' choice of contraceptive method (Fisher Freman-Halton Exact Test=15.692, p=0.037). However, decision-making authority did not significantly influence contraceptive method choices (Fisher-Freman-Halton Exact Test=17.455, p=0.295). Reasons for choosing specific family planning methods among study participants. The main reasons mentioned included safety (30.9%), convenience (23.6%), husband's preference (16.3%), and side effects (15.2%) (Figure 1). Availability of contraceptive techniques at primary healthcare centers and hospitals. The most commonly administered contraceptives were the combination oral contraceptive pill (COCP) and progestogen-only pill (POP), accounting for 17% and 12%, respectively. 58% of the respondents considered private clinics as a viable option for contraception (Figure 2).

Discussions

The findings of this study provide valuable insights into the usage and prevalence of modern and traditional contraception and health behaviors in women residing in Kirkuk City, Iraq. The study revealed contraceptive usage rates among the participants, reporting that 373 (74.6%) of married women used contraceptives, while 127 (25.4%) did not. The prevalence of contraceptive use is higher than that reported in Iraq in 2021 (58%), followed by neighboring countries, such as the UAE (33.4%), Kuwait (35.5%), and Saudi Arabia (66.5%) (United Nations, 2020; Alenezi and Haridi, 2021). The most commonly used contraceptive method is condom use, followed by natural contraception. These findings are consistent with the preference for traditional or natural withdrawal as a contraceptive method rather than modern methods owing to its accessibility, lack of supplies or clinic visits, safety, lack of known adverse effects, and non-interference with breastfeeding. However, it is important to note that withdrawal is less effective than modern contraceptives. The study also found that a significant proportion of women used intrauterine devices (IUDs) and oral contraceptive pills (COCP), while other methods such as implants and injectables were less commonly used. These findings differ from those of a study conducted in Kirkuk City on displaced women, which reported a higher utilization rate of contraceptive pills and IUDs (Mustafa, 2019). Variations in contraceptive preferences may be influenced by factors such as availability, cost, side effects, and personal preferences, which make modern methods less popular among study participants. These factors also influence modern contraceptive methods. Concerns about the side effects and misunderstandings surrounding modern contraceptives have been reported in previous studies and have significantly influenced the choice of modern contraceptive methods usage (Wasti, 2017; Imam and Khan, 2019; Berglas et al., 2021). The study also found that the decision-making process regarding contraceptive methods involved both husbands and wives in most participants. This highlights the importance of including both partners in family planning decisions, and considering their needs and preferences. Additionally, the study revealed that private clinics were the preferred choice for obtaining contraception, which may be attributed to the lack of medical specialists, particularly for IUD insertion in family planning units, and the availability of the desired techniques. These findings are consistent with previous research highlighting the importance of addressing healthcare provider availability and the availability of desired contraceptive methods, particularly modern methods (Mushy et al., 2020; Salih, 2022). This study also determined the cultural and societal factors that could indirectly affect women's contraceptive use in Iraq. The patriarchal nature of Iraqi society, cultural preferences for larger families, religious influences, and informal relationships all contribute to a complex set of factors that influence women's contraception use. These factors emphasize the need for comprehensive reproductive health interventions that consider cultural and societal contexts and promote gender equality and women's empowerment in Iraq, particularly in Kirkuk City. Furthermore, the study revealed that women aged 30–35 years comprised the largest age group, accounting for 25.6% of the participants. This age group is of particular importance in the context of reproductive health and family planning initiatives as they have unique birthing and contraceptive needs and challenges. These findings are consistent with previous studies conducted in the Qaladzi district and Najaf City, which also found a high prevalence of women aged 30-37 years (Hussain and Lefta, 2020; Ibrahim and Abdulsahib, 2022). This highlights the importance of considering regional variations in reproductive health needs and tailoring interventions accordingly. One significant finding of the study was the relatively common occurrence of multiple gravidae among the study population, with the highest percentage falling into the 3-4 pregnancies group at 39.4%. This finding is consistent with research conducted in Ethiopia, which showed a similar prevalence of 3-4 pregnancies (Geremew and Gelagay, 2018). It is worth noting that while many women had experienced multiple pregnancies, a considerable number also had fewer deliveries, potentially due to factors such as fertility complications or personal choices. This finding contradicts a study conducted in Ethiopia, which reported that women had a median of 3 births, with a minimum of one and a maximum of 10 births (Gebremariam and Hadush, 2017). These findings highlight the importance of reproductive health and family planning interventions that address the diverse needs and preferences of women in Kirkuk City. Miscarriage is another important aspect of reproductive health, and the study found that a substantial number of women (36.6 %) had experienced one to two miscarriages. This prevalence of miscarriage is consistent with a study conducted in Duhok, which reported a 39% prevalence in women with a history of miscarriages(Alsanity and Hasan, 2023). Healthcare providers must address and support women who have experienced miscarriages, as evidence suggests that women should use contraception for at least six months after a miscarriage before attempting to conceive again to reduce the risk of another miscarriage (Yland et al., 2023). This study also examined the interpregnancy interval (IPI) and menstrual cycle regularity, both of which are important factors in women's reproductive health. Most participants had an IPI of 1-2 years, with a high proportion experiencing short IPIs. Short IPIs have been associated with an increased risk of adverse maternal and fetal outcomes, such as preterm birth and low-birth-weight infants (Schmalenberger et al., 2021). However, long-term IPIs may have their own set of challenges, including increased maternal age and declining fertility rates (Akamike et al., 2020). Therefore, health care providers must educate women on the importance of optimizing their IPIs for optimal maternal and infant health outcomes. Additionally, 39.2% of the participants reported having irregular menstrual cycles, which can pose challenges in accurately predicting ovulation and identifying the fertile window, reducing the chances of conceiving. Evidence reported that Modern contraceptives, particularly hormonal contraceptives, can alter menstrual cycles in several ways, including irregular bleeding and spotting, lighter and more regular periods, heavier bleeding, and missed periods of time. Combination methods such as pills, patches, and rings can make periods lighter, shorter, and more regular, whereas hormonal IUDs, such as Mirena, can reduce heavy bleeding and prevent missed periods (Baird and Glasier, 1993; Andi et al., 2014; Alyahya et al., 2019; Ahinkorah, 2020; Creinin et al., 2021). Addressing the underlying causes of menstrual irregularities can help improve the fertility outcomes in these women. In conclusion, the findings highlight the importance of addressing the unique needs and challenges of women in their twenties and thirties. These findings have important implications for reproductive health interventions and family planning initiatives in Iraq, and highlight the need for comprehensive approaches that consider regional variations, cultural factors, and the preferences of both partners. Future longitudinal studies are recommended to monitor contraceptive use over time and to identify patterns that can inform targeted interventions.

This study investigated the factors influencing modern contraceptive usage among married women of childbearing age in Kirkuk City, Iraq. It provides updated insights into the prevalence and modern contraceptive methods used by the participants. However, the study faced potential constraints due to cultural issues, such as limited women using modern contraceptive methods because of reproductive health and modern contraceptive literacy among participants. Another limitation of the study is the small number of reproductive-aged women visiting family planning centers. In addition, the use of convenience sampling resulted in a lack of generalizability because of sample bias. However, this limitation was fixed using a large sample size.

Conclusion

Health care availability, safety, side effects, reproductive health, and personal choices affect modern contraceptive use. Addressing these variables and providing thorough knowledge and access to modern contraceptives helps couples make informed reproductive health decisions, empowers women to regulate their fertility, make decisions that supports their personal and reproductive goals, and improves health and well-being.

Availability of data and material

All data generated or analyzed during this study are available from the corresponding requests.

Funding Source

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Conflict of Interest

Not applicable.

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ORIGINAL ARTICLE

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Self-efficacy in increasing physical activity of coronary heart disease patients: a cross-sectional study

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ABSTRACT

Introduction: Patients with coronary heart disease who engage in low physical activity are at an increased risk of morbidity and mortality. Self-efficacy, a key determinant of physical activity adherence, may hinder or enable engagement in exercise, particularly in patients with low self-efficacy. This study aimed to determine the association of physical activity and self-efficacy in patients with coronary heart disease.

Methods: A cross-sectional study was conducted among outpatients of coronary heart disease at a cardiovascular center. A total of 238 coronary heart disease patients were included in the study using a purposive sampling technique. The self-efficacy was measured using the cardiac self-efficacy scales (CSE), and the physical activity was measured using the long form International Physical Activity Questionnaire (IPAQ). Data analysis used the Chi-square test, Spearman correlation test and multivariate linear regression.

Results: Self-efficacy was strongly positively correlated with physical activity in coronary heart disease patients ($r = 0.956$; $p = 0.001$). Domain-specific correlations included domestic ($r=0.419$, $p<0.001$), work ($r=0.383$, $p<0.001$), leisure time ($r=0.296$, $p<0.001$), and transport ($r=0.247$, $p<0.001$). Multiple linear regression analysis showed that employment status had the most significant negative impact on physical activity ($B = -246.477$), while age ($B = 123.889$) and self-efficacy ($B = 93.513$) were positively associated with physical activity. These results indicate that higher self-efficacy and older age are linked to increased physical activity, whereas employment status is associated with decreased physical activity.

Conclusions: In this population, self-efficacy, remaining working status and age are important factors of physical activity in coronary heart disease patients.

Keywords: coronary heart disease, good health and well-being, physical activity, self-efficacy

Introduction

Coronary heart disease (CHD) is the world's biggest killer, responsible for 16% of the world's total deaths (World Health Organization, 2020). According to data from the American Heart Association (2022), approximately 19.1 million deaths were attributed to cardiovascular disease globally in 2020, and 244.1 million people in 2020 were living with ischemic heart disease. In Indonesia, the mortality rate of CHD is quite high, reaching 1.25 million in a population of 250 million (Kementrian Kesehatan Republik Indonesia, 2020). The prevalence of heart disease in Indonesia is 1.5%. The prevalence of heart disease in West Sumatra is higher than the national prevalence (1.6%) (Kementrian Kesehatan Republik Indonesia, 2018). CHD is a plaque build-up in the heart's arteries that could lead to a heart attack (American Heart Association, 2015). Patients with cardiovascular disorders have a high risk of morbidity and mortality because they tend to have a sedentary lifestyle. A previous study found that most CHD patients were less physically active (81.82%) (Setyaji, Prabandari and Gunawan, 2018). Another study found that there are still 6.2% of CHD patients who do not comply with regular physical activity (Al-Zaru et al., 2022). Frequent exercise can alleviate symptoms, boost myocardial perfusion, and enhance quality of life (Pool et al., 2019). A sedentary lifestyle raises blood cholesterol and causes visceral fat to accumulate; this is followed by a cellular and tissue-level innate and adaptive immune response that results in a chronic low-grade vascular inflammation, a critical regulatory mechanism in the pathophysiology of atherosclerosis (Alves et al., 2016). Patients who have an active lifestyle have a 50% lower risk of mortality than physical inactivity patients (Gonzalez-Jaramillo et al., 2022).

Physical activity is becoming an essential aspect in the secondary prevention of CHD to reduce the impact of the disease, slow its progress, and prevent recurrence, which can improve endothelial function and stop the progression of coronary stenosis, partly through anti-atherosclerotic effects on platelets and leukocytes (Alves et al., 2016; Winzer, Woitek and Linke, 2018). Regular physical activity can reduce the risk of morbidity and mortality of all risks of cardiovascular disease, including CHD (Francavilla et al., 2007; Merbawani, 2022).

Patients must have the self-assurance to modify their lifestyle in order to manage risk variables when engaging in physical exercise (Rippe, 2019). Self-efficacy, or the conviction that one can take action to accomplish particular objectives, is essential for altering one's own behavior. When comparing patients with high self-efficacy to respondents with low self-efficacy, the former group displayed better health behaviors; in particular, the former group appeared to be more disciplined in applying healthy behavior patterns, health checks, and physical activity (exercise) (Rokhayati and Rumahorbo, 2020). Self-efficacy and physical activity have been linked positively in the past; CHD patients who felt more confident in their abilities were more likely to engage in physical activity on a regular basis (Siow et al., 2018). A study suggested that self-efficacy was identified as a correlate of physical activity (Bauman et al., 2012). Increased physical activity is the primary aim of a rehabilitation program for coronary heart disease. Low levels of health self-efficacy may serve as a barrier to regular physical activity in CHD patients (Bachmann et al., 2015).

The treatment of CHD patients at the National Cardiovascular Center Harapan Kita, a cardiovascular center in Indonesia, has integrated physical activity as a component of the cardiac rehabilitation program (Pusat Jantung Nasional Harapan Kita, 2024). However, this approach is not yet prevalent in other hospitals in Indonesia. In West Sumatra, the treatment of CHD patients in cardiovascular centers is primarily focused on medical care, with less attention paid to the importance of physical activity. There is a lack of adequate follow-up, which is crucial for ensuring the optimal physical well-being of patients. Physical activity plays a vital role in restoring the functional capacity, fitness, and recovery of CHD patients (Alves et al., 2016; Winzer, Woitek and Linke, 2018).

Prior research indicates that individuals with CHD exhibit low levels of physical activity (Setyaji, Prabandari and Gunawan, 2018; Al-Zaru et al., 2022). Furthermore, self-efficacy plays a role in physical activity adherence applied by CHD patients (Bachmann et al., 2015; Siow et al., 2018). However, the correlation and strength of its effect on the physical activity of CHD patients has yet to be identified. For this reason, further analysis needs to be carried out related to the correlation of self-efficacy with physical activity of CHD patients. This study aimed to identify the correlation, direction, and strength of self-efficacy with physical activity in CHD patients.

Materials and Methods

Study design and setting

A cross-sectional study was conducted among the outpatients with CHD in the cardiovascular center of Dr.M.Djamil Hospital from May to July 2023. This hospital is a Type A hospital situated in the city of Padang in the Indonesian province of West Sumatra. This Cardiovascular Centre serves as the primary referral centre for cardiovascular care within the Central Sumatra region, encompassing the provinces of West Sumatra, Riau, Jambi and Bengkulu.

Samples, criteria and sampling technique

In total, 238 patients were recruited using purposive sampling technique. The inclusion criteria for this study were patients with medical diagnoses of ST-Elevation Myocardial Infarction (STEMI), Non-ST-Elevation Myocardial Infarction (NSTEMI), and Unstable Angina Pectoris (UAP) who were able to communicate effectively. Medical diagnoses were derived from the patient's medical records, which were accessed by medical records staff. The exclusion criteria included patients with comorbidities, respiratory problems, and those experiencing pain or shortness of breath. The sample size was determined using the Lemeshow formula (Enderlein, 1991), which is particularly useful for calculating sample sizes in epidemiological studies. This formula considers the expected prevalence of CHD conditions (STEMI, NSTEMI, and UAP), the desired level of precision, and a 95% confidence level. Additionally, a power analysis was conducted to confirm that the sample size was sufficient to detect a statistically significant effect, targeting a power of 0.80. These statistical techniques were employed to recruit adequate participants, ensuring that the study findings are reliable and generalizable to the broader population of CHD patients.

Variables and measurements

The independent variable was self-efficacy, and the dependent variable was physical activity. The research instrument used Sullivan's Cardiac Self-Efficacy Scale (CSES) questionnaire to measure self-efficacy. This questionnaire has been found valid and reliable based on the internal consistency test results with Cronbach's alpha value of 0.95. The CSES questionnaire consists of three dimension: control symptoms, control illness and maintain functioning (Sullivan et al., 1998; Fors et al., 2015). The long form International Physical Activity Questionnaire (IPAQ) was used to measure physical activity, consisting of four domains including work domain, transport domain, domestic domain and leisure time domain. The validity and reliability test results on IPAQ were valid and reliable, with a significant Cronbach's alpha value of 0.625, which means it is reliable. The IPAQ consists of 27 questions covering respondents' activities over the past seven days. Physical activity scores were calculated using the IPAQ scoring protocol in metabolic equivalent (MET) minutes/week. The IPAQ was translated into Indonesian and underwent a validity and reliability test (Dharmansyah and Budiana, 2021).

Data collection

The research teams carried out data collection. The researcher informed each respondent of the purpose of the study and they provided informed consent. Respondents filled out a 10 -15-minute questionnaire and the researcher accompanied the respondents while they did so.

Statistical analysis

Univariate analysis is described based on the assessment results of each variable, and then the mean, standard deviation, minimum, and maximum are calculated. Meanwhile, the bivariate analysis used the Spearman correlation test to determine the correlation between self-efficacy and physical activity. The study used the Chi-square test to examine the relationship between respondent characteristics and physical activity. Multivariate linear regression was used to identify associated factors related to physical activity among CHD patients. Confidence intervals (CI) were set at 95%, with a p-value < 0.05 considered significant. All the analysis was done using SPSS 20.0 version.

Ethical consideration

Ethical consideration approval from the Health Research Ethics Committee of RSUP. Dr.M. Djamil Padang, number LB.02.02/5.7/357/2023. Each respondent was informed about the objective of the study, the methodology to be employed, the potential limitations, the potential risks, the potential benefits, the confidentiality of the data and their option to take part on a voluntary basis. All respondents provided informed consent to participate in this study. All data collected will be kept confidential and published anonymously. Ethics approval and consent to participate.

Results

Patients characteristics

In total, 238 patients were included in the study, and their characteristics are presented in Table 1. The vast majority were male (92%), elderly (70-79 years) (80.3%), and married (93.3%). The highest level of education was high school (41.2%), most were not working (83.6%), and the majority lived with a partner (94.1%). Most respondents suffered from CHD <5 years (87.4%), and the majority had undergone percutaneous coronary intervention (PCI) (92.9%). The average self-efficacy value of respondents is 47.24 (SD = 2.95) (Table 1).

Physical activity

Table 2 shows that the average physical activity value was 624.29 MET minute/week (SD= 365.66). The domestic domain has a high average value among other physical activity domains (228.09 MET minute/week) with a standard deviation of 216.39. Meanwhile, the work domain has the lowest average value, 84.54 MET minute/week (SD=206.12).

Associations of patients' characteristics and physical activity

In Table 3, almost all of the patients' characteristics below are related to physical activity from light to

Table 1. Demographic characteristics of CHD patients (n=238)

Characteristics	N	%	Mean	SD
Gender				
Male	219	92.0		
Female	19	8.0		
Age			63.10	6.371
Pre-elderly (60-69 years)	47	19.7		
Elderly (70-79 years)	191	80.3		
Marriage				
Married	222	93.3		
Unmarried	16	6.7		
Educational level				
Elementary school	32	13.4		
Junior high school	51	21.4		
Senior high school	98	41.2		
University	57	23.9		
Employment status				
Work	39	16.4		
No work	199	83.6		
Living with				
Spouse	224	94.1		
Child	14	5.9		
Duration of disease				
≤ 5 years	208	87.4		
> 5 years	30	12.6		
Percutaneous coronary intervention				
Yes	221	92.9		
Never	17	7.1		
Self-efficacy			47.24	2.95

moderate levels, where employment status is the most influential (p<0.001) then marriage (p=0.005), age (p=0.008), living with a partner (p=0.012) and educational level (p=0.037). In the employment status section, respondents who do not work do more low-level physical activity. In contrast, respondents who work do more moderate levels of physical activity, so employment status influences the respondents' level of physical activity.

Correlation of self-efficacy and physical activity

The results of further analysis showed a significant correlation of self-efficacy and physical activity in CHD patients with a positive relationship direction and powerful relationship strength where the value of r = 0.956. The direction of a positive relationship means that the more self-efficacy increases, the more physical activity of CHD patients at Dr. M. Djamil Hospital. For further analysis, the correlation of self-efficacy and each physical activity domain can be seen in Table 4. Our data showed that each domain had a corrected correlation with all physical activity domains, with a higher correlation between the domestic domain (r =0.419), work domain (r = 0.383), leisure time domain (r = 0.296), and transport domain (r = 0.247).

Table 3. The associations of respondent characteristics and physical activity of CHD patients (n=238)

Characteristic	Physical Activity		*p*-value
	Low n (%)	Moderate n (%)	
Gender			0.585
Male	118 (53.8)	101 (46.1)	
Female	9 (47.3)	10 (52.6)	
Age			0.008*
Pre-elderly	17 (36.1)	30 (63.8)	
Elderly	110 (57.5)	81 (42.4)	
Marriage			0.005*
Married	113 (50.9)	109 (49)	
Unmarried	14 (87.5)	2 (12.5)	
Educational level			0.037*
Elementary school	20 (62.5)	12 (37.5)	
Junior high school	30 (58.8)	21 (41.1)	
Senior high school	56 (57.1)	42 (42.8)	
University	21 (36.8)	36 (63.1)	
Employment status			<0.001*
Work	9 (23)	30 (76,9)	
No work	118 (59.2)	81 (40.7)	
Living with			0.012
Spouse	115 (51.3)	109 (48.6)	
Child	12 (85.7)	2 (14.2)	
Duration of disease			0.550
≤ 5 years	112 (53.8)	96 (46.1)	
> 5 years	15 (51.7)	14 (48.2)	
Percutaneous coronary intervention			0.639
Yes	117 (52,9)	104 (47)	
Never	10 (58.8)	7 (41.1)	

*statistically significant p < 0.05. The Chi-square test.

Associated factors related to physical activity in CHD patients

The results of the multivariate linear regression analysis in Table 5 show that maintaining working status had the most substantial influence on the physical activity of CHD patients (B = -246.477), followed by age (B = 123.889), and self-efficacy (B = 93.513). No working respondent has minus 246.477 METS of physical activity comparing with working people. Pre-elderly respondents have more than 123.889 METS physical

Table 2. Physical activity of CHD patients (n=238)

Variable	Mean	SD	Min	Max
Physical activity	624.29	365.66	80	2574
Work domain	84.54	206.12	0	2508
Transport domain	98.95	167.38	0	1080
Domestic domain	228.09	216.39	0	870
Leisure time domain	210.63	197.89	0	1089

Table 4. The correlation of physical activity domains and self-efficacy in CHD patients

Physical activity domain	**Self-efficacy**	
	r	***p-value***
Work domain	0.383	<0.001*
Transport domain	0.247	<0.001*
Domestic domain	0.419	<0.001*
Leisure time domain	0.296	<0.001*

*statistically significant p < 0.05. The Spearman correlation test.

activity than elderly. And people with self-efficacy have more than 93.513 METS physical activity than people with no self-efficacy about physical activity.

Discussions

This study aimed to identify the correlation of self-efficacy and physical activity among CHD patients. The study found a correlation of self-efficacy and physical activity in CHD patients with a positive relationship direction and a powerful relationship strength. This association demonstrates that CHD patients who have higher levels of self-efficacy also have higher levels of physical activity. According to earlier research, patients with CHD who have high levels of self-efficacy also have lower levels of physical activity (Mahmudiono et al., 2021; Han and Won, 2022; Ni Kadek, Puspawati and Lisnawati, 2023). Patients with CHD who had higher levels of self-efficacy also engaged in more physical activity (Tang et al., 2019). According to a different study, patients with CHD who have low health self-efficacy find it difficult to engage in regular physical activity (Bachmann et al., 2015). Nearly half of the participants in another study that examined physical activity in CHD patients engaged in low-intensity exercise (Merbawani, 2022).

The cardiovascular health benefits of a physically active lifestyle for CHD patients highlighted the need for strategies to increase physical activity in this population. Overall, self-efficacy plays a role in the physical activity levels of patients with CHD. The capacity of one's own beliefs to shape behavior or attitudes is referred to as self-efficacy (Fors et al., 2015). A person's health behavior in managing symptoms and adhering to a CHD treatment plan is positively impacted by their level of self-efficacy (Alamsyah, Dewi and Utomo, 2020). Individuals who possess a high level of self-efficacy will possess the confidence to control their behavior in order to enhance their health and maintain a healthy lifestyle (Lu et al., 2020). Self-efficacy in CHD patients can generate adaptive behavior such as physical activity, regular exercise, and compliance in the disease treatment process, namely efforts to reduce or control risk factors that are detrimental to health in CHD patients.

The correlation of physical activity domain and self-efficacy found that the domestic domain has sufficient correlation strength with self-efficacy compared to other domains. The domestic domain includes moderately active housework, childcare, and adult care (Cusatis and Garbarski, 2019). Age, marriage, education level, keeping working, and living arrangement can all have an impact on the low and moderate physical activity levels identified in this study. According to the study, physical activity and employment are significantly correlated (Kwak et al., 2016; Farradika et al., 2019). This significant relationship can be seen in this study, which found that occupation respondents were more out of work than working (83.6%) with low physical activity levels (59.2%). A study showed that participants who did not work had more sedentary time than participants in low-level occupations.

One biological element that has a substantial impact on physical activity is age (Carrasco et al., 2021). In age, respondents are more in the elderly age range (80.3%) with low levels of physical activity (57.5%), so that age also significantly affects physical activity. In line with the research of Mbambo, Tlou and Dlungwane (2019), age is a factor significantly related to physical activity. Adherence to physical activity in these patients was correlated with their educational attainment and frequency of follow-up visits (Acar et al., 2017). According to the survey, people with higher levels of education engage in greater physical activity than people with lower levels of education in Europe (Dhuli et al., 2022). People are more likely to follow a healthy lifestyle to prevent sickness if they have a greater degree of education (Rippe, 2019). Thus, most of the respondents in this study carried out physical activity

Table 5. The associated factors related to physical activity in CHD patients

Factors	**Physical Activity**				
	B	**SE**	**Beta**	**t**	***p*-value**
Age	123.889	54.813	0.135	2.260	0.025*
Marriage	-51.694	46.175	-0.071	-1.120	0.264
Education level	-27.596	15.743	-0.073	-1.753	0.081
Employment status	-246.477	59.667	-0.250	-4.131	0.000*
Living with a partner	33.670	49.538	0.043	0.680	0.497
Self-efficacy	93.513	5.103	0.754	18.324	0.000*

statistically significant p < 0.05. The multivariate linear regression.

following the standards for implementing a healthy lifestyle. A study found that self-efficacy affects physical activity in patients with CHD, where physical activity was found to have a significant positive correlation (Han and Won, 2022). Self-efficacy becomes the most important factor for managing cardiovascular disease because improving patient outcomes depends on involvement in self-activity management, lifestyle modification, and risk factor control (Kargar, Khademian and Rambod, 2021).

The study has several strengths, including the findings which support the theory that self-efficacy plays an important role in the adherence of CHD patients to physical activity regimes. The instruments employed have been validated and demonstrated reliability in the context of heart health-related research. The study employed a range of statistical techniques, including the Chi-square test, the Spearman correlation test, and multivariate linear regression, which afforded a more comprehensive understanding of the relationship between variables. A limitation of this study is that the data were collected at a single point in time, which precludes the examination of changes over time. The use of purposive sampling may introduce bias, as the sample selected may not be fully representative of the general CHD patient population, which may affect the generalizability of the results. Despite the control of several variables, including employment status and age in this study, there are numerous additional factors that may influence physical activity that have not been assessed. Furthermore, the measurement of physical activity relies on respondents' reports, which are susceptible to recall bias or subjective interpretation.

Conclusion

Keeping working may be beneficial for physical activity in coronary heart disease status. Self-efficacy strongly correlates with increasing physical activity in coronary heart disease patients. Increasing self-efficacy in patients can increase physical activity in the four domains of physical activity in patients with coronary heart disease. Therefore, to increase the self-efficacy of CHD patients, nurses have an essential role as educators in providing health education and motivating CHD patients to implement regular physical activity to prevent disease recurrence.

Availability of data and material

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Conflict of Interest

No potential conflicts of interest.

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ORIGINAL ARTICLE

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Caregiving experiences among parents of children with physical and intellectual disabilities: a qualitative systematic review

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ABSTRACT

Introduction: Research indicates that parents of children with disabilities undergo more significant stress and experience poorer mental and physical health outcomes in comparison to parents of children who do not have disabilities. This study aimed to identify caregiver experiences encountered by parents of children with physical and intellectual disabilities.

Methods: The study used a systematic review method with the guidelines of Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) and PRISMA 2020. The review focused on parents caring for children with physical and intellectual disabilities. The literature was searched for relevant studies from five electronic databases including PubMed, CINAHL, Web of Science (core collection), Cochrane, and Scopus. This systematic review examined 14 articles out of a total of 63,400 articles found. The study used a thematic analysis method to analyze the study.

Results: Providing care for children with physical and intellectual disabilities requires addressing a variety of challenges. It is critical to have a comprehensive understanding of these intricacies to ensure that families receive the necessary support and interventions. Our synthesis identified seven themes: (1) gendered and emotional experiences, (2) compromising quality of life: physical and psychological impact, (3) lack of knowledge about disabilities, (4) lack of social support, (5) stigma, (6) uncertain future of the recipient, and (7) unavoidable caregiving responsibility.

Conclusions: The results of this study provide recommendations that health professionals and researchers further explore these challenges and strive to build a supportive and inclusive environment that recognizes the unwavering dedication of parents and prioritizes the optimal care and development of children with disabilities.

Keywords: children, disability, parent, qualitative systematic review

Introduction

Raising children with disabilities can be a challenging experience for parents, often leading to higher levels of stress. Compared to parents who do not have disabled children, those who are raising children with disabilities tend to have poorer mental and physical health outcomes (Bray et al., 2017; Fritz, 2020; Iacob et al., 2020; Panczykowski et al., 2022). Raising a child with a disability can present unique challenges for parents; it requires significant emotional, physical, and financial resources (Yuen Shan Leung and Wai Ping Li-Tsang, 2003; Neely-Barnes and Dia, 2008; Isa et al., 2016; Aktan, Orakcı and Durnalı, 2020). Research indicates that parents who care for children with disabilities, whether physical or intellectual, may experience heightened levels of chronic stress and poor health outcomes (Song and Singer, 2006; Cramm and Nieboer, 2011; George, Shacter and Johnson, 2011; Peer and Hillman, 2014; Patton et al., 2018).

An estimated 1.3 billion people, representing 16% of the world's population, are affected by disability (WHO, 2023). The prevalence of physical disabilities such as cerebral palsy ranges from 2.6 to 3.2 per 1,000 children, while estimates of the prevalence of intellectual disabilities vary, with recent data suggesting 11.1 to 12.2 per 1,000 children (Maenner et al., 2016; McGuire et al., 2019). The Convention on the Rights of Persons with Disabilities defines "living with a disability" as the condition of having a long-term physical, mental, intellectual, or sensory impairment that, when combined with the environment, restricts an individual's ability to participate in society on an equal footing with others. Children and adolescents with disabilities represent a diverse group, with each individual having unique life experiences. They reside in all communities and may be born with or develop distinct impairments that, when considered within their environment, can result in difficulties with functions such as vision, mobility, communication, self-care, and socialization (UNICEF, 2023). This systematic review specifically concentrated on intellectual and physical disabilities due to their distinct health requirements, intricate health profiles, experiences with healthcare disparities, and the consequent policy implications associated with these disabilities (Liao et al., 2021; Hassett et al., 2024).

Parents with children who have disabilities face unique challenges when it comes to providing care for their offspring (Panczykowski et al., 2022). To fully appreciate the extent of these challenges, it is essential to understand the specific obstacles each parent encounters. Qualitative studies have revealed that parents bear the emotional burden of caring for their children and must prioritize their own well-being (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021; Vatne et al., 2023). Implementing effective nursing strategies to enhance parents' experience can significantly contribute to improving the care of children with disabilities (Murdoch and Chang, 2022).

The existing literature highlights the need for a comprehensive systematic review on the experiences of parents of children with physical and intellectual disabilities. While some reviews have focused on specific aspects, such as general practice experiences (Thomas et al., 2023) and fathers' perspectives (Marsh, Brown and McCann, 2020), a holistic review is still lacking. Current research emphasizes the increased stress levels and health risks faced by these parents (Peer and Hillman, 2014), as well as the challenges in navigating healthcare systems and societal stigma (Codd, Andrews and Roberts, 2023; Thomas et al., 2023). However, there remains a need for more diverse perspectives and a focus on mothers and fathers across different life stages, justifying the need for a comprehensive systematic review.

The primary aim of this study was to conduct a comprehensive review of the themes that arose from the experiences encountered by parents of children with physical and intellectual disabilities. Physical disabilities refer to conditions that affect an individual's mobility, physical functional capacity, agility, strength, and stamina, such as cerebral palsy and multiple sclerosis (Hodge, 2019). Meanwhile, intellectual disability involves significant limitations in intellectual functioning and adaptive behavior, originating during the developmental period. It affects reasoning, problem-solving, planning, learning, communication, social participation, and independent living (Gopalan, 2016; Tassé, Luckasson and Schalock, 2016). By exploring these challenges, the study aims to understand parents' experiences in such situations comprehensively. The insights gained from this study could prove invaluable as a reference for future research endeavors that aim to delve deeper into the difficulties experienced by parents caring for disabled children. Notably, the authors of this systematic review have formulated the following research question for the study: “What themes emerged from the experiences of parents with physical and intellectual disabilities?”

Materials and Methods

Review design

The qualitative systematic review adhered to the guidelines for systematic reviews outlined by Bettany-Saltikov and McSherry (2016), which involves a seven-step process. First, the review question was formulated to ensure clarity and focus. Second, objectives, inclusion, and exclusion criteria were specified. Third, a comprehensive and systematic search of relevant literature was conducted. Fourth, appropriate studies were selected for inclusion in the review. Fifth, the methodological quality of the research papers included was evaluated. Sixth, relevant data were extracted. Last, the findings were synthesized, summarized, and presented (Bettany-Saltikov and McSherry, 2016). This review also adhered to the Enhancing Transparency in

Table 1. Critical appraisal of studies.

	Aims clearly reported	**Adequate reporting of sample**	**Adequate reporting of data collection methods**	**Adequate reporting of data analysis methods**	**Appropriate Research design**	**Appropriate recruitment strategy**	**Appropriate Data collection method**	**Appropriate data analysis method**	**Researcher–participant relationship considered**	**Ethical issues considered**
Hu *et al.* (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	No
Hamedanchi *et al.* (2016)	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Cannot tell	Yes
Douglas, Redley and Ottmann. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Pancsofar *et al.* (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	No
Willis *et al.* (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	No
Cameron and Cooper. (2020)	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Dunn, Jahoda and Kinnear. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Rafferty, Tidman and Ekas. (2020)	Yes	Yes	Cannot tell	Yes	Yes	Yes	Cannot tell	Yes	Cannot tell	No
Tekola *et al.* (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Kyle Jackson and Andipatin. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	No
Uribe-Morales, Cantero-Garlito and Cipriano-Crespo. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
L. Murdoch and Chang. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Vatne *et al.* (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Tekola *et al.* (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes

Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines (Tong et al., 2012).

Search strategy

A thorough and systematic search was conducted to identify relevant studies from five electronic databases including PubMed, CINAHL, Web of Science (Core Collection), Cochrane, and Scopus. The search process was comprised of three steps. First, appropriate keywords were identified in Medical Subject Headings (MeSH). The four primary concepts searched were '(parents OR caregivers OR mother OR father OR parent) AND (disability OR disabilities OR disabled OR impairment OR impaired OR special OR special needs) AND (children OR adolescents OR youth OR child or teenager) AND (experiences OR perceptions or attitudes OR views OR feelings OR qualitative or perspective).' Second, a comprehensive search was devised to conduct a thorough search plan that incorporated index terms, keywords, and Boolean operators to merge the search terms within and across all four concepts. Truncation symbols were utilized to render the search plan more efficient and effective. Third, to ensure a thorough search for any relevant literature, we manually examined the reference lists of all eligible studies (Cooper et al., 2018).

Eligibility criteria

The eligibility criteria for the study were established based on its research design, context, participants, and the phenomenon of interest. In order to be deemed eligible, the study was required to meet the following specific criteria: i) it must have a qualitative research design; ii) it should focus on exploring the experiences of parents of children with intellectual and physical disabilities; iii) the study must concentrate on parents of children with disabilities aged 18 years or younger; iv)

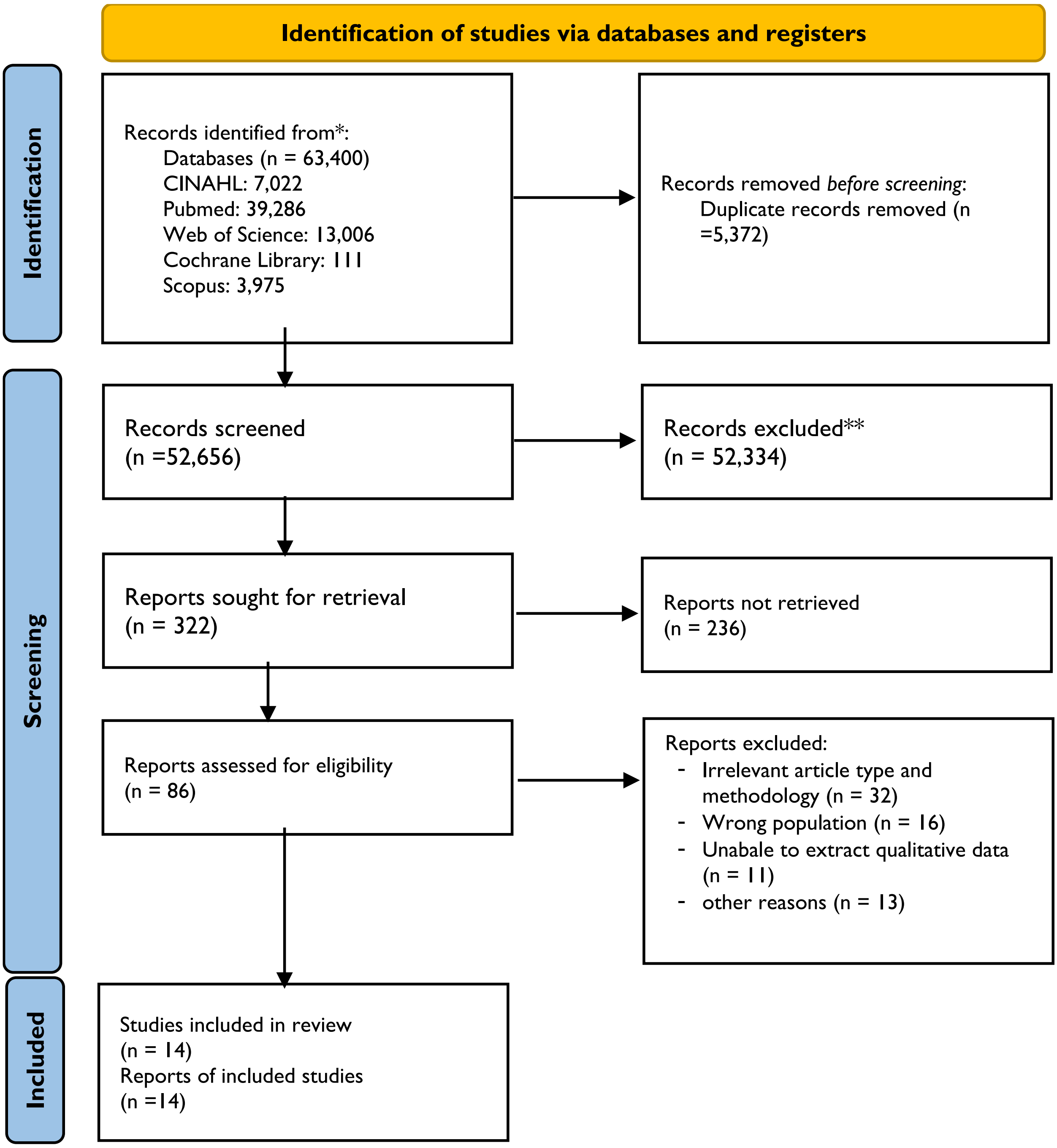

Figure. 1. PRISMA flow chart

the study must include parents (either father or mother) of children with disabilities; v) it must be written in English.

We have employed the following criteria to exclude studies: i) studies published in a language other than English; ii) studies that include treatment or intervention studies and clinical trials; iii) non-research articles, editorials, opinion pieces, conference abstracts, or proceedings; iv) cohort studies; v) studies pertaining to health services offered by non-registered health professionals; vi) studies involving animal research.

Study selection

During the study selection process, we followed several steps. First, we conducted a thorough search for relevant articles, both published and unpublished, dating back to the earliest available records up until January 2024. We then saved all the results in EndNote 20. The second step involved sorting the collected articles. Two independent reviewers, M and IC, participated in this process without knowing each other's findings. They carefully examined the remaining research works based on titles and abstracts and selected relevant articles that met the eligibility criteria for full-text screening. There were no conflicts during this review process.

The initial search found 63,400 articles. Using EndNote software, 5,372 studies were removed due to duplication. We screened 52,656 publications during title and abstract screening, with 52,334 deemed ineligible. We sought retrieval of 322 article reports, but 236 were not retrieved (the full-text was unavailable). Eighty-six reports were assessed for eligibility, 32 were excluded due to irrelevant article types and methodologies, 16 due to the wrong population, 11 were unfit to extract qualitative data, and 13 for other reasons. Ultimately, 14 sources were included in our final analysis. The process used to select the sources is presented in Figure 1 through the PRISMA flow chart.

Quality appraisal

The authors, in pairs, independently performed the quality assessment of the included papers using the Critical Appraisal Skills Programme (CASP) - Qualitative Research Checklist (Critical Appraisal Skills Programme, 2019). This checklist comprises ten items that evaluate the suitability and clarity of each primary study. There were no conflicts during this review process. The result of the quality appraisal is presented in Table 1. None of the papers were excluded based on the quality appraisal results.

Data extraction

The data collected comprised a comprehensive study breakdown, including the author(s), year of publication, country of origin, study aim(s), design, sampling, data collection method, analysis, sample characteristics, constructs, and findings. The extraction form was subjected to a pilot test in three studies, and no further modifications were deemed necessary. Two reviewers collected the data independently to minimize the possibility of errors. To resolve conflicts during the extraction process, we conducted several meetings to facilitate discussions and reach a consensus on data coding.

Data synthesis

Data were extracted and recorded using a table consisting of author name, year, method, and theme findings from each study. Based on the coding, an initial thematic map was developed to distill overarching themes. The authors collectively examined the significance and interconnectedness of different themes across the data set. The themes were carefully scrutinized, reviewed, and defined until agreement was reached. Using thematic analysis, we then grouped them into themes based on similarities (Braun and Clarke, 2006). The thematic analysis process consists of six critical phases. First, the researcher must gain a deep understanding of the obtained data. Next, the researcher is responsible for generating initial codes. Subsequently, pertinent themes in the data are identified. Following this, a comprehensive review of the identified themes is conducted. The researcher then proceeds to define and name the themes. Finally, a comprehensive report is crafted based on these analyses (Braun and Clarke, 2006).

Results

The results are presented in three sections: characteristics of included studies, research method, and research findings (main themes).

Characteristics of included studies

Participants

Fourteen studies were conducted involving parents, with one study extending to include other family members such as grandparents and uncles (Hu et al., 2015). Among these, eight studies focused exclusively on fathers (Cameron and Cooper, 2020; Dunn et al., 2021; Jackson and Andipatin, 2021; Pancsofar et al., 2019; Rafferty et al., 2020; Uribe-Morales et al., 2021; Vatne et al., 2022), one on mothers (Murdoch and Chang, 2022), and four included both parents (Hamedanchi et al., 2016; Willis et al., 2019; Tekola et al., 2020; 2022). One source, however, referred to parents without specifying further details (Douglas et al., 2017).

The research involved parents aged between 25 and 72 years and children aged from 1 to 21 years. The studies included 89 girls and 47 boys, with eight studies not providing data on the children's gender. Among the parents, there were 148 mothers and 168 fathers. Only one study specified the gender of five grandparents and one uncle, which included four females and three males.(Hu et al., 2015). One study did not provide information about the gender of the parents involved (Douglas, Redley and Ottmann, 2017).

Diagnosis

Seven studies focused on intellectual disabilities (Hamedanchi et al., 2016; Yang, Byrne and Chiu, 2016; Douglas, Redley and Ottmann, 2017; Willis et al., 2019; Dunn, Jahoda and Kinnear, 2020; Tekola et al., 2023; Vatne et al., 2023). Others had complex diagnostic disabilities such as autism, deafblind (Pancsofar et al., 2019), dyspraxia (Jackson and Andipatin, 2021), Down syndrome, Mowat Wilson syndrome, and ADHD accompanied (Uribe-Morales et al., 2021).

Countries

The majority of articles (*n*=8) come from the European continent such as Norway, Spain, Ireland and the UK (Willis et al., 2019; Cameron and Cooper, 2020; Dunn et al., 2021; Uribe-Morales et al., 2021; Murdoch and Chang, 2022; Vatne et al., 2022;). Two articles were from Asia, such as China and Iran (Hu et al., 2015; Hamedanchi et al., 2016; Yang, Byrne and Chiu, 2016). Two were from the South Africa (Jackson and Andipatin, 2021; Tekola et al., 2022), two articles were from the United States (Pancsofar et al., 2019; Rafferty et al., 2020) and one article was from Australia (Douglas et al., 2017).

Settings

The studies were conducted in different settings such in the children's school (Hu et al., 2015; Pancsofar et al., 2019; Uribe-Morales et al., 2021; Tekola et al., 2022), the participant's home (Cameron and Cooper, 2020) and both (Willis et al., 2019; Vatne et al., 2022).Two researches were conducted online (Rafferty et al., 2020; Murdoch and Chang, 2022), while others did not mention the place of research. This series of studies primarily aimed to understand the experiences and challenges faced by parents, particularly fathers, of children with physical and intellectual disabilities. They investigated aspects including the parenting experiences, of children with disabilities, and the role and impact of parenting. The sample sizes varied significantly with 136 participants in total, ranging from as few as four to as many as 42 participants. The studies recruited participants based on their stated objectives, with some focusing solely on children, parents, or both, and none relied solely on parents to access children's experiences.

Data collection

The predominant research methodology for gathering data from parents involved using semi-structured individual, as seen in approximately seven articles (Douglas et al., 2017; Pancsofar et al., 2019; Willis et al., 2019; Cameron and Cooper, 2020; Rafferty et al., 2020; Dunn et al., 2021; Uribe-Morales et al., 2021; Murdoch and Chang, 2022) and focus group interviews (Rafferty et al., 2020). Additionally, six studies utilized unstructured deep interviews (Hu et al., 2015; Hamedanchi et al., 2016; Jackson and Andipatin, 2021; Tekola et al., 2020; 2022; Vatne et al., 2022).

Data analysis

The analysis results indicate that thematic analysis was widely adopted as the most commonly employed method for qualitative data interpretation in the studies under review. Four studies used grounded theory (Hamedanchi et al., 2016; Cameron and Cooper, 2020; Rafferty, Tidman and Ekas, 2020; Lauren Murdoch and Chang, 2022), two used content analysis (Pancsofar et al., 2019; Vatne et al., 2022), phenomenological (Murdoch and Chang, 2022), transcript analysis (Hu et al., 2015), discourse analysis (Uribe-Morales et al., 2021), and thematic analysis (Douglas et al., 2017; Jackson and Andipatin, 2021; Tekola et al., 2022).

Main themes

This section presents a synthesis of the themes identified across the studies, organized under differences in caregiving experiences faced by parents with physical disabilities and those with intellectual disabilities.

Gendered and emotional experiences

Gender roles may influence expectations regarding physical caregiving tasks. Fathers with physical disabilities might grapple with societal perceptions of masculinity when faced with caregiving responsibilities compared to mothers. However, in some communities, mothers with intellectual disabilities, often primary caregivers, may face heightened scrutiny and support for their caregiving abilities compared to fathers.

Parents of children with intellectual disabilities sometimes have mixed emotions and doubts about their ability to provide care for their children (Yang, Byrne and Chiu, 2016). However, fathers' experiences were unique (Dunn et al., 2021). Five of 17 studies said fathers tend to have mixed feelings about caregiving tasks when considering their careers, while mothers don't (Hamedanchi et al., 2016; Yang, Byrne and Chiu, 2016; Douglas et al., 2017; Dunn et al., 2021; Jackson and Andipatin, 2021). Fathers, in particular, may need to reassess their priorities and redefine their parenting role. This could mean adjusting their work schedules, reducing their working hours, or leaving their jobs altogether to care for their children. As a result, they may need more time for leisure activities, spending time with their partners, or taking care of themselves (Hamedanchi et al., 2016; Douglas, Redley and Ottmann, 2017k). On the other hand, fathers may question their identities as men and fathers in light of societal expectations that view caregiving roles as non-masculine. These challenges are complex and require careful consideration. *"I had to give up working and not* *working err...it is...and for a man deciding not to work to care, to care for the children, and understand our biology and how we are shaped you know and understand social pressure on males being a provider and things like that and so it's, for me as a person..."* (Cameron and Cooper, 2020).

Two studies found that single mothers of children with intellectual disabilities often face a variety of difficulties, including financial instability, social stigma, and inadequate support systems (Willis et al., 2019; Tekola et al., 2022). Parents of children with a physical disability frequently compare their children's behavior and communication with healthy individuals of the same age. Consequently, some parents experience helplessness, upset, entrapment, judgment, and isolation due to their own and others' negative perceptions of their child's behavior and communication. The discourses of shame and blame serve as constraints for them. *"So, it does make me feel really, really guilty... the fact that giving up work meant that she's had to, you know .... When other people are going out and decorating the house we've had to make do with what we've had"* (Dunn, Jahoda and Kinnear, 2020).

Compromising quality of life: physical and psychological impact

Two studies found that parents who have various health issues, including diabetes, high blood pressure, heart disease, and insomnia, face significant challenges in managing their healthcare needs. These challenges include difficulties finding time for regular medical checkups and treatment (Hu et al., 2015). "As she got older, I refused to consider myself getting older and it took me a long while to start using the hoist and things that were provided. But I realized, after a few problems with health wise, that meant I better start using the hoist" (Dunn, Jahoda and Kinnear, 2020). The fathers have conveyed the considerable burden their caregiving duties exerted on their emotional and physical wellness over an extended period

Ten studies have shown that caregivers who have children with intellectual disabilities often suffer from chronic depression and poor health, which can significantly impact their overall quality of life. These caregivers frequently experience negative emotions like feeling low, hopeless, helpless, and a sense of meaninglessness (Yang, Byrne and Chiu, 2016). Although they face difficulties, they continue to recognize the importance of their duty as guardians (Pancsofar et al., 2019). Providing care for children with intellectual disabilities can present a significant emotional burden to their parents. These parents may face numerous challenges in supporting and caring for their children. "Well, it was a blow, a difficult period, I am still in psychological treatment for it, and well, it is something difficult to fit in, it is something that is going to be for life and that does not have a solution as such" (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021).

Lack of knowledge about disabilities

Five studies found that parents with intellectual disabilities understand less about the disabilities their children have than physical disabilities (Jackson and Andipatin, 2021; Tekola et al., 2022). Many families struggle with the lack of awareness about their child's disorder, including its implications and available therapeutic options. This affects the family's financial stability and puts pressure on the father to assume a more traditional provider role, adding to the stress of explaining the disorder and its impact on others, such as schools (Pancsofar et al., 2019). Parents should empower themselves by gaining knowledge, skills, and resources to facilitate their children's physical activity (Hu et al., 2015; Willis et al., 2019). Health professionals should provide parents with condition-specific information to help them better understand their infant's condition. Unfortunately, only a minority of parents report receiving such information. *"...still to this day, there is nothing that is specific to children with Down syndrome from health professionals. It's like you're the first person ever who has had a child with Down syndrome"*(Douglas, Redley and Ottmann, 2017).

Lack of social support

All 17 studies found that both parents of children with intellectual disabilities and physical disabilities experienced lack of community support such as family, government and financial support. Parents of children with intellectual disabilities often require more specialized and comprehensive support services tailored to cognitive functioning (Hamedanchi et al., 2016; Dunn et al., 2021;), whereas parents with children having physical disabilities may focus on adaptive strategies and accessible environments (Willis et al., 2019; Pancsofar et al., 2019; Jackson and Andipatin, 2021; Uribe-Morales et al., 2021).

Caregivers feel they receive little support from society and believe that the government needs to pay more attention to this vulnerable group. They also face difficulty in accessing future public services and welfare provisions. Effective coordination and communication among various agencies are crucial in facilitating the search for information and resources. Families have expressed concerns regarding limited support from services and are apprehensive about the availability of future care options (Pancsofar et al., 2019). The vast majority of parents hold the view that the society is not adequately equipped with the necessary facilities and resources to enable optimal participation of individuals with intellectual disabilities in various aspects of life. *"I go to the place where they primarily accept the child, and if I go somewhere and they reject him, I would certainly terminate my relationship"* (Hamedanchi et al., 2016). The participants expressed a desire for social acceptance and a sense of belonging for both themselves and their children. Most of the mothers mentioned that they wanted to feel accepted by people and participate in social activities with all members of their family (Hu et al., 2015).

Ten research studies have demonstrated that caregivers of children affected by intellectual disabilities or physical disorders often limit their exposure to public spaces. They tend to prefer staying at home while providing care to their children with intellectual disabilities, as opposed to venturing out to public places where they might face discrimination. As a result, some caregivers may have to reduce their social interactions with friends (Willis et al., 2019; Tekola et al., 2020). *"There is a huge pressure. There is exclusion starting from my family and there are very difficult situations, but I don't have a choice but to accept that. There is a problem when we go on the road and when people see us and even in our family. You will be excluded eh ...especially from my family, nobody accepted me including my mother. Because of this, I am not living in the community. I am living only with my child..."* (Tekola et al., 2020). Moreover, parents of children with disabilities often struggle to include them in schools and communities (Pancsofar et al., 2019; Willis et al., 2019). This can lead to uncomfortable and even humiliating experiences when the child is in public (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021).

The research conducted on the topic of parents with children having intellectual disabilities has consistently underscored the importance of social support. However, the study participants expressed dissatisfaction with the lack of significant public or government support. They highlighted their need for financial assistance and professional guidance to care for their child with intellectual disabilities effectively (Hu et al., 2015; Yang, Byrne and Chiu, 2016; Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021). *"Most families like us* [who have a child with intellectual disability] *are not rich, because our savings have mostly been spent on medical treatments for the child's disability. The hospitals providing rehabilitation services are far away, in the developed cities. So we had to pay for traveling fee and spend lots of time"* (Yang, Byrne and Chiu, 2016),

Stigma

All 14 studies found that both parents of children with intellectual disabilities and physical disabilities experienced stigma. Parents with children having intellectual disabilities encounter significant stigma and legal challenges related to their parenting capabilities (Hamedanchi et al., 2016; Dunn et al., 2021), whereas parents with children having physical disabilities may face more practical barriers related to accessibility and economic stability (Pancsofar et al., 2019; Willis et al., 2019; Jackson and Andipatin, 2021;Uribe-Morales et al., 2021).

Many uncertainties arise due to negative attitudes toward individuals with intellectual disabilities and developmental disorders (Yang, Byrne and Chiu, 2016; Tekola et al., 2020). Several parents also mentioned how they would isolate themselves and their children from social life due to the stigma they faced (known as affiliate stigma). However, many participants felt isolated and unsupported and had to take care of their child's needs independently, which left them feeling like they had to "fend for themselves" (Vatne et al., 2023).

Children with developmental disorders face various types of stigma, including courtesy stigma, public stigma, and affiliate stigma. Consequently, they often find it challenging to be included in other children's activities and games. Some parents report being stared at and pitied by the public when they are with their children. *"The attitude of other people, because x [my child] can listen but can't talk, they say, why doesn't your child talk. My neighbors used to say my child is Duda* [tongue-tied]. *They were saying, did you give birth to a Duda? They were teasing me. They were making fun of me saying her oldest child is like this. They were saying I must have done something* [to cause the child's condition]. *They were saying all of this in my presence, but I used to pretend that I was not listening but cry when I got home"* (Tekola et al., 2020).

Uncertain future of the recipient

Four studies have revealed that parents of children with intellectual disabilities often harbor concerns about the future and the well-being of their offspring (Douglas et al., 2017; Cameron and Cooper, 2020; Rafferty et al., 2020; Tekola et al., 2022;). Parents of children with physical disabilities often focus on health management and maintaining independence (Jackson and Andipatin,

2021) while those with children having intellectual disabilities face uncertainty regarding legal rights, ongoing support needs, and societal acceptance (Hamedanchi et al., 2016).

Parents of women with intellectual disabilities were typically more cautious on marriage issues rather than physical disabilities. In particular, they are troubled by the financial, emotional, and daily care requirements that their children may require after the parents' demise. Fathers, in particular, are anxious about the future as their health declines. The marriage paradox, which individuals often face with intellectual disabilities, is another concern that weighs on parents' minds. However, despite their worries, parents find strength in the benefits they have received and the challenges they have surmounted while tending to their children and family (Yang, Byrne and Chiu, 2016; Rafferty, Tidman and Ekas, 2020; Tekola et al., 2020). *"I cannot help sighing whenever I think about my child's future. It is always a big rock in my mind. I have no idea about what he can do independently once he enters the society. No one will want to employ him because of his incompetence"* (Yang, Byrne and Chiu, 2016).

The news of a child's disability can be devastating, making it difficult for parents to cope. It's a time filled with fears, worries about the future, and uncertainty as fathers begin to plan for their children's future and accept that there will come a time when they can no longer look after them. This brings several concerns, such as anxiety about the quality of care that their child will receive. Feeling that they cannot rely on the system to care appropriately for their child is the leading cause of stress for parents when they try to envision their child's future (Douglas, Redley and Ottmann, 2017; Cameron and Cooper, 2020). "*What he is going to be like when he grows up? Like I say he is probably going to be stuck to us for the majority of his life anyway...*" (Cameron and Cooper, 2020).

Unavoidable caregiving responsibility

Two studies found that caring for a child with an intellectual disability is seen as an inevitable duty, seamlessly woven into the fabric of daily life (Willis et al., 2019; Douglas et al., 2017). Numerous caregivers have expressed their unwavering commitment to assisting their children with intellectual disabilities in making progress as part of their caregiving responsibilities. Focusing on the obligation to improve or rehabilitate has helped these caregivers remain dedicated to their caregiving duties and make informed decisions regarding their child's care (Yang, Byrne and Chiu, 2016; Willis et al., 2019). "*Needless to say, it is my duty to care for my daughter's daily life, such as cooking for her, dressing her, washing her clothes, and preventing her from hurt. I am her mother. These are what I should do. No one can do it better than me. Every parent would do the same thing for their child"* (Yang, Byrne and Chiu, 2016). Caring for children with disabilities is a shared responsibility, particularly when their children require constant care to manage daily struggles (Douglas, Redley and Ottmann, 2017).

Discussions

This qualitative systematic review aims to identify and synthesize evidence about the experiences of parents with children who have physical and intellectual disabilities. Our analysis revealed seven themes: (1) gendered and emotional experiences, (2) compromising quality of life: physical and psychological impact; (3) lack of knowledge about disabilities; (4) lack of social support; (5) stigma; (6) uncertain future of the recipient; and (7) unavoidable caregiving responsibility

Gendered and emotional experiences

The discussion about caregiving roles for fathers and mothers, especially in the context of their careers, highlights significant gender-based disparities and societal expectations. Fathers often feel conflicted about caregiving tasks due to traditional role expectations tied to their identities as providers. While fathers struggle with the potential impact of caregiving on their careers, mothers do not face the same level of conflict. This difference may be rooted in long-standing societal norms that primarily assign caregiving responsibilities to females (Yang, Byrne and Chiu, 2016). Single mothers encounter a distinct set of challenges, including financial instability, social stigma, and inadequate support systems. These difficulties can exacerbate the stress of balancing work and caregiving, making it even more critical to address societal structures that fail to adequately support single parents (Willis et al., 2019).

When fathers take on caregiving roles, they encounter distinct identity challenges. Societal expectations often categorize caregiving as a non-masculine activity, causing fathers to question their roles as men and parents. Cameron and Cooper (2020) exemplify this struggle from a father's perspective who had to reconcile his decision to prioritize caregiving over working. The quote mirrors the internal conflict experienced by many fathers: the pressure to conform to the traditional male provider role versus the personal desire or necessity to engage in caregiving. The complexity of these issues requires a multifaceted approach. Addressing financial and structural support for single mothers is essential, as is challenging the rigid gender norms that dictate caregiving roles. Encouraging a societal shift toward viewing caregiving as a shared responsibility can help alleviate the pressure on fathers to conform to traditional roles and enable more equitable participation in caregiving tasks.

The challenges faced by parents of children with intellectual disabilities are multifaceted and often fraught with emotional and practical difficulties. Parents frequently experience a mix of emotions and may harbor doubts about their abilities to provide care. Fathers, in particular, may encounter significant adjustments as they need to reassess their priorities and redefine their roles within the family (Yang, Byrne and Chiu, 2016). This may entail modifying their work schedules, reducing their hours, or even departing from their jobs entirely to meet the needs of their children. These adaptations can have far-reaching implications for their personal and family lives.

Caregivers often experience challenges in comparing their children's behavior and communication with typically developing peers, leading to feelings of helplessness, frustration, entrapment, judgment, and isolation. Negative perceptions from others can exacerbate these emotions, as societal expectations and stereotypes about intellectual disabilities impose additional burdens on caregivers. The story of a parent feeling guilty about making financial sacrifices to provide care is emblematic of the pressures and discourses of shame and blame many caregivers face (Dunn, Jahoda and Kinnear, 2020). The emotional toll on caregivers is significant and multifaceted, with guilt being a common experience among parents who must make substantial sacrifices, such as giving up work, which can lead to financial constraints (Dunn, Jahoda and Kinnear, 2020).

Compromising quality of life: physical and psychological impact

Providing care for children with physical and intellectual disabilities is a complex task that demands a great deal of attention and dedication from parents. The journey of caregiving is marked by various complexities that encompass not only the practical aspects of meeting the child's needs but also the emotional, social, and financial dimensions (Hamedanchi et al., 2016). One of the primary challenges in caregiving involves the day-to-day tasks associated with meeting the child's physical and medical needs. This includes tasks such as assisting with mobility, managing medications, and attending to specialized healthcare requirements. The demands of daily care can be physically exhausting, and parents often find themselves navigating a healthcare system that may lack adequate support and resources (Smith, 2020).

Caring for a child with disabilities can present significant emotional challenges for parents. Research indicates that parents of such children often grapple with elevated levels of stress, anxiety, and feelings of social isolation (Brown, Harry and Mahoney, 2018). These emotional impacts are not solely attributable to the child's condition but rather stem from the ongoing uncertainty and difficulties that accompany long-term caregiving.

Lack of knowledge about disabilities

The studies reveal the challenges faced by caregivers of children with intellectual disabilities who have intellectual or physical disorders themselves. Often, these caregivers limit their exposure in public spaces and social circles to avoid discrimination (Chien et al., 2015; Willis et al., 2019; Tekola et al., 2023). This struggle for inclusion extends to schools and communities, adding another layer of complexity to their experiences (Pancsofar et al., 2019; Willis et al., 2019). Sadly, the presence of their children in society often leads to uncomfortable and even humiliating encounters (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021). These findings emphasize the urgent need for greater societal awareness, empathy, and targeted interventions to create a more inclusive and understanding environment for caregivers and their children with intellectual disabilities.

Lack of social support

This review illustrates that individuals tasked with caring for those with intellectual disabilities face a dual challenge of societal neglect and insufficient governmental support. These caregivers express concerns about the inadequacy of available resources and attention for their difficult and often emotionally draining work. The lack of available public services and support programs worsens the challenges experienced by families in need (Yang, Byrne and Chiu, 2016). In addition, ineffective communication and coordination among different agencies make it more difficult for caregivers to obtain essential information and resources. Pancsofar et al. (2019) point out that families perceive a dearth of support services and foresee limited future care options. According to studies conducted by Hamedanchi et al. (2016), the majority of parents feel that society does not have sufficient resources and facilities to allow individuals with intellectual disabilities to be included and participate meaningfully. This multifaceted challenge calls for urgent attention and collaborative efforts from both policymakers and societal stakeholders to address the existing gaps and enhance the overall well-being of this vulnerable population.

Although social support is essential, studies consistently show that participants perceive a need for more substantial public and government support. The participants unanimously agree that they need practical assistance, particularly in the form of financial aid and professional guidance, to help them navigate the challenges of caring for a child with intellectual disabilities. This collective call for tangible support (Hu et al., 2015; Yang, Byrne and Chiu, 2016; Douglas, Redley and Ottmann, 2017; Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021) underscores the urgent necessity for targeted interventions that address the identified gaps in support services. The findings underscore the significance of acknowledging the critical function of social support and actively implementing measures that address the particular needs articulated by caregivers in their pursuit to provide optimum care for their children.

Parents who care for children with disabilities play a critical role in enriching not only their families but society as a whole. Acknowledging and appreciating the significant challenges they face in this endeavor is essential (Hu et al., 2015). The potential for personal distress among parents poses a genuine concern, and its ripple effect can impact the child's overall well-being and the entire family unit (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021). Understanding and addressing these challenges is imperative to fostering a supportive environment that recognizes the resilience of these families while ensuring the optimal care and development of children with disabilities. By identifying the unique hurdles these parents face, we can work toward implementing targeted interventions and support systems that enhance these families' overall quality of life and contribute to a more inclusive and compassionate society (Yang, Byrne and Chiu, 2016).

Raising children with disabilities can be financially challenging. Families often face additional costs related to medical treatments, therapies, adaptive equipment, and specialized education, which can strain their finances (Jones et al., 2017). Unfortunately, financial assistance and support services are limited, compounding the financial difficulties. The impact of these economic challenges goes beyond the immediate parent-child relationship and affects siblings' interactions. Siblings of children with disabilities may face unique experiences, such as changes in family routines, feelings of neglect, and the need to adapt to their brother or sister's specific needs (Meadan, Halle and Ebata, 2010). While some siblings may develop remarkable empathy and resilience, others may face emotional challenges, highlighting the delicate balance within sibling relationships.

Stigma

One significant concern is the stigma experienced by these families, which frequently results in social isolation. Many parents report refraining from social interactions to avoid the adverse judgment and pity directed toward their children. This phenomenon, known as affiliate stigma, impacts children and their families, who seek social acceptance and a sense of belonging (Hu et al., 2015). Mothers, in particular, express a strong desire to be embraced by society and to engage in social activities with their families. However, the pervasive stigma often excludes them and lacks support (Vatne et al., 2023).

The stigma and lack of social support experienced by parents of children with intellectual disabilities and developmental disorders create significant challenges. Addressing these issues requires a comprehensive approach that includes social support networks, public education, inclusive policies, community activities, and professional training. By fostering a more understanding and supportive environment, we can help alleviate these families' burdens and promote their well-being and social inclusion.

Uncertain future of the recipient

Research indicates that parents/caregivers of individuals with intellectual disabilities are primarily concerned about their children's futures. Future caregiving provision and marriage are critical issues (Wong et al., 2004). The impact of future uncertainties related to intellectual disabilities has been observed to cause chronic anxiety and depression among parents (Haley and Perkins, 2004). In some extreme cases, parents have made unconventional decisions, such as arranging marriages for their children with intellectual disabilities to strangers, in order to secure future caregiving. The complex interplay between future uncertainties, parental well-being, and unconventional decisions underscores the need for a nuanced understanding of the multifaceted challenges faced by families navigating the intricacies of intellectual disabilities (Yang, Byrne and Chiu, 2016).

Unavoidable caregiving responsibility

Caring for a child with disabilities can significantly affect the relationship between a parent and their child. The considerable demands of caregiving can increase the parent's attention and involvement, often altering the typical roles of parent and child. The parent may assume the roles of nurturer, caregiver, therapist, and advocate for their child's needs (Lloyd et al., 2019). The demands of caring for a child with disabilities can be emotionally and physically taxing for parents, which can either strengthen their familial bonds through shared challenges or introduce strains. In addition, parents may experience social isolation due to the unique needs and demands of caregiving. They may struggle to participate in social activities due to the necessity for specialized care and attention, leading to feelings of loneliness and exclusion (Turner et al., 2019).

The policy implication based on findings

The qualitative systematic review underscores the intricate challenges experienced by parents caring for children with physical and intellectual disabilities. The findings suggest several policy implications aimed at improving the quality of life for these families and fostering inclusivity in society. The proposed measures include tailored support programs for male and female caregivers, expanded access to comprehensive care services, mental health support, educational workshops, and financial assistance. Furthermore, policies to facilitate long-term planning for the caregiving needs of individuals with disabilities are needed.

One limitation of this systematic review is that it only included publications written in English. This could have impacted the search results and study findings, potentially introducing selection bias. Additionally, as this review was qualitative in nature and the reviewers were not the principal investigators of the included studies, there is a possibility that specific nuances and subtleties may not have been fully captured, potentially enriching and deepening the findings.

Conclusion

Understanding and providing care for children with physical and intellectual disabilities necessitates addressing a multifaceted array of challenges. It is imperative to possess a comprehensive understanding of these intricacies to ensure that families receive the requisite support and interventions. Healthcare professionals and researchers are actively exploring these challenges and endeavoring to establish a supportive and inclusive environment that acknowledges the unwavering dedication of parents and prioritizes the optimal care and development of children with disabilities.

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Conflict of Interest

No potential conflicts of interest.

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Tabel 2. Articles included in the review.

Author and Years	Country	Parents	Children	Type of Disability	Aim of Study	Qualitative methods and analysis	Theme
Hu et al. (2015)	China	N=26 parents Mother (13) Father (7) Grandparents (5) Uncle (1) Gender Male (9) Female (17)	N=26 Children Type Autism (5) Intellectual Disability (7) Cerebral Palsy (4) Fragile X syndrome (5) Down Syndrome (5)	Developmental disabilities	To describe the perceptions that Chinese families of children with developmental disabilities have pertaining to their needs	Focus group discussions and in-depth interviews with transcript analysis	• Survival needs • Sufficiency needs Enhancement needs
Hamedanchi et al. (2016)	Iran	N=10 elderly parents Gender Female (5) Male (5) aged (60–72 years)	N=10 children	Intellectual disabilities	To describe the unpleasant and bitter experiences of the elderly parents of children with intellectual disability.	Unstructured in-depth interviews with phenomenological analysis	• Inappropriate behavior toward the child in the society, the society's failure to support the child with intellectual disability, • Sorrows experienced by parents, the child's problems. • barriers in the care of children with intellectual disability. • Limitations due to aging.
Douglas et al. (2017)	Australia	N=11 parents	N=11 Children Down Syndrome (7) Cerebral Palsy (3) Unspecified (1) Gender Male (8) Female (3) Age (1 – 6)	Intellectual disability (Down Syndrome, Cerebral Palsy)	To explore the information needs of parents of infants with an intellectual disability in the first year of life.	Semi-structured interviews c with descriptive thematic analysis	• The infant's condition. • The infant's specific needs • Available supports and ser vices
Pancsofar et al. (2019)	United States	N=15 fathers	N=15 children Deafblind (11) Autism (4) Age (3-21)	Complex Disabilities: Deafblind and Autism	To investigate fathers' construction of their involvement in their children's education	Semi-structured interviews with content analysis	• It's different than with your other kids: Constructing fathering of children with complex disabilities. • How do you balance that? Fathers' work experiences and school involvement, and • Tag team: Co-parenting relationships and fathers' school involvement. • Identified that explored the intersections between fathers'

Author and Years	Country	Parents	Children	Type of Disability	Aim of Study	Qualitative methods and analysis	Theme
							work experiences and co-parenting relationships in their school involvement experiences.
Willis et al. (2019)	Norway	Forty-four parents (26 mothers, 18 fathers)	31 children with a range of disabilities Type Cerebral Palsy (12), GMFCS, Acquired brain Injury (2), Intellectual Disability (17 Gender Male (18) Female (13) Age (6-17)	Cerebral Palsy, GMFCS, Acquired brain Injury, Intellectual Disability	To explore how an ecological intervention encourages parents of children with disabilities to develop as facilitators, to enable ongoing physical activity participation in a child's local environment	Semi-structured interviews with grounded theory	• Active ingredients of the intervention that enabled learning and empowerment to transpire. • Parent learning and empowerment as a process, • Related outcomes
Cameron and Cooper (2020)	British	N=4 fathers Age (30-59)	N=5 children Gender Boy (4) Girl (1) Age (5-14)	Learning disabilities	To get as close as possible to understanding the experience of these fathers in their role as carers	Semi-structured interview with interpretative phenomenological analysis	• Fatherhood: not doing enough, not doing it right". • Crossing worlds: relearning how to communicate and reclaiming fatherhood. • "Uncertain futures."
Dunn, Jahoda and Kinnear. (2020)	UK	N=7 older fathers Age (61-68)	N=7 children Gender Female (4) Male (3) Age (28-37)	Intellectual disability	To gain a more in depth understanding of older father carers' experiences of parenting.	Semi-structured interviews with constructivist grounded theory analysis	• Wearing different hats: how fathers' sense of identity had altered over the years. • Family comes first": importance placed on the family unit. • "Getting on in years": the challenges faced by ageing fa theirs parenting their son/daughter
Rafferty et al. (2020)	USA	N=28 fathers	N=28 Children Autism spectrum disorder (ASD) (12) ASD/ID (n = 16)	Children with autism spectrum disorder with or without intellectual disability	To examine perceptions of parenting roles and father–child rela tionship quality in fathers of children with asd and asd/id.	Interview with phenomenological analysis	• Pre-birthexpectations • Adjustments • Experiences • Co-parenting • Quality of father–child relationships
Tekola et al. (2020)	Ethiopia	N=14 mothers and 4 fathers Age 25-50	N=14 Intellectual Disability	Development disorder	To explore perceptions and experiences of stigma among parents of children with dd in ethiopia and examine the	in-depth interviews with using thematic analysis	• Dimensions of parents' perceived stigma experiences • Public stigma

Author and Years	Country	Parents	Children	Type of Disability	Aim of Study	Qualitative methods and analysis	Theme
			6 = Autism primary diagnosis while the other four autistic children exhibited delays in one or more areas of development, such as language, motor skills, or cognitive abilities. Gender: Female 5 Male 13		contributing and protective factors for internalised stigma based on the perspectives of the parents themselves		• Courtesy stigma • Affiliate stigma • Perceived consequence of stigma • Parents' positive social experiences/or lack of stigma • Factors influencing affiliate stigma. • perceived family support and acceptance • increased awareness about dd
Jackson and Andipatin (2021)	South Africa	N=14 fathers mean age of 41	N=14 children Gender Female (1) Male (13)	Dyspraxia *(physical disability)*	To explore the subjective challenges that fathers experience in parenting a child that presents with dyspraxia in the cape metropole area	Semi-structured individual interviews with thematic analysis	• Health literacy • Helplessness • Circumscribed interactions • Schools' acquiescence • Lack of support
Uribe-Morales et al. (2021)	Spanish	N=7 young fathers Age (36-49)	N=9 children with various diagnoses. Gender Male (7) Female (2) Age (1 -14)	Children with various diagnoses (hearing impairment, 1P36 deletion syndrome, Down syndrome, Mowat Wilson syndrome, ADHD accompanied by high abilities and oppositional defiant disorder, and ASD)	To explore the perception and experience of fathers of children with disabilities in caring for their children; to know their role and how these tasks impact their daily life, health and physical, mental and/or emotional well-being.	Semi-structured interviews with discourse analysis	• Shared responsibilities • Somewhat difficult to fit in • Either you join or you split.
Murdoch and Chang (2022)	England	N=6 mothers Age (35 – 60)	N=6 Children Age (3-18)	Children with learning disabilities (LD)	To explore how parents experienced caring for their child with LD and procedural anxiety in hospital.	Semi-structured interviews with interpretative phenomenological analysis	• Emotional toll: parents characterized their experiences as highly emotional; reporting feeling stressed, anxious, and worried. • Restraint and holding parents spoke of their experiences of restraint which were largely viewed as negative and sometimes inappropriate. • Advocacy: parent articulated their responsibility as advocates for their children.

Author and Years	Country	Parents	Children	Type of Disability	Aim of Study	Qualitative methods and analysis	Theme
							• Going it alone: parents were extremely proactive in managing their child's anxieties, but some also felt highly pressurized and isolated. • Inconsistency and uncertainty: parents experience consist ency and uncertainty in their children's care from health care professionals which led to anxiety and frustration.
Vatne et al. (2022)	Norway	N=7 fathers	N=7 children	Intellectual disability diagnosis; three with co-morbid conduct disorders. Two children had a diagnosis of progressive nature, one with physical manifestations, the other with both intellectual and physical manifestations.	To explore men's experience of being a father in families with childhood disability.	Semi-structured interviews with conventional content analysis	• Children's needs in the father child relationship, • Fathering behavior perceived to meet children's needs, • Fac tors perceived to influence father behaviors, and • psychological wellbeing among fathers
Tekola et al. (2023)	Ethiopia	N=14 mothers and 4 fathers Age 25-50	N=14 Intellectual Disability 6 = Autism primary diagnosis while the other four autistic children exhibited delays in one or more areas of development, such as language, motor skills, or cognitive abilities. Gender: Female 5 Male 13	Autism, cerebral palsy, Intellectual Disabilities, ADHD	To explores the experiences of parents) raising children with developmental disabilities in urban and rural Ethiopia	Interviews with thematic analysis	• Socio-cultural beliefs influenced recognition of and responses to delays/differences. • Nuanced and diverse family relationships and social life. • Multiple and intersecting struggles • 'My child is my jewel': parents' faith, positive outlook, and hope.

AUTHORS INDEX

VOLUME 19 ISSUE 3 MAY 2024

SUBJECT INDEX

VOLUME 19 ISSUE 3 AUGUST 2024

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AUTHOR INFORMATION PACK

Update: March 2022

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I. DESCRIPTION

Jurnal Ners provides a forum for original research and scholarships relevant to nursing and other health-related professions. Jurnal Ners is a scientific peer-reviewed nursing journal that is published biannually (April and October) by the Faculty of Nursing Universitas Airlangga, Indonesia, in collaboration with the Central Board of the Indonesian National Nurses Association.

The journal particularly welcomes studies that aim to evaluate and understand the complex nursing care interventions which employ the most rigorous designs and methods appropriate for the research question of interest. The journal has been publishing original peer-reviewed articles of interest to the international nursing community since 2006, making it one of the longest standing repositories of scholarship in this field.

Jurnal Ners offers authors the benefits of (1) A highly respected journal in the nursing field; (2) Indexed in major databases, such as SCOPUS, Science and Technology Index (SINTA); Directory of Open Access Journal (DOAJ); (3) Rapid initial screening for suitability and editorial interest.

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II. FOCUS AND SCOPE

The scope of this journal includes studies that intend to examine and understand nursing health care interventions and health policies which utilize advanced nursing research from the Asian perspective. Jurnal Ners publishes research related to clinical settings, community, and health policy in Asia from comparative and international views.

We aim to evaluated and understand the complex nursing care intervention on Fundamentals of Nursing, Clinical Nursing, Community, and mental health nursing. The journal also committed to improving the high-quality research by publishing analytic techniques, measures, and research methods, not an exception to systematic review papers.

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SCHIZOPHRENIC CLIENTS

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Table 1. Effects of plant growth regulator types and concentrations on embryogenic callus induction from leaf tip explants of *D. lowii* cultured in ½ MS medium supplemented with 2.0 % (w/v) sucrose under continuous darkness at temperature of 25 ± 2 °C after 60 days of culture

Table 3. Maternal and child health care-seeking behaviour for the last pregnancy in women aged 15 – 45 years old

Type of care	Age Groups (Years)							
	<30		30 - 39		40 - 45		All Age	
	n	%	n	%	n	%	n	%
Place for antenatal care								
Village level service (Posyandu, Polindes or Poskesdes)	1	9.1	1	4.6	1	3.5	3	4.8
District Level service (Puskesmas/Pustu)	2	18.2	7	31.8	1	3.5	10	16.1
Hospital, Clinics, Private Doctor or OBGYN	1	9.1	4	18.2	2	6.9	7	11.3
Private Midwife	7	63.6	10	45.5	25	86.2	42	67.7
Place of Birth								
Hospital	5	50.0	5	22.7	4	13.8	14	23.0
Birth Clinic/Clinic/Private health professional	5	50.0	15	68.2	21	72.4	41	67.2
Puskesmas or Pustu	0	0.0	2	9.1	0	0	2	3.3
Home or other place	0	0.0	0	0	4	13.8	4	6.6
Ever breastmilk								
No	1	9.1	1	4.6	1	3.5	3	4.8
Yes	10	90.9	21	95.5	28	96.6	59	95.2
Exclusive breastfeeding								
No	4	36.4	10	45.5	18	62.1	32	51.6
Yes	7	63.6	12	54.6	11	37.9	30	48.4

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Reference to a Book:

de Virgilio, C. & Grigorian, A. 2019, 'Surgery: A case based clinical review' in Surgery: A Case Based Clinical Review, pp. 1-689.

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Harper, M.S. 2021, 'Mental health and mental health services' in Services to the Aging and Aged: Public Policies and Programs, pp. 283-297.

Reference to a Website:

WHO (2021) *WHO Coronavirus Disease (COVID-19) Dashboard: Situation by Country, Territory & Area*.

Reference in Conference:

Yuarnistira, Nursalam, N., Rachmawati, P.D., Efendi, F., Pradanie, R. & Hidayati, L. 2019, 'Factors Influencing the Feeding Pattern of Under-Five Children in Coastal Areas', IOP Conference Series: Earth and Environmental Science.

Reference in Statute:

Pemerintah RI (2014) *Undang-Undang Republik Indonesia Nomor 38 Tahun 2014 Tentang Keperawatan*. Indonesia. Available at: https://peraturan.go.id/common/dokumen/ln/2014/uu38-2014bt.pdf.

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