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framework........ 403

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SEARCH STRATEGY

Set No.	Searched for	Databases	Results
S7	pharmacy	Ebook Central, Public Health Database, Publicly Available Content Database	322023*
S6	"pharmacy"	Ebook Central, Public Health Database, Publicly Available Content Database	291670*
S5	"pharmacy" AND PEER(yes)	Ebook Central, Public Health Database, Publicly Available Content Database	214027*
S4	"pharmacy"	Ebook Central, Public Health Database, Publicly Available Content Database	291670*
S3	food pharmacy	Ebook Central, Public Health Database, Publicly Available Content Database	117998*
S2	new pharmacy	Ebook Central, Public Health Database, Publicly Available Content Database	244929*
S1	pharmacy	Ebook Central, Public Health Database, Publicly Available Content Database	322023*

* Duplicates are removed from your search, but included in your result count.

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Exploring the impact of engagement in mental health and substance use research: A scoping review and thematic analysis

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ABSTRACT (ENGLISH)

Background

There is growing evidence demonstrating the impact of engaging people with lived experience (PWLE) in health research. However, it remains unclear what evidence is available regarding the impact of engagement specific to mental health and substance use research.

Methods

A scoping review of three databases and thematic analysis were conducted. Sixty-one articles that described the impact of engagement in mental health and substance use research on either individual experiences or the research process were included.

Results

Key topics include (a) the impact of engagement on individual experiences; (b) the impact of engagement on the research process; and (c) facilitators and barriers to impactful engagement. Studies largely focused on the perceived positive impact of engagement on PWLE (e.g., personal and professional growth, empowering and rewarding experience, feeling heard and valued), researchers (e.g., rewarding experience, deeper understanding of research topic, changes to practice), and study participants (e.g., added value, fostered a safe space). Engagement activities were perceived to improve facets of the research process, such as improvements to research quality (e.g., rigour, trustworthiness, relevance to the community), research components (e.g., recruitment), and the research environment (e.g., shifted power dynamics). Facilitators and barriers were mapped onto the lived experience, researcher, team, and institutional levels. Commonly used terminologies for engagement and PWLE were discussed.

Conclusion

Engaging PWLE—from consultation to co-creation throughout the research cycle—is perceived as having a positive impact on both the research process and individual experiences. Future research is needed to bring consistency to engagement, leverage the facilitators to engagement, and address the barriers, and in turn generate research findings that have value not only to the scientific community, but also to the people impacted by the science.

Patient or Public Contribution

PWLE were engaged throughout the scoping review process, including the screening phase, analysis phase, and write-up phase.

FULL TEXT

INTRODUCTION

The past two decades have demonstrated a shift towards engaging people with lived experience (PWLE) in health research as collaborators, rather than as study participants.[1] Often referred to as patient engagement, consumer engagement, patient and public involvement, or co-production, engagement in research involves authentic and ongoing collaboration with PWLE across the research cycle, from conceptualization to dissemination.[2] PWLE can be engaged on a continuum, ranging from consultation and advisory roles to equal partnerships, leadership, and decision-making roles.[3] Engagement in research has been framed as a way to improve research quality and relevance of study findings to the community, in addition to being an ethical imperative.[4]

Funding bodies are increasingly interested in supporting researchers who engage PWLE throughout the research process to improve the impact, quality, and relevance of the research they fund.[5–7] For instance, institutions such as the Centre for Engagement and Dissemination in the United Kingdom,[8] Patient-Centered Outcomes Research Institute in the United States,[6] and the Canadian Institutes of Health Research Strategy for Patient-Oriented Research in Canada[2] have set guidelines and policies around engagement in health research. As institutions continue to set national standards around engagement, efforts should be made to mitigate potential harms from tokenistic and inequitable practices.[9] This is especially important as engagement in research is often critiqued for having limited representation of socially marginalized groups (e.g., racialization, low income) among collaborators.[10,11]

The shift from passive recipients to active experts, researchers, and leaders has fueled an expanding body of democratic research in the mental health and substance use field. The moral obligation of engagement is especially relevant to this field given the historical oppression and coercive practices in psychiatry that have left patients silenced, without power, and as passive recipients of care.[12] Grassroots movements in the late twentieth century played a key role in dismantling power dynamics and challenging current practices in psychiatry, along with advocating for the involvement of PWLE as key knowledgemakers within systems restructuring and research.[12,13] Yet, there is work to do to continue unpacking past practices, especially as ongoing progress is often overshadowed by research priorities rather than challenging power structures within institutions.[14]

There is growing evidence demonstrating the impact of engagement in health research. Previous engagement research suggests that the way impact is measured and reported is inconsistent and limited to subjective accounts of impacts.[15–17] Evidence from reviews that assess impact varies regarding the impact on *who*, such as the impact on individuals (e.g., PWLE and researchers)[18] or *what*, such as the impact on research design and delivery (e.g., recruitment rates in clinical trials).[19,20] Similar to how evidence-based medicine is viewed as the gold standard in health research, current practices in health research largely focused on measuring the impact of engagement on the research process.[9] However, especially in the mental health field, framing engagement as solely valuable to the research itself risks undermining the ethical imperative behind engagement activities.[21]

Recent reviews have described the impact of engagement in health research;[18,20,22] however, it remains unclear what evidence is available regarding the impact of engagement specific to mental health and substance use research. Indeed, the assumptions underlying impact in health research may not apply to a mental health and substance use context given the abundant presence of power imbalances, the perceived vulnerability of PWLE, and the stigma around the capacity of PWLE to consult in research projects.[12,13] Therefore, this scoping review aims to map the literature on how the impact of engagement is conceived in mental health and substance use research. A scoping review is ideal for this study as the topic is an emerging field, with a wide range of designs across studies, allowing for a flexible approach—an important feature as the state of the evidence and methods is unclear.[23] The specific objectives of this review are to map the impact of engagement on both individual experience and the research process and identify key barriers and facilitators to impactful engagement. The following research questions are identified:

- 1.

  What is known from the existing empirical literature about the impact of engagement in mental health and substance use research?

- 2.
  What are the barriers and facilitators to impactful engagement in mental health and substance use research?

METHODS

The present scoping review was guided by Arksey and O'Malley's framework[24] and the enhanced framework by Levac and colleagues.[25] The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews checklist was followed to ensure methodological and reporting quality.[26] This review follows the Canadian Institutes of Health Research (CIHR) definition of patient engagement in research, which is defined as 'meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation'.[2] The term 'patient engagement' is only used for clarity purposes as it is commonly used in health research. In response to the expressed preferences of our lived experience panel, we refer to people with lived experience engaged in research projects as PWLE instead of the term 'patient'—this is for clarity purposes; it should be noted that researchers can also identify as PWLE and apply their lived experience to research.[27,28]

Patient and public involvement

The scoping review process involved PWLE during the screening phase, analysis phase, and write-up phase. As detailed in Section 2.4, the screening phase involved two PWLE. During the analysis phase, the results were presented to the Lived Experience Advisory Group at the Centre for Complex Interventions within CAMH. Based on the feedback from the first meeting, the results were refined to replace 'patient' with 'people with lived experience,' in addition to examining terminology in the analysis. The refined results were brought back to the group in the second meeting during the write-up phase. Lastly, multiple manuscript versions were further refined by two PWLE, who are also included as co-authors.

Eligibility criteria

Eligibility criteria are shown in Table 1. The Population, Concept, and Context (PCC) framework by the Joanna Briggs Institute was used to identify relevant studies for this scoping review.[29] For the *population*, this review includes studies that focus on PWLE of mental health or substance use challenges (any age group), and have been engaged or involved in mental health or substance use research as collaborators (e.g., advisors, co-researchers). The *concept* of the scoping review is the impact of engagement, including reported outcomes on individual experiences and the research process. The *context* of the review is limited to engagement in mental health and substance use research in the past decade to capture the impacts related to the current state of engagement practices. Articles that look at engagement outside of a research context, for example only in the context of health care policy and governance work, were excluded as the justification, processes, and impact may differ. There were no limitations for the geographical location.

Table 1 Search criteria for the scoping review.

Search terms	Concept 1: Engagement	Concept 2: Mental Health	Concept 3: Impact

	Patient participation/**OR** (patient* or client* or public or ‘service user*’ or youth or consumer* or citizen*) adj2 (participat* or engag* or invol*) **OR** ‘liv* expertise’ or ‘lived experience’ or ‘peer* researcher*’ or ‘co-researcher*’ or ‘expert* by experience*’ or ‘patient* partner*’ or ‘patient* advisor*’ or ‘co-produc*’ or ‘co-design’	Mental Health/**OR** (mental* or psychiatr* or psycholog*) adj2 (health* or ill* or hygiene or disorder* or distress*) **OR** (drug* or substance* or alcohol*) adj2 (abus* or addict* or depend* or misus* or use* or dependen* or disorder*)	(improv* or strength* or inform* or increase* or impact* or facilitat* or support*) adj3 (research* or method* or design or outcome* or recruit* or study or team*)
Databases	Medline (Ovid), CINAHL (EBSCO), and PsycINFO (ProQuest)		
Inclusion	• (a) academic journal articles, including full-length original research (e.g., qualitative, quantitative, mixed or multi-methods, case studies), brief reports, or commentaries/viewpoints that provide an overview of the engagement process in a project		
	• (b) focused on ‘patient engagement’ in a research context		
	• (c) specific to mental health or substance use research		
	• (d) published in English		
	• (e) published between 2012 and 2022		
Exclusion	• (a) defined ‘patient engagement’ as patient retention or engagement in clinical decisions (e.g., patient care and shared decision-making)		
	• (b) did not include a research context (e.g., studies looking at engagement in non-research government setting)		
	• (c) did not describe the impact of engagement		
	• (d) focused primarily on neurological, developmental, or physical disorders		

	• (e) reviews, protocols, conference abstracts
	• (f) focused only on family engagement
	• (g) commentaries/viewpoints that did not provide a description of the engagement process in a project
Time	The scoping review was conducted in June 2022 and included studies published between the period of January 2012 and June 2022.

Note: An asterisk is used to represent a ‘wildcard’ or unknown character.

Information sources and search strategy

The search strategy was developed in consultation with a health sciences librarian. The following electronic databases were searched in June 2022: Medline (Ovid), CINAHL (EBSCO), and PsycINFO (ProQuest). Academic articles were limited to after 2012 due to engagement in mental health and substance use research growing substantially in the past decade; it also maximized relevance to current engagement frameworks.

A full description of search terms and strategies is shown in Table 1. As ‘patient engagement’ is broadly defined, without consistent terminology, multiple search strategies were piloted to identify appropriate keywords. After an initial search was conducted to determine which terms reflect the phenomena in the research question, the following combination of search terms were used to broadly define PWLE, such as *patient*, client*, public, service user*, youth, consumer**, and *citizen**. To capture engagement, search terms such as *engag*, participat**, and *invol** were used adjacent to the term for PWLE, in addition to other terms such as *co-researcher*, co-design**, and *co-produc**. Search terms such as *mental, psychiatr*, psycholog*, substance** were used adjacent to *health*, use*, disorder** to situate the search in the field of mental health and substance use. Lastly, search terms such as *impact*, support**, and *improv** were included to capture studies that discussed the impact. The search terms were adapted for each database concerning the proximity operators, truncations, and wildcard symbols.

Selecting sources of evidence

All articles identified in each database search were imported to Covidence (www.covidence.org), a systematic review software. Upon uploading the search results from each database, duplicates were removed. Titles and abstracts were screened by three reviewers (including two PWLE) for relevance to the PCC eligibility criteria. Following this step, two reviewers screened 20 of the 160 articles selected for full-text review, yielding a κ value of 1. Given the perfect agreement, one reviewer screened the remaining articles to further validate eligibility and identify relevant publications from the listed sources. A total of 61 articles were deemed eligible for data extraction.

Data charting and analyses

Informed by Arksey and O'Malley and Levac and colleagues,[24,25] a data charting tool was developed iteratively by NYS and LDH to extract information from the 61 articles. The data charting form was created on Microsoft Excel and initially piloted on 20 articles, enabling the refinement of the charting tool before its use in this study. The tool included article characteristics, key variables relevant to the PCC criteria, and findings related to the research questions. The following data were abstracted: (1) general information (authors, title, publication year, journal, country, article type); (2) study design (population, setting, methods, objectives, whether a reporting guideline is used); (3) engagement context (level of engagement, whether sociodemographics for PWLE such as gender and race/ethnicity were reported, the term used to describe engagement, whether PWLE were included as co-authors); (4) concepts (outcomes, focus on individual experiences or research process); and (5) key findings (impacts, facilitators, barriers). Note, data on PWLE as co-authors were removed due to the subjectivity and uncertainty of accurately identifying their lived experience status in the authorship list. Facilitators and barriers were added as data items during the pilot data charting process due to the dominance of these factors in the selected articles and the richness of information they provided.

In addition to the data charting tool, the 61 articles were uploaded to NVivo 12 and analysed by a single coder (NYS) using the codebook approach to thematic analysis.[30] Here, themes are conceptualized as topic summaries.[30] An initial coding framework was developed by NYS based on the piloted data charting process. Throughout the process, additional codes and themes were developed inductively and refined through weekly meetings with two of the authors (NYS, LDH). The codes and themes were further refined through feedback from a larger research team within the same unit, of which many team members identified as having lived experience, in addition to the unit's Lived Experience Advisory Group. Lastly, using the text frequency option on NVivo 12, we explored the most commonly used terminologies for ‘engagement’ and ‘people with lived experience’. This was added at a later phase as a separate analysis from the thematic analysis and was based on the feedback from the Lived Experience Advisory Group.

Synthesis of results

The extracted data from Excel and NVivo were collated and summarized in a narrated format according to the key outcomes related to the research questions: impact on individuals, impact on the research process, and facilitators and barriers to impactful engagement. The evidence is also presented through tables and a diagram. The tables include the study characteristics, findings related to the facilitators and barriers, and commonly used terminologies. A figure is used to summarize the impact of engagement on PWLE, researchers, study participants, and the research process.

RESULTS

The search strategy yielded 2879 citations after removing 986 duplicates. After reviewing 2879 titles and abstracts, followed by 160 full-text records, 61 articles were included in the scoping review (Figure 1). The majority of studies were published in 2019–2022 and came from the United Kingdom, Australia, or Canada (Table 2). The 61 articles consist of 21 reflection/description of process papers, 20 qualitative studies, 5 quantitative studies, 4 viewpoints/commentaries, 3 case studies, and 1 priority-setting paper. Key topics include (a) the impact of engagement on individual experiences; (b) the impact of engagement on the research process; and (c) facilitators and barriers to impactful engagement. All 61 articles described the impact of engagement on either individual experiences or the research process (Figure 2).

Figure 1. PRISMA-ScR flow diagram of article selection. PRISMA-ScR, Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews.

Table 2 Study characteristics (total = 61 studies).

Characteristic	Count
Study type	
Reflection or description of the process	21

Qualitative	20
Mixed or multi-method	7
Quantitative	5
Viewpoint or commentary	4
Case study	3
Priority setting	1
Country	
Canada	12
United States	7
United Kingdom	23
Australia	13
New Zealand	1
Ireland	1
Germany	1
Norway	1
Sweden	1
Year of publication	
2019–2022	36
2015–2018	18
2012–2014	7
Guidelines followed	
Followed GRIPP or GRIPP2	8
Did not follow GRIPP or GRIPP2	53

Abbreviations: GRIPP, Guidance for Reporting Involvement of Patients and the Public.

Figure 2. The impact of engagement on individuals and the research process in mental health and substance use research. LE, Lived experience.

Impact of engagement on individual experiences (*N* = 48)

Perceived impacts related to individual experiences were described in 48 articles (Figure 2). Here, 35 articles described the impact of PWLE, 26 articles described the impact on researchers, and 11 articles described the impact on study participants.

Impact on people with lived experience (*N* = 35)

The impact of engagement on PWLE was described in 35 articles. Engagement activities were seen as providing positive opportunities for PWLE, including personal and professional growth,[31–41] in addition to building knowledge and skills.[32–35,37–40,42–51] Many studies noted that PWLE found engagement to be a meaningful, empowering, and rewarding experience.[32,34,42,43,52,53] Moreover, PWLE described the impact of engagement on the self, such as feeling heard and valued,[31,32,35,36,38,43,45,49-51,54-59] building confidence,[32,34,37-39,41,42,54,60-63] feeling less alone in their experiences,[39,64] transforming their narrative (e.g., new self-understanding),[31,34,39,41,43,49,50,54] and having a positive impact on their mental health and recovery.[36,39,41,42,52,65] Lastly, PWLE reported feeling a sense of strengthened agency and control, including their ability to influence and change research.[31,34,35,41,46,65,66]

Impact on researchers (*N* = 26)

Despite 26 articles reporting on the impact of engagement on researchers, the findings are less extensive compared to PWLE. Several studies noted that researchers found engagement to be valuable and rewarding,[35,37,42,44,45,65,67-69] giving them a deeper understanding of the research topic and lived experience perspectives.[43,44,47,54,56,70] Researchers also found that engagement added value to their research,[35,44,47,62,71-74] brought a new perspective to the research project,[38,44,49,65,69] and was a valuable means of bringing about change in research.[75] In three studies, researchers reported finding lived experience as an irreplaceable expertise.[44,51,69] Engagement resulted in changes to their research practice,[37,39,47,59,60,65,76] in addition to strengthening their commitment to engagement going forward.[37,47,67]

Impact on study participants (*N* = 11)

Although the evidence is limited, some studies reported that engagement had a positive impact on the experiences of participants in a research project. Including PWLE in the research process was seen as an added value to participants,[32,39,68] was considered to have made a positive difference to participants,[63,77] and was found to create a safe space for participants.[57,78] Moreover, two studies noted that engagement increased the retention of study participants.[44,77] Overall, engagement helped ensure that the research was accessible, acceptable, and relevant to participants[50,65,77] and that study materials were appropriate for participants.[51,59]

Impact on the research process (*N* = 50)

Fifty studies described the impact of engagement on the research process (Figure 2). The impact was threefold: engagement positively influenced research quality, research components, and the research environment.

Research quality (*N* = 42)

Forty-two studies reported that engagement improved the quality and rigour of the research.[42,44,57,66,69,72,77,79,80] Many studies reported perceived improvements to the data and findings, including improvements to data interpretation and analysis,[32,37,42,70,80] reflexivity,[69,81] authenticity and accuracy of findings,[38,57,82] trustworthiness and credibility of data,[65,69,79,83] depth and richness of data,[32,36,44,51,56,57,60,63,66,68,69,80,83,84] and validity.[36,37,57,80,85,86] Engagement also strengthened study design and methods.[32,34,39,43,57,66-68,71,77,83,87] For example, this included improvements to data collection for qualitative studies, such as enhanced rapport with participants[36,37,56,63,68,69] and improved interview guides.[32,37,44,48,51,56,68,80] Although only reported in a limited number of quantitative studies, authors considered that engagement can lead to the development of a clinically appropriate psychometric assessment,[88] inform the selection of quantitative measures and/or analysis plan for trials,[49,67,87] and inform eligibility criteria for trials.[87] Most importantly, engagement was seen to increase relevance to the community and service users.[35-37,44,45,47,50,51,56-59,65,68-70,77,80,82,85-89]

Research components (*N* = 32)

PWLE was considered to improve research components by informing a range of ideas and outcomes;[32,34,43,66-68,71,77,80] this included defining and refining research questions,[42,43,51,68,77] identifying relevant research areas,[50,55,66,68] and improving the ethics review process by further highlighting ethical issues that may have otherwise been overlooked.[35,44] Several studies reported that engagement increased the recruitment of study participants.[32,35,42,44,57,69,72,77,80] However, one study reported no impact on trial recruitment.[90] Engagement was reported to inform and improve knowledge dissemination activities[32,37,48,51,60,63,68,80] and service design.[67,69,88] Overall, engagement was seen as an added value to the research project[33,34,41,43,58,59,65,67,69,71,83,89] and was considered to contribute to study success.[33,37,44,61,67,88]

Research environment (*N* = 20)

Engagement was considered to impact both the research team and the broader research environment. In terms of the team environment, PWLE improved decision-making and communication,[43,50,55,67,83] fostered reciprocal learning between PWLE and researchers,[44,47,49,57,58,61,89] enabled a positive change in the organizational culture,[56,76] and added diverse perspectives to the research teams.[35,44,69] In terms of the broader environment, PLWE engagement challenged stigma[36,40,43,70] and shifted power dynamics.[54,89]

Facilitators and barriers to impactful engagement

The majority (*N* = 51) of the studies identified facilitators and barriers to impactful engagement in mental health and substance use research (Table 3). The studies were categorized into four levels of barriers and facilitators: lived experience level, researcher level, team level, and institutional level.

Table 3 Barriers and facilitators to impactful engagement in mental health research.

	Barriers to impactful engagement	Facilitators to impactful engagement
	Lived experience level	
Intrapersonal factors	Feeling anxious or nervous;[39,40,48,59] feeling isolated from other community partners;[60] feeling disconnected, unsupported, or disengaged;[34,36,49,50,67,80] skepticism, mistrust, or perceived risks;[49,57,60,62] negative experiences;[50] attendance issues;[32,35] varying levels of interest and availability[34,40,43]	Feeling accepted and valued;[32,34,35,37,38,41,48,51,56,59,65,80] trust;[35,49,51,58,60] self-awareness;[42] seeing their feedback incorporated[32,36–38,45,87]

Roles and responsibilities	Having their other identities ignored;[49] given limited information;[48] not compensated;[50] learning curve;[67]	Contributions are formally recognized;[41,51,61,80] continuity with roles;[32,37,57,67,80] given time to contribute;[32,80] having supports and resources available;[37,49,50,55,59,61,65,76,80] included in consensus-building or decision-making;[37,49,53,57,63,70] co-chairing meetings;[49,60,86] expertise in addition to lived experience;[46,49,58]
Logistical	Technological barriers;[32] language barriers;[34] travel and geographical barriers;[32,34,57,76]	Fair compensation;[39,40,45,48,50,53,57–59,61,80] training and/or mentorship[32,33,35,39,42,44,50,56,57,59,61,62,65,68,71,80,84,87,91]
Researcher level		
Knowledge		
Attitudes and perceptions	Limited awareness of engagement opportunities;[65] limited understanding of patient experiences;[75] not knowing how to properly engage;[91] pushback from researchers;[51,61,72] only participating in engagement activities because it is required;[77] valuing institutional knowledge over lived experience;[47,50,61,65,75] researcher identity[66]; paternalistic attitudes (e.g., patronizing)[75]	Listening and open to feedback;[41,65] recognizing power differences;[65,80,85] advocating for engagement;[45,51,58,75] valuing lived experience as an expertise;[38,45,49,61] perceived support from colleagues[72]
Logistical		Engagement training and/or mentorship for researchers;[40,47,72,77,91]
Team level		
Communication	Poor communication;[34,40,46,48,50] use of jargon;[38,49,57,61,65,80] not integrating feedback from PWLE[65,80]	Pre- and de-briefs;[37,39,49,55,57,61,67,78] listening to each other;[37,38,41,45] clearly defined roles;[45,48,50,57,61,80] honest and open conversations;[37,49,55,80] transparent and clear communication;[49,57,60,61,80,87] plain language;[59,67,79,85] understanding different preferences;[49,59,80] strong support and values set as early as possible;[43,62,67] reciprocity between researchers and patients.[31,33]

Team dynamics/interactions	Differing or conflicting views;[36,37,49,50,65,67,76,85] tokenism;[33,36,42,53,61,65,67,71,72,77,80,85] stigma and/or prejudice[36,40,42,47,49-51,75,76]	Building trust;[37,49,57,70,85] established relationships or rapport early on;[37,40,46,58,67] inclusive, safe, and non-judgmental team environment;[37,38,42,45,49,58,59,61,64,67,85] investing in team relationships;[37,38,49,56-59,60,70,76,85] reciprocity and mutual learning;[38,41,49,58,63,76,85,89] shared values;[63] supportive and respectful team;[34,35,41-43,49,55-59,61,63,67,71,72,77,84,85] power-sharing[34,36-38,46,47,49,53,56-58,63,67,70,80,87]
Planning and implementation	Lack of diversity/representativeness;[43,50,67,80] missing or limited engagement in early stages;[50,65,87] transactional/superficial involvement;[36,80] disorganized;[50] lack of continuity with roles[72,80]	Anti-oppressive and/or trauma-informed lens;[36,53,58,61,85] strong commitment to engagement;[32,48,72] engagement at early stages;[40,50,59,76,77,80,84,85,87,89] engagement throughout the research process;[40,43,77,80,84] diverse representation of lived experiences;[37,53,55,56,80] flexibility throughout the research process;[32,37,40,45–47,49,57,59–61,70,76,77,80,87] providing a range of opportunities;[35,55] having an engagement coordinator;[50,60,67,72,80] well-planned engagement;[32,80] ongoing reflective practice[57,87]
Institutional level		
Resources	Time constraints;[37,42,53,62,65–67,71,72,76,80,87,92] limited funding and financial resources;[32,37,48,57,62,65–67,72,75,77,80,91] reliance on one organization[43]	External partnerships;[35,43,48,50,54,55,57] networks and more resources available;[65,91] establishing a lived-experience researcher group;[73,74] support from organization;[62,65,92] support from funders;[62,77,91] incentives for engagement[77]
Institutional structures and culture	Competitive nature of research environment;[42,59,66,67,71,72,76,77] research culture;[49,51,53,76,77] resistance to change;[47,67,75,91] hierarchies within research;[49,51,75] bureaucratic requirements;[47,57,76] ethics board;[47,59,62,75–77] power differences;[36,40,43,47,49,51,57,60,72,75,91] ‘us’ versus ‘them’ culture (e.g., having their lived experience ignored, not disclosing their lived experience);[49,58] lack of community accountability for researchers[36]	Organization's readiness for change;[56] lived experience representation at the leadership level;[32,53] institutional requirements for engagement;[73] expectations set by funders or institutions for high levels of engagement;[62,70,72,74,91] flexibility within hospital structures;[32,33]

Lived experience level (*N* = 35 studies)

The literature related to facilitators and barriers at the level of PWLE included personal factors that influence engagement, such as emotions and perceptions, roles and responsibilities, and others. Most common facilitators included training and/or mentorship,[32,33,35,39,42,44,50,56,57,59,61,62,65,68,71,80,84,87,91] feeling accepted and valued,[32,34,35,37,38,41,48,51,56,59,65,80] having supports and resources available,[37,49,50,55,59,61,65,76,80] and fair compensation.[39,40,45,48,50,53,57-59,61,80] Common barriers included PWLE feeling disconnected, unsupported, or disengaged,[34,36,49,50,67,80] in addition to skepticism, mistrust, or perceived risks.[49,57,60,62]

Researcher level (*N* = 18 studies)

Researcher-level facilitators and barriers were less frequently reported compared to other levels and largely related to researchers' knowledge, attitudes, and perceptions regarding engagement. Some studies noted facilitators such as recognizing power differences,[65,80,85] advocating for engagement,[45,51,58,75] and valuing lived experience as expertise.[38,45,49,61] Engagement training and mentorship was also seen as an important facilitator for researchers.[40,47,72,77,91] Common barriers included researchers valuing institutional knowledge over lived experience,[47,50,61,65,75] and pushback from researchers.[51,61,72]

Team level (*N* = 45 studies)

Team-level facilitators and barriers are the most frequently reported, described across 45 studies. Facilitators and barriers related to planning and implementation, communication, and team interactions. Critical facilitators for the planning and implementation of successful engagement include engaging PWLE at early stages in the research process[40,50,59,76,77,80,84,85,87,89] and flexibility throughout the research process.[32,37,40,45–47,49,57,59–61,70,76,77,80,87] Barriers include a lack of diversity among PWLE[50,65,87] and limited engagement in early stages.[43,50,67,80] Common communication facilitators include holding pre- and de-briefs,[37,39,49,55,57,61,67,78] ensuring transparent and clear communication,[49,57,60,61,80,87] and clearly defining roles.[45,48,50,57,61,80] Barriers at the team level include the use of jargon among team members.[38,49,57,61,65,80] Several studies referenced facilitators regarding team interactions, such as supportive and respectful teams.[34,35,41–43,49,55–59,61,63,67,71,72,77,84,85] The current literature also suggests the importance of inclusive, safe, and non-judgmental team environments for successful engagement activities.[37,38,42,45,49,58,59,61,64,67,85] However, tokenism[33,36,42,53,61,65,67,71,72,77,80,85] and conflicting views[36,37,49,50,65,67,76,85] are frequent barriers to the successful engagement of PWLE.

Institutional level (*N* = 37 studies)

Barriers and facilitators to engagement at the institutional level are described across 37 studies. These relate to the institution's culture and structures, in addition to the resources provided by institutions (e.g., resources from organizations, and funding bodies). For the institution's culture and structure, the expectations set by institutions for high levels of engagement[62,70,72,74,91] facilitated impactful engagement. However, commonly cited barriers included power differences,[36,40,43,47,49,51,57,60,72,75,91] the competitive nature of the research environment (e.g., fast-paced, heavy focus on outputs),[42,59,66,67,71,72,76,77] and the research culture itself.[49,51,53,76,77] In terms of resources, external partnerships[35,43,48,50,54,55,57] and support from funding bodies[62,77,91] were seen as critical facilitators, while time constraints[37,42,53,62,65–67,71,72,76,80,87,92] and limited funding[32,37,48,57,62,65–67,72,75,77,80,91] were major barriers.

Commonly used terminologies

The most commonly used terminologies for engagement and PWLE are shown in Table 4. Out of 61 studies, commonly used terminology for engagement across the included studies was ‘participatory research’ (31.1%), ‘patient and public involvement’ (29.5%), ‘coproduction’ (27.9%), and ‘service user involvement’ (23.0%). Commonly used terminology for people with lived experience included ‘patient’ (59.0%), ‘service user’ (52.5%), and ‘consumer’ (34.4%).

Table 4 Most commonly used terminology related to engagement across studies (*N* = 61).

	Frequency[b]	%
Most commonly used term for "engagement" in each study[a]		
Participatory research	19	31.1
Co-production	17	27.9
Patient and public involvement	18	29.5
Service user involvement	14	23.0
Consumer involvement	8	13.1
Co-design	8	13.1
Patient engagement	7	11.5
Consumer research	7	11.5
Youth engagement	4	6.6
Youth participation	4	6.6
Youth involvement	4	6.6
Lived experience involvement	3	4.9
Lived experience research	3	4.9
Involvement of people with lived experience	2	3.3
Peer co-facilitation	1	1.6
Expert by experience involvement	1	1.6
Most commonly used term for "people with lived experience" in each study		
Patient	36	59.0
Service user	32	52.5
Consumer	21	34.4
Co-researcher	19	31.1

Peer	15	24.6
Youth	16	26.2
People with lived experience	13	21.3
Young people	12	19.7
Experiential expert	9	14.8
Consumer researcher	8	13.1
Service user researcher	8	13.1
Peer researcher	4	6.6
Individuals with lived experience	4	6.6
Expert by experience	3	4.9
Peer worker	2	3.3
Community partner	1	1.6
Patient researcher	1	1.6
Lived experience researcher	1	1.6
Individual with lived expertise	1	1.6

Note: (a) Excludes reference list. (b) Frequency refers to occurrence of term across the included studies.

DISCUSSION

This scoping review identified 61 articles that discuss the impact of engagement in mental health and substance use research between 2012 and 2022 and provides an overall picture of the available evidence on engagement in the mental health and substance use field. Overall, engagement was considered to have a positive impact on individual experiences and the research process. Most studies focused on subjective accounts when reporting on impact; this included a range of positive impacts on PWLE, researchers, and study participants. Engagement activities were commonly reported to improve facets of the research process, such as research quality, research components, and the research environment. As the review additionally synthesizes facilitators and barriers to engagement at the lived experience, researcher, team, and institutional levels, it can serve as a foundation for future research aiming to engage PWLE in mental health and substance use research.

Epistemic versus ethical justification for impact

Our findings indicate similarities between mental health, substance use, and other health research fields regarding the perceived impacts on the research process. For instance, reviews in health research have reported the positive impact of engagement on research design, study recruitment,[93] and data collection.[6,93,94] These findings demonstrate an emphasis on epistemic benefits, such as the 3R's of research—rigour (e.g., rigour related to study design), relevance (e.g., relevance to population needs), and reach (e.g., dissemination and knowledge translation).[95] Note, engagement in mental health research is critiqued for overemphasizing epistemic benefits rather than ethical ones.[21] If research teams focus solely on impacts related to epistemic benefits while neglecting ethical imperatives, the justification for engagement risks being treated as a means to an end of achieving better research, rather than being an intrinsically good and democratic process.[96]

Much like the studies included in our review, the broader health literature focuses on process indicators and the perceived impact of engagement rather than empirical outcomes.[6,20] For example, a recent systematic review by Wiles et al.[20] found that measures for the effect of engagement in randomized controlled trials are limited to process indicators such as recruitment. Moreover, Forsythe et al.[6] note in their review that the subjective nature of study descriptions, as well as the lack of experimental studies, make it difficult to measure the magnitude of engagement impacts. Reviews have additionally highlighted the need for quantitative and experimental studies that measure empirical outcomes of engagement, including the costs and benefits of engagement.[97,98] However, others argue that quantitative approaches are less useful for evaluating the impact of engagement given its complex and context-dependent nature.[94]

Evidence-based medicine and power

The understanding of impact within academic institutions remains heavily influenced by evidence-based medicine, which at times can be counterintuitive to engagement as it undervalues the needs of PWLE.[99] Traditionally, evidence-based medicine has been considered to devalue lived-experience knowledge by perpetuating evidence hierarchies and failing to address power imbalances (especially apparent in the mental health field).[100] Several barriers in our review reflect the prioritization of evidence-based medicine over lived-experience knowledge. Barriers such as valuing institutional knowledge over lived experience, hierarchies within research, and power imbalances retain a hierarchical view of the evidence, and ultimately, limited engagement impacts. Reflecting on our findings, recognizing power imbalances and the importance of power-sharing should be a priority for engagement activities in mental health and substance use research.[21]

Evidence related to the impact of engagement on power differences is rarely cited in health research.[9] However, this is less of the case for mental health and substance use research. In our review, several articles reported power-related impacts on the research environment (e.g., challenged stigma, shifted power dynamics) and on PWLE (e.g., empowerment, strengthened agency, and control). While these findings suggest a shift away from epistemic justifications for engagement, whether and how power shifts occur across socially marginalized groups in mental health and substance use research remains unclear. For instance, applying an anti-oppressive lens to engagement activities was only mentioned in a few studies.[36,53,85] Additionally, the impact of institutional changes on diffusing power imbalances in mental health and substance use research should be further explored. This could include processes such as embedding PWLE in research leadership roles such as voting members on executive committees (as demonstrated in the ACCESS Open Minds network[53]) and as co-chairs (as illustrated in the PARTNERS2 research program[49] and DeStress study[60]).

Individual experiences

Discussion of the impact on individual experiences is emerging, yet remains limited in mental health and substance use research. Evidence from this review indicates the perceived value of engagement to PWLE, researchers, and study participants. Almost a decade ago, a review by Brett et al.[18] examined the impact of engagement in health research on individuals, including PWLE and researchers. Reflecting on the present review, Brett et al.[18] identified empowerment and skill-building as the impact on PWLE, and a deepened understanding of their research for researchers. Other studies, such as one by Staley et al.,[101] discuss how greater focus is needed on how engagement impacts researchers. Our review revealed limited evidence on the impact of engagement on researchers compared to PWLE—this remains a major gap in mental health and substance use research. Our findings also reveal a paucity of research on facilitators to engagement at the researcher level. These gaps should be further investigated as the positive impact on researchers could potentially shift attitudes toward engagement within institutions, lifting a barrier to engagement.[91]

Inconsistent reporting

At the same time as the debates on the justification for evaluating impact, researchers have also highlighted inconsistent reporting of engagement in health research.[102] Our findings demonstrate a similar case for mental health and substance use research. Across the included studies, there were inconsistencies with terminologies used for engagement, and considerable variation in the details provided on engagement activities, characteristics of PWLE involved, and impact on the research. Reporting guidelines such as the GRIPP2 checklist can promote transparency and consistency when reporting on the impact of engagement in a study.[16,102] However, the GRIPP2 checklist is not specific to mental health and substance use research, which may explain why it was followed in only 8 of the 61 articles included in this review. The use of reporting guidelines for engagement in mental health and substance use research should be further explored, including the development of a guideline specifically tailored to the unique characteristics and challenges of this field. Without consistent reporting, a fulsome understanding of the impact of engagement in mental health and substance use research—whether on individuals or the research process—will remain unclear.

Strengths and limitations

The strengths of this study include the use of multiple databases, a comprehensive search strategy, and thematic analysis, in addition to engaging with PWLE throughout the scoping review process. However, several limitations warrant consideration. First, the review was limited to academic journal articles; it is possible that the grey literature could include facets missing in the academic press related to impact. Future reviews may benefit from expanding the search strategy to include the grey literature. Second, the articles came from high-income countries and were only in English; therefore, they may not be generalizable to other settings. Third, the review may have missed relevant articles given the wide range of terminology related to engagement in mental health and substance use research. Similarly, articles with PWLE as researchers were not explored (e.g., survivor-led research), which is an important topic for future research. Fourth, the inconsistent and largely subjective impacts reported across the literature may have influenced the study findings. Future research may benefit from standardized reporting of engagement impacts for reproducibility; however, this should not overshadow the ethical imperatives for engagement. Lastly, no assessment of the risk of bias or critical appraisal was conducted for this review, although this is not required for scoping reviews.[26]

CONCLUSION

This scoping review presents a comprehensive overview of the current literature on engagement impacts in mental health and substance use research. Additionally, facilitators and barriers to impactful engagement were identified at the lived experience, researcher, team, and institutional levels, which can be leveraged to improve engagement practices. Engaging PWLE throughout the research cycle—from consultation to co-creation—was perceived as having a positive impact on both the research process and individual experiences. Future research is needed to bring consistency to engagement, leverage the facilitators to engagement, and address the barriers such as power differences. This would in turn generate research findings that have value to the scientific community, but also to the people impacted by the science.

AUTHOR CONTRIBUTIONS

Natasha Y. Sheikhan was responsible for leading all stages of the scoping review. Natasha Y. Sheikhan and Lisa D. Hawke contributed to the study conception and design. Material preparation, data collection and analysis were performed by Natasha Y. Sheikhan, Lisa D. Hawke, and Shelby McKee. All authors contributed to the interpretation of emerging findings through several rounds of feedback on the draft manuscript, which was drafted by Natasha Y. Sheikhan. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

Institutional ethics approval was not required for this scoping review as it retrieved and synthesized data from already published studies.

DETAILS

Subject:	Barriers; Mental health; Databases; Substance use; Collaboration; Credibility; Health care policy; Recruitment; Facilitators; Substance abuse; Decision making; Rigour; Drug use; Medical research; Medical screening
Company / organization:	Name: Canadian Institutes of Health Research; NAICS: 541714
Identifier / keyword:	lived experience; mental health; patient and public involvement; patient engagement; patient-oriented research; substance use
Publication title:	Health Expectations; Oxford
Volume:	26
Issue:	5
Pages:	1806-1819
Publication year:	2023
Publication date:	Oct 2023
Section:	REVIEW ARTICLES

Publisher:	John Wiley &Sons, Inc.
Place of publication:	Oxford
Country of publication:	United States, Oxford
Publication subject:	Public Health And Safety
ISSN:	13696513
e-ISSN:	13697625
Source type:	Scholarly Journal
Language of publication:	English
Document type:	Journal Article
Publication history :	
Online publication date:	2023-06-06
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Publication history :	
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Document 2 of 30

The impact of expert by experience involvement in teaching in a DClinPsych programme; for trainees

and experts by experience

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ProQuest document link

ABSTRACT (ENGLISH)

Introduction

There is a growing acknowledgement of the value of creating partnerships between those delivering and those accessing health services. Less is known about this in the context of clinical psychology doctoral training programmes. This study explores the models of involvement of experts by experience (EbEs) in teaching on a DClinPsych course in England; the impact of this both for EbEs and trainee clinical psychologists and whether improvements are required to better meet their needs.

Methods

An audit of current involvement was conducted by reviewing course records. Two survey questionnaires designed around commonly used frameworks of participation and reflective learning were completed by EbEs and trainees. Thematic Analysis was used to evaluate the written feedback from the surveys.

Results

Records of current EbE involvement were found to be lacking in detail and sometimes missing. Key themes extrapolated from the surveys highlighted the importance of EbE involvement in supporting the wellbeing of EbEs and the learning experiences of trainees.

Conclusions

Recommendations with regard to the processes for future involvement of EbEs in teaching are put forward.

Patient or Public Contribution

A carer of a service user was consulted about the design of the participant information sheet, consent form and the survey questionnaire which was sent to the EbEs. A trainee clinical psychologist was also consulted to provide a trainee perspective on the above forms and the survey questionnaire that was sent to trainees. Further to this, the first author's supervisor identifies as a user of physical and mental health services and provided continued supervision and support regarding the direction of the study including the research questions, design, methodology and interpretation of results.

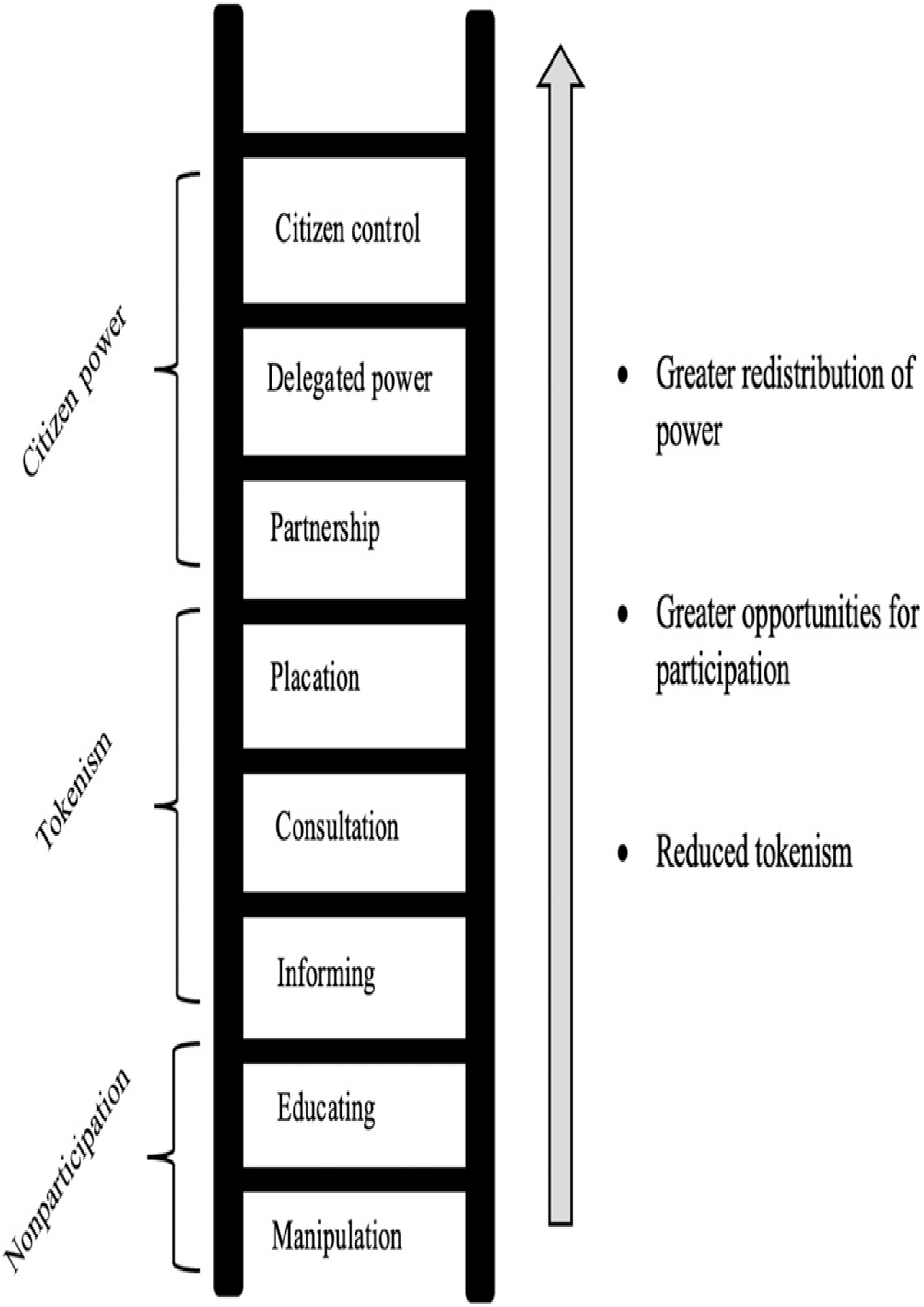
FULL TEXT

INTRODUCTION

Experts by experience (EbEs) are people with lived experience of using or caring for someone who uses health or social care services.[1] EbEs are thought to bring invaluable insights and perspectives, via their personal expertise, to the training of health practitioners.[2] The importance of encouraging patient participation and co-production has been emphasised in statutory guidance,[3] and there is growing recognition of the value of EbE involvement in NHS training programmes such as the Doctorate in Clinical Psychology (DClinPsych).

Impact of involvement for EbEs

Closer partnerships between EbEs and organisations involved in their care can bring about a sense of empowerment, confidence and wellbeing for EbEs.[4,5] This is thought to in part be due to a breaking down of stigmatising power differentials through greater contact between EbEs and professionals, in the context of equal status.[6,7] The redistribution of power hierarchies is central to the Ladder of Participation[8]; an eight-step model that provides a benchmark for understanding different levels of involvement, ranging from 'manipulation' to 'citizen control' (Figure 1).[8] It measures the extent to which EbEs are provided with opportunities to exert influence and power in the health system and their own care,[9] taking account of their personal 'choice' over the position they wish to hold.[10] Despite national guidelines, research studies show that there can be a gap between what is recommended and what is delivered with regard to EbE involvement in healthcare training settings.[11,12] Therefore, there is an ongoing need to evaluate the level of EbE involvement in clinical psychology training, to ensure that it remains beneficial and meaningful, rather than tokenistic, for those involved.[13]



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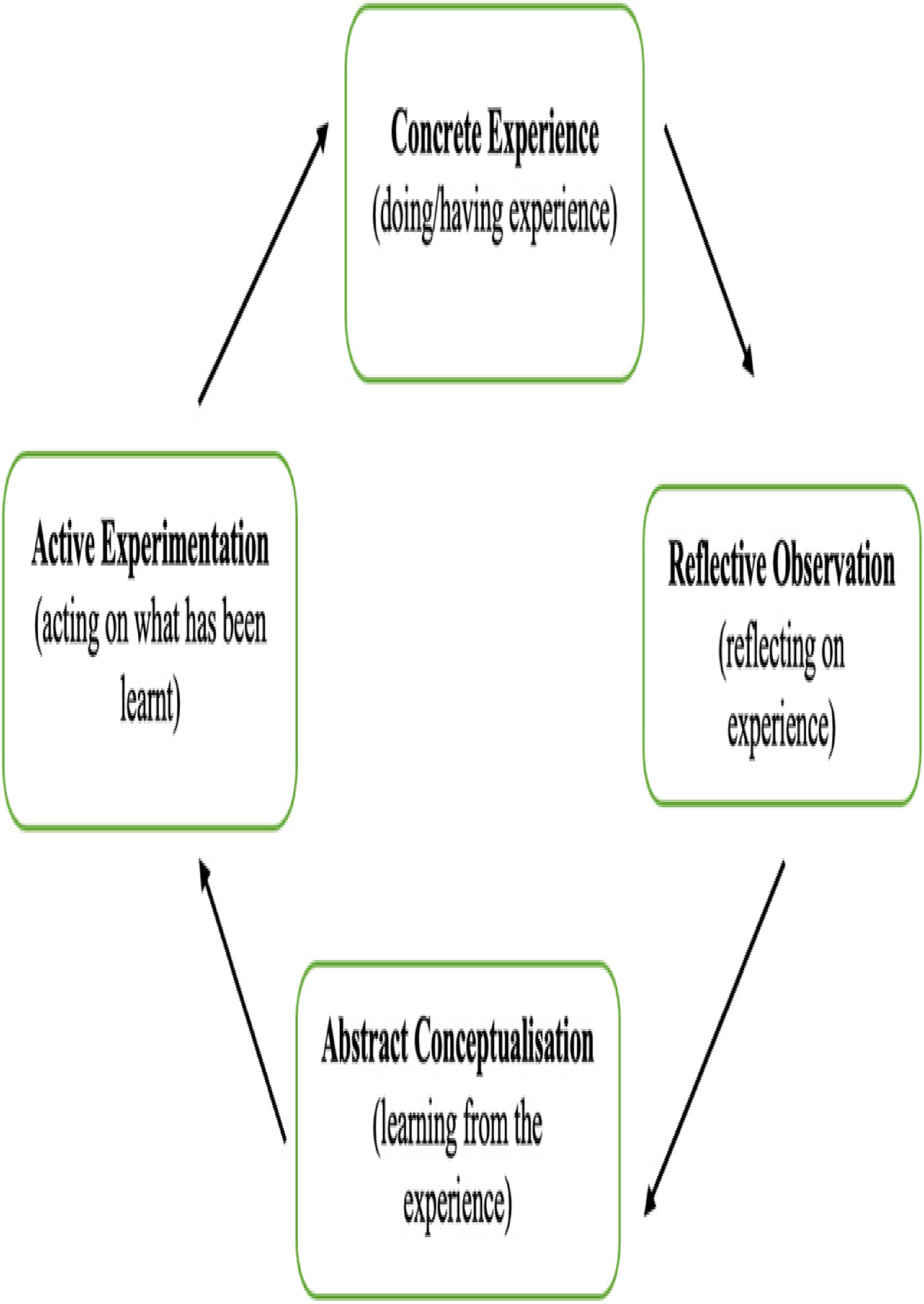
The impact of involvement for students

Studies show that students, including clinical psychology doctorate trainees, feel that EbE involvement in their education, can improve their clinical practice by helping them reflect on their therapeutic relationships.[14,15] The process of learning is promoted by experiences of reflection that occur within a social context.[16,17] In line with Kolb's reflective cycle (Figure 2), EbE involvement in teaching may offer greater opportunities for learning by reaching students on an emotional level and supporting the transformation of experience into learning and new behaviour.[17,18] Kolb's reflective cycle has been used to conceptualise the process by which EbE involvement in social work training can promote trainee learning by building greater reflective awareness that can then be taken into their practice.[19] As yet, this model has not been used to evaluate the impact of EbE involvement in the training of trainee clinical psychologists.



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In line with ongoing plans to increase EbE involvement in a UK DClinPsych course and move towards a position of co-production (Appendix A), this study aimed to explore the following research questions:

- 1.
How are EbEs currently involved in teaching on a DClinPsych course?

- 2.
How are EbEs and trainees impacted by EbE involvement in teaching?

- 3.
What do EbEs and trainees think could be improved with regard to EbE involvement in teaching?

METHODSDesign

The study employed a qualitative survey design that was approved as a service improvement project by the local NHS Trust. It was guided by the Model for improvement and aimed to gather the information required to generate change ideas and recommendations for EbE involvement in teaching on a DClinPsych course.[20] The survey approach was chosen to allow for a broader range of perspectives to be collected, compared to an interview approach which may not reach as many participants.

Participants

Two participant groups were recruited by email via a DClinPsych course in the United Kingdom; EbEs and first-year trainee clinical psychologists. The trainees were all in the first year of a 3-year Doctorate in Clinical Psychology (DClinPsych) which is a course that incorporates academic teaching, research and clinical placements for trainee clinical psychologists.

The EbEs were recruited from a ‘People's Experience Group' (PEG) that was affiliated with the specific DclinPsych course under assessment in this study. This group included representatives with personal experience accessing services or caring for people accessing services that clinical psychologists work in. The role of the EbEs in this group was to provide lived experience perspectives across a range of areas of the course, including teaching.

Procedure

An initial audit of the record of EbE involvement in teaching was conducted by requesting information by email from 13 course teaching leads regarding the number of teaching sessions that included EbEs, and details of the format of involvement.

The online survey platform, Qualtrics, was used to create and store answers from two separate survey questionnaires that were provided to the PEG and trainees respectively. Each survey began with an initial participant information sheet and consent form that participants were required to complete before progressing to the full survey. The PEG survey included a demographics questionnaire which was followed by 15 questions that were underpinned by the Ladder of Participation.[21] Therefore, questions targeted the broad themes of ‘level of involvement’ (e.g., ‘what kind of way were you involved in teaching?’), ‘impact’ (e.g., ‘How might PEG involvement in teaching impact PEG members?’) and ‘improvement’ (e.g., ‘how would you like PEG involvement in teaching to change?’) (Appendix B).

The trainee survey included 10 questions that were underpinned by Kolb's Learning Cycle.[17] In this way, the questions targeted the different stages of Kolb's reflective learning cycle, for example, ‘Please explain how EbE have been involved in teaching’ (concrete experience), ‘How have you found the experience?’ (reflective observation), ‘What have you learnt about your own practice from EbEs in teaching?’ (abstract conceptualisation), and ‘How has EbE involvement changed your attitude, behaviour and practice?’ (active experimentation) (Appendix C).

Data analysis

The thematic analysis procedure described by Braun and Clarke[22] was used to manually code and analyse key themes in survey responses. The PEG and trainee surveys were analysed separately.

The free text for each survey was read and reread to ensure familiarisation. Key words or phrases were highlighted, and the 'comment' function in Word was used to develop initial codes alongside the text data. These codes were then organised into categories of repeated patterns, or themes. An inductive approach to analysis was taken, to ensure that the themes would closely reflect participants' experiences rather than be driven by specific research questions. Provisional themes were reviewed to check that they (a) reflected the codes, and (b) reflected the semantic content of the data set as a whole. Interpretations and conclusions were reviewed and discussed in meetings with the research team. The research team was made up of a trainee, PEG member and course tutor. It was therefore important for them each to reflect on their own positions in relation to the topic and how this might influence their interpretation of the data. Where possible, the words used by participants were included in the theme title. Quantitative data derived from the two surveys were summarised by descriptive statistics.

RESULTS

The initial audit of EbE involvement in teaching revealed that 9 out of the 13 teaching streams involved EbEs in teaching in some way. The teaching areas covered were: 'Equality, Diversity and Inclusion', 'Working Age Adult', 'Research', 'Older Adult', 'Neuropsychology', 'Health', 'Forensic', 'Intellectual Disability' and 'Advanced Therapeutic Interventions'. Types of involvement included: (1) EbEs talking about their experiences of certain conditions, and the processes of receiving diagnoses and psychology involvement, (2) EbEs co-designing and co-facilitating the teaching sessions and (3) EbEs facilitating small group discussions. Two of the 13 teaching leads contacted were not able to provide any data due to recently being appointed to the post and therefore not having access to previous records of EbE involvement.

Overall, the audit demonstrated that there was no current centralised or agreed upon method for recording data about EbE involvement, and the level and detail of data recorded varied across teaching.

PEG survey

Of the 14 PEG members who were provided information about the study, 12 (83%) consented to complete the survey. Two of these 12 did not continue past the initial consent stage, leaving 10 participants who completed the survey in full. The majority were female (60%), aged 36+ (90%) and identified as white (80%). Seven had been PEG members for 1–2 years and three for 10 years. Eight considered themselves to have a mental health difficulty, seven a physical health difficulty and three stated they were caring for someone with a mental health difficulty. Five had completed a bachelor's degree and one a doctorate degree. Four were retired, three were working part-time, one was self-employed and one was a student. The majority identified with a religion (six Christianity, two Islam) and five of these were actively practising.

The initial questions on the survey asked about their level of involvement in teaching in the 2020 academic year. Seven PEG members stated that they had been directly involved in teaching, with the majority having heard about involvement through a course email or PEG meeting. They identified types of involvement as 'talking about lived experience in large or small groups', 'co-presenting' and 'leading small group discussions'. Three PEG members stated that they had not been made aware of the opportunities available for involvement.

Thematic analysis yielded four themes: (1) 'informing change', (2) 'bringing purpose to experiences', (3) 'educating by 'making it real' and (4) 'ensuring empowerment'. The fourth theme encapsulated three subthemes: 'flexible opportunities', 'keeping EbEs informed' and 'potential for distress or discomfort'. These themes are presented below and supported by excerpts from the survey.

Informing change

Eight (80%) of the PEG members surveyed, commented on a motivation to bring about change in themselves, the trainees, and future clients. Two EbEs also named specific clinical areas in which they hoped to influence through involvement.

I hoped that, by discussing good and bad experiences, we could influence future outcomes for clients in a similar position to us. (EbE 3)

Bringing purpose to experiences

All 10 PEG members wrote about the process of making sense of their lived experiences through participation in teaching, and how this creates purpose and builds their self-confidence.

This teaching helps me both to appreciate the journey I have been on, the extent of my knowledge, gives me confidence… (EbE 1)

Four PEG members wrote about the role of involvement in developing their own interests and knowledge.

… I personally have benefited from being involved…helping my own research. (EbE 6)

Educating by 'making it real'

Seven PEG members (70%) felt that involvement helped trainees reflect on lived experiences, to a greater extent than in other more theory-based lectures.

Lived experience says more than just reading from a book, people can relate. (EbE 10)

A couple of PEG members also commented on the value of the interactions between trainees and EbEs in lectures.

Clinical psychologist trainees can learn a lot from people with experience and ask questions. (EbE 8)

Ensuring empowerment

All 10 PEG members commented on the importance of considering steps to ensure EbEs feel empowered in teaching. Within this overarching theme, three subthemes highlighted factors that PEG members felt influenced this sense of empowering.

Flexible opportunities

Several PEG members felt that further training in teaching delivery, including training in using 'Zoom', would support them and their future careers.

Getting more training and certificates that may help us getting into employment or education in the future. (EbE 10)

The ability to join teaching sessions online was also thought to be an important factor for increasing access, for one PEG member:

Virtual access has enabled me to be involved, without concern about accessibility issues and travel. (EbE 6)

Keeping EbEs informed

Three PEG members commented on the importance of having information about the teaching session beforehand and a space to debrief afterwards.

It is helpful to always have a pre-meeting to meet the tutor and discuss and plan how you are going to be involved. (EbE 4)

Potential for distress or discomfort

All PEG members felt there was potential for discomfort or distress for the EbEs involved in teaching, due to the nature of the content or the questions asked.

…although there may be slightly uncomfortable moments when boundaries are challenged and pushed. However, that generally means one is learning. (EbE 1)

One PEG member felt that the responses of trainees and co-facilitators during teaching had an impact on their experience.

If the students and tutors seemed uninterested, there was no positive feed-back from them. (EbE 2)

Trainee survey

Of the 30 trainees who were provided with information about the study, 27 (90%) consented to complete the survey, and 20 of these continued with the survey after consenting. Nineteen completed the survey in full, and one trainee partially completed the survey.

Thematic analysis yielded five themes: (1) ‘Connecting with “lived realities”’, (2) ‘How to be a better clinical psychologist’, (3) ‘Involvement consolidates learning’, (4) ‘Emotional impact’ and (5) ‘Integrating EbEs into teaching’. Each theme encapsulated several subthemes which are described below and supported by excerpts from the survey.

Connecting with ‘lived realities’

Most of the trainees (75%) commented on their gained insight and understanding of experiences from hearing about the ‘lived realities’ of EbEs in teaching. They emphasised the value of connecting on an emotional level with EBEs, in a way that is less possible in other teaching. They also reflected on how this influenced them and built their confidence as professionals.

Hearing from a carer &a person with learning disabilities was a really important moment in teaching for me, as this is an area that I don't know well and felt intimidated by. Hearing from EBE normalised and humanised what had up until that point had felt theoretical and distant, and made me more confident going forward. (T7)

The whole journey

A number of trainees emphasised the value of hearing about the ‘journey’ of the EbE, in terms of the onset and development of difficulties, rather than just focusing on the here and now.

It has made me more appreciative of people's journeys before they come to see psychology, for example have they got a child with a learning disability, did they go through a mental health crisis in a different country, have they had a life changing injury? (T21)

Permission to be curious

Trainees valued the opportunity to speak more informally with EbEs in small groups and have permission to ask questions.

They are so powerful and insightful and it's such a privilege to hear people's narratives and be able to ask questions… They're often the things that would be difficult to ask someone in session so the chance to have this is really valuable. (T14)

How to be a better clinical psychologist

Fifteen Trainees (75%) identified a range of ways in which EbE involvement in teaching supported them to develop their skills as clinical psychologists.

Putting learning into practice

They wrote about the importance of EbEs in giving them knowledge that can be translated into the clinical setting.

I also found it helpful to hear some of their more negative experiences of services, as I have tried to bear those in mind and avoid similar practice on placement. (T3)

Specific and nonspecific skills

Trainees felt that EbEs helped them build an understanding of developing comprehensive assessments and formulations of clients.

It has highlighted some of my blindspots in assessments (what I don't think to ask), enhanced my formulation skills… particularly in terms of relationship to help for people who have had negative experiences of services. (T18)

At the same time, a number of trainees emphasised their learning around the importance of nonspecific skills such as empathy and listening, which they felt was less present in other lectures.

It reminds me to be a human. With all the complex formulation and evidence bases we learn, it is sometimes easy to forget the softer skills of compassion, empathy and kindness, which are arguably more important than the theory… (T9)

Systems

Trainees commented on their growing understanding of the importance of working with systems around clients, as a result of the EbE involvement in teaching. Five trainees felt they had gained insight into the role of carers and the importance of supporting them as well as the clients.

Hearing from carers as well as the EbE themselves has encouraged me to think about how to support not just individuals, but whole families which may be impacted. (T2)

A greater understanding of organisational issues was also named by trainees who felt they had learned more about how these systems can be a barrier to care.

… I have learned more about the difficulties and barriers that people face with regards to our national health service, which is depressing at times. (T4)

Involvement consolidates learning

Forty percent of trainees wrote about the impact that EbE involvement had on the quality of their learning and memory for the information discussed.

Emotional learning

Eight trainees talked about the role of emotional learning in promoting their ability to remember and act on teaching that had involved EbEs.

It is often an emotional interaction to hear from EbEs. It has been difficult to listen to some of them, but they are the teaching sessions that stand out in my mind as being the most powerful and we have the most to learn from. (T21)

Reflecting on assumptions

Three trainees shared that hearing from EbEs had helped them reflect on their own assumptions about different client groups, influencing their approach in clinical settings.

Having one EbE discussing their experience of dementia hugely challenged my preconceptions of individuals living with dementia…I really tried to bear this learning in mind when delivering post-diagnostic groups for people with a recent diagnosis of dementia, and felt it enabled me to instill hope with more conviction… (T3)

Emotional impact

Sixty-five percent of trainees recognised the impact of the emotional content of lectures involving EbEs on themselves, both personally and professionally.

Reigniting passion and striving for change

Nine trainees spoke about having their passion for the clinical psychology role reignited after hearing from EbEs. They linked this to a desire to bring about positive change as professionals, and to the systems they work in.

It has reminded my why we do the job that we do. I find after sessions with EbEs I have a real fire in my belly again! (T21)

…often the stories told by EbEs makes me feel sad about the state of our health service, the barriers and obstacles faced by our clients. These are however important issues to highlight, and as young trainees it facilitates an attitude of striving and hoping for implementing change within these systems. (T4)

Support for trainees

Six trainees wrote about finding some EbE teaching sessions emotionally challenging to ‘sit with’. One trainee suggested a need to support trainees following these sessions, and another felt it was helpful when lecturers prepared them for emotional content and gave them time to process it following lectures.

…I think sometimes stories can be harrowing, and it's really useful for the session leader to name this, and make sure we take time out for ourselves after meeting them (i.e. by putting the stories just before lunch, etc). (T9)

While being exposed to these feelings of distress was felt to be crucial by one trainee, they also recognised the limits of online teaching in ensuring trainees connect with these experiences.

… it can be hard to sit with that emotion on Zoom vs in the room, although I think it is important for us as trainees to be exposed to these discussions early in training. (T15)

Integrating EbEs into teaching

There was an overarching theme of trainees (70%) considering the process in which EbEs were involved in teaching sessions.

Disparity of involvement

Ten trainees made reference to a disparity in level and type of involvement across streams and client groups, stating hopes of hearing more wide-ranging perspectives.

Would be nice to hear from some children and young people… (T4)

…it would have been really helpful to hear from individuals with lived experience who may not quite fit v specific diagnostic criteria, or who may have had alternative reflections on diagnoses. (T3)

Tokenism and power

Trainees reflected on the power balance between EbEs and the other facilitators in teaching. While some trainees noted strengths in co-delivery, others felt more could be done to ensure the roles were shared more evenly between facilitators.

The lecturers always placed a great emphasis on them being co-deliverers with an even power dynamic. (T7)

…wondered why they couldn't be involved in delivering material, rather than only being able to speak about their direct experiences?… Sometimes I felt like they were being exhibited, for us to ask nosy questions. (T13)

Ensuring time for reflection

An important aspect of integrating EbEs into teaching, noted by five trainees, was the need to ensure trainees had time to reflect on and process what they had heard.

… it would be useful if more tasks ask us to take account of what we have learned from an EbE/ask us to reflect on what we might do differently after listening to an EbE share their experiences. (T18)

Support for EbEs

Eight trainees considered ways of supporting EbEs to ensure they had a helpful experience of teaching. They recognised the possibility of EbEs feeling uncomfortable when asked certain questions, and therefore the importance of trainees and EbEs agreeing on how to navigate challenging questions.

…it was always helpful to navigate this discussion with some ‘ground rules’ (e.g. saying that they can simply choose not to answer any questions that feel too personal/uncomfortable). (T15)

One trainee felt that EbEs needed further support with online tech support during teaching sessions.

… a little more time needed to be given to supporting EBEs with the tech required for online teaching…it would have been useful for session leaders to have a practice run with them to make sure the tech is working smoothly, as sometimes we got less time with the EBEs due to tech issues. (T9)

DISCUSSION

This study aimed to examine the level and impact of EbE involvement on a UK DClinPsych course to ensure a meaningful process for those involved. The findings below are discussed in relation to the three research questions; (1) ‘How are EbEs currently involved in teaching on a DClinPsych course?’, (2) ‘How are EbEs and trainees impacted by EbE involvement in teaching?’ and (3) ‘What do EbEs and trainees think could be improved with regard to EbE involvement in teaching?’

The initial audit revealed that records of involvement varied in quality across teaching, with some gaps in evidence regarding whether EbEs were involved at all in some teaching areas. The lack of consistent record keeping meant that it was not possible to report on the number of lectures that involved EbEs, however, nine of the 13 teaching streams were found to involve EbEs in some way. Levels of involvement varied, with some EbEs choosing to talk about their personal experiences, and others co-presenting teaching material or being more actively involved in the design and production of a lecture. At the same time, some EbEs reported to have not been made aware of their options for involvement. Therefore, the degree to which power was shared, and therefore the level of participation,[8] appeared to vary across teaching and EbE.

The PEG survey showed that involvement such as sharing personal experiences or answering trainee questions promoted self-confidence and a sense of purpose from creating positive change for others. The PEG survey also highlighted the need for EbEs to be fully informed and supported in teaching, through the provision of information, debrief meetings and further training where appropriate. Therefore, while these findings are consistent with other studies showing that service user involvement in mental health systems has therapeutic benefits for EbEs,[23] there is also a need to ensure they are properly supported to ensure their involvement lands higher on the ladder of participation.[8] These results align with similar studies of EbE involvement in health education[24,25] which emphasise the importance of sensitively involving EbEs in teaching processes to ensure the processes are purposeful and not tokenistic.

The trainee survey indicated that EbE involvement in teaching promoted a Kolb reflective learning process (1984) by firstly exposing trainees to personal experiences which they then reflected on, through discussion and personal reflection, to guide their future practice. The trainees felt they gained insights into the skills and knowledge required for practicing as clinical psychologists, including assessment and formulation skills, systemic working and nonspecific skills such as empathy, normalising and validation. Additionally, trainees reflected on having actively made changes to their clinical approach (Active Experimentation)[17]; following teaching with EbEs. In line with research,[18] the trainees felt they remembered more from teaching involving EbEs due to having a greater emotional connection with the material covered. Similar to the PEG responses, trainees felt that EbE involvement could be distressing and that both EbEs and trainees should be better supported by creating clear ‘ground rules’ for EbE sessions, and incorporating more time for reflection. In line with the audit, trainees felt there was some disparity in level of involvement from different patient groups across teaching, and felt this was an area for improvement, to move closer to co-production.

Limitations

The survey methodology, while chosen purposely to allow access to a greater number of participants, was limited with regard to the level of exploration afforded around each question. Additionally, recruitment of EbEs through the PEG is likely to have reduced the heterogeneity of the sample, as many of them were highly educated and interested in research. There is therefore scope for future research to incorporate wider recruitment strategies and utilise interview methods to enhance the current findings.

The analysis and interpretation of the results are likely to have been influenced by the positions and perspectives of the researchers. The team worked closely to ensure that the codes and themes closely matched the extracts to ensure that important aspects of the data were not overlooked.[26] Finally, the attrition from consent to completion may have been the result of the participants forgetting to finish the survey once started. This therefore could have been minimised had the researcher provided further prompts to encourage completion.

Clinical implications and future directions

The lack of recorded data with regard to EbE involvement in teaching, suggests a centralised and agreed up system be created for inputting data related EbE involvement. This should include both what is offered and what is taken up. This would ensure that EbEs are afforded choice over the position and role they wish to hold.

Based on the survey feedback, it is recommended that the service consider ways of increasing the variety of EbE perspectives included in teaching, to encourage richer reflections and learning. Steps to promote the wellbeing of EbEs and trainees should include planning and debriefing meetings for EbEs and greater time for reflection for trainees. It is also recommended that trainees be made aware of EbE involvement and appropriate areas for discussion in advance. It may be appropriate to consult the PEG group about opportunities for training, such as in technical support if necessary.

CONCLUSION

PEG members and trainees showed considerable agreement with regard to the impact of EbE involvement in teaching. Issues around methodology and sampling have guided suggestions for future research. Recommendations for the service are hoped to enhance the training of clinical psychologists and therefore benefit future clients and services they work with.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

According to the HRA decision tool, this project falls into the category of service evaluation/audit. Therefore, NHS approval was not required. Service evaluation approval will be sought before commencing the project.

AAppendixPEG 3-YEAR PLAN

The People's Experience Group 3 Year phase Plan

Year 1—2020/2021	Year 2—2021/2022	Year 3—2022/2023
Design and embedding	Improving	Maintaining and continue move towards co-production

The PEG aims to develop a selection process for new membership, with the aim of increasing diversity and experience within the group. The course will run an open day for interested parties to hear more about the role. An information sheet and role specification will be developed and shared with interested parties. Following this, a one-to-one meeting will be held and if it's felt by both parties that joining the PEG would be of benefit, a 3-year term of office will begin. This includes an induction training session and induction pack. New members will be allocated a mentor (who will initially be a course staff member but as the PEG is further established, experienced PEG members will be mentors). The PEG will meet quarterly and will comprise: •– Approximately 8 people with personal experiences •– 2 course staff •– one trainee from each year (minimum) There will be PEG representation in all streams. Academic (co-facilitating teaching), clinical (attendance at the practice and placement committee) and research (attendance at PAS, consulting on trainee research projects and attendance at the research committee). A PEG member will be represented on each course committee (including admissions) and will feedback to the PEG group quarterly. A PEG member will also attend GTiCP.	The second year of the PEG implementation will focus on building on the initial progress from year one. This includes: *Research* PEG members with an interest and/or experience in research will act as collaborators/co-supervisors (as appropriate) for trainee research projects. This will include training for PEG members interested. The PEG will have greater involvement with trainee research through informal lunches following PEG meetings. Trainees can join the lunch to discuss their project and research ideas in a less formal setting with members, to share ideas and promote collaboration. *Academic* A PEG member will be linked in with each stream lead to provide input when reviewing the content of teaching for the following year, and to review trainee's feedback on teaching for each stream. *Admissions* The aim by this stage is to include a PEG member in the video task design and production. In addition, we plan to have a PEG member available each day at interviews to welcome applicants and to be involved in invigilating the video task.	Further aims for the final phase include an increase in PEG presence for admissions, with a PEG member on each panel for clinical interviews and a member working with the video task team. PEG members will also sit on interview panels for new course staff. In addition, the formation of a young person's PEG will begin. The aim is to establish a small (3–4 person) group who meet biannually comprising young people and young carers. The remit of this group will be much smaller than the original PEG. By this phase the aim is to recognise and measure the impact of the existing PEG group through a PEG annual report and research project. PEG members who were recruited in 2020 will be reaching the end of their term of office and future recruitment and signposting will be considered. Finally, future aims will include a PEG conference and publication of any research projects. PEG members will be paid for their time in accordance with Oxford Health FT guidelines.

BAppendixPEG SURVEY QUESTIONS

Identifying levels of participation
Were you made aware of opportunities available to you for getting involved with teaching on the DClinPsych course in 2020–2021?
If applicable, how did you hear about the types of opportunities available? (please state ‘n/a’ if not applicable)
Were you involved in teaching in the 2020-2021 academic year?
If yes to q 3: In what capacity were you involved?
Please can you expand on your answer (we want to understand more about your individual experience)
What made you decide to get involved?
If you were not involved, please state your reason for this
Is there anything else that you feel would be important to share with us about any reasons for or barriers to getting involved with teaching?
Impact
Do you think it is important for PEG members to be involved in some way with teaching prospective clinical psychologists?
How do you think PEG members can help improve the teaching experience for prospective clinical psychologists?
What do you think is the positive impact for PEG members specifically, for being involved in teaching?
What do you think is the negative impact for PEG members specifically, for being involved in teaching?
Improvement
Would you like to be involved in teaching in a different kind of way than is available to you now?
If applicable, please explain how would you like PEG involvement in teaching to change and what difference this would make to you?
What else might improve the way PEG members are involved in teaching? Please explain your answer

C**AppendixTRAINEE SURVEY QUESTIONS**

Concrete experience
How were experts by experience involved in your teaching?

Reflective observation
How have you found the experience of experts by experience being involved in teaching?
Overall, how satisfied were you with the involvement of experts by experience in teaching?
Overall, how much would you say you have benefitted from experts by experience being involved in teaching?
What worked with regard to experts by experience being involved in teaching?
What didn't work with regard to experts by experience being involved in teaching?
How are you impacted emotionally by expert by experience involvement in teaching?
Abstract conceptualisation
What have you learnt about your own practice from expert by experience involvement?
What could be improved with regard to EbE involvement in teaching?
What would be the impact of these changes, for you as a trainee?
Active experimentation
How has EbE involvement in teaching changed your attitude, behaviour or practice?

DETAILS

Subject:	Health services; Mental health services; Experts; Teaching; Clinical training; Questionnaires; Trainees; Clinical psychology; Polls &surveys; Health status; Research methodology; Experience; Codes; Reflective learning; Psychologists; Clinical psychologists; Reflective teaching; Well being; Learning; Archives &records; Participation; Power; Surveys; Mental health; Research design; Partnerships
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The elephant in the room: Family engagement in mental health and substance use research

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FULL TEXT

INTRODUCTION

There is a growing emphasis in academic research on engaging people with lived experience (PWLE) of mental health and/or substance use challenges in research projects.[1] People and communities with lived experience can be included in all aspects of research processes, which is increasingly encouraged by funding bodies and institutions. While engagement has grown rapidly in recent years,[2] the movement is built upon decades of progressive experience in decentring academic work across disciplines through key informant collaboration. Lived experience engagement in research, also known as ‘patient engagement’ or ‘patient and public involvement’, provides many benefits to the research process, as PWLE are subject-matter experts and key stakeholders. PWLE engagement occurs across the health disciplines, in a wide variety of research designs, including an extensive body of mental health and substance use research.[2] Engaging PWLE promotes the inclusion of perspectives that matter, and stimulates the healing of the injustices of past and current imbalances and inequities in health care and research settings. To ensure that engagement is meaningful and not tokenistic, and thus remains ethically conscious, it is important to reflect on the conceptualization of engagement: what is engagement, who is engaged, and why?[3]

Amongst definitions of PWLE, family members or caregivers of people with mental health or substance use challenges are often included.[4] Families can offer a holistic view of a person's life, observing long-term trends in behaviour, as well as baselines, relationships and a historical synopsis of attempted treatment and self-management strategies and interventions, helping to bridge the gaps in self-reported measures of their loved ones. Family members can provide insights about the experience of living with someone with mental health or substance use challenges, caring for them, advocating for them, amplifying their voices and supporting them in their service-seeking journeys, and about their own roles in family-centred care. Supportive families can contribute to recovery and may play an important role in system navigation. Engaging family members in research gives them the opportunity to have their voices heard and to help make changes for other families. In areas of health in which the caregiving role is substantial or PWLE inputs may sometimes be limited, such as infant or early childhood mental health, or dementia, family members are often the primary engagement target and informants. However, across mental health and substance use more broadly, family members are often secondary to the engagement of people with direct, personal lived experience, even though they may fill a primary caregiving role.

While the general principles of engagement are similar across areas of health,[4] there are considerations specific to mental health and substance use, and particular considerations when engaging families. Engagement in research can have many positive impacts.[2] However it can also have negative impacts when conducted tokenistically or otherwise inappropriately, through erasure, marginalization, and stigmatization. Family members, who may feel marginalized, excluded, and even traumatized as they navigate the mental healthcare system with their loved one, can be further marginalized, excluded, and traumatized if they are engaged tokenistically,[5] doing more harm than good as they relive their traumas. Other factors important to consider in family engagement include complex family dynamics and the impact of stigma and marginalization, alongside the many barriers to effective lived experience engagement.[2] For family members, as for PWLE, it is important to conduct engagement in ways that are genuine, accessible, inclusive, destigmatizing, empathetic and trauma-informed.[6] However, there is a dearth of literature specific to family engagement in mental health and substance use research.

Given the complexities of family engagement in mental health and substance use research and the potential for tokenistic and unhelpful engagement, researchers are encouraged to reflect upon their motivations to engage families. Rather than engaging without reflection, because engagement represents a growing movement, they are advised to carefully consider the characteristics of their study and their target population to determine whether family engagement is appropriate for a given study. To aid in this decision, we propose a number of reflection points, described below and represented in Table 1. Key considerations include: (1) the relevance of the research question and study design to family members, (2) the representativeness of families and (3) whether family engagement is welcomed by all stakeholders. These reflections can guide a researcher's decision about when and whether to engage families, within the context of the study at hand. The decision points are not fast rules, but general reflection points and suggestions. A single response in the '*Consider not engaging families*' category (Table 1) does not definitively preclude family engagement, but signals the need to reflect carefully on whether, why, and how family engagement might be appropriate, or inappropriate, for the study at hand. Multiple such responses suggest that family engagement may not be appropriate for the study. However, if formal family engagement is opted against in a given study, researchers might consider other creative ways to access family perspectives as part of their work.

Table 1 Areas of reflection when deciding whether to engage families in mental health and substance use research.

Aspect of the research and engagement context to consider			Consider engaging families	Consider not engaging families
Relevance of the research question and study design to families	The research is about family experiences or perspectives, or family-centred care, or care that was codesigned with families.	Yes	✓	
		No		✓
	Families are participants in the study.	Yes	✓	

		No		✓
	PWLE are able to represent themselves fully in response to the research question.	Yes		✓
		No	✓	
Representativeness of families	The supportive families available for engagement are representative of the target population.	Yes	✓	
		No		✓
	The target population is highly affected by family violence, family trauma, or high levels of family conflict.	Yes		✓
		No	✓	
Family is welcomed by all stakeholders	Researchers have reflected on any biases they may have against families and recognize a genuine benefit of having family members at the table.	Yes	✓	
		No		✓
	The research team has specific questions for family members and is willing to directly incorporate their feedback.	Yes	✓	
		No		✓
	The PWLE engaged support a family engagement component.	Yes	✓	
		No		✓

Abbreviation: PWLE, people with lived experience of mental health or substance use challenges.

RELEVANCE OF THE RESEARCH QUESTION AND STUDY DESIGN TO FAMILY MEMBERS

Consistent with the purposes of authentic engagement, family members can be productively engaged when the research is directly relevant to them, in a manner that creates a shared purpose of work on the topic of the research. While some research in the mental health and substance use sphere directly addresses the experiences and perspectives of families or caregivers, such as family-centred treatment research and family-centred research designs, much of it does not. If a research question directly addresses family or caregiver experiences or roles, the research is testing an intervention for or with family members, it includes family members as study participants or it addresses an intervention that was codesigned with family members, the engagement of families is immediately relevant. In these cases, family members can productively advise on the research questions, processes and findings. However, if a study is addressing the experiences of PWLE, without a family component, or if PWLE can fully represent their experiences without the need for family perspectives, the relevance of engaging family members is not as immediately apparent. It is important to recognize that family members invest considerable personal time, effort, and emotional labour into the engagement process.[5] It is therefore essential to focus engagement efforts on projects in which family voices are appropriate, needed, welcomed, and valued.

REPRESENTATIVENESS OF FAMILIES

Across engagement, it is important that the people engaged are representative of the target population. Definitions of families are diverse, including chosen families, family structures beyond the nuclear household, and families with diverse gender and sexual characteristics. It is important to consider the representativeness of families engaged across equity, diversity, and inclusion considerations, with trauma-informed approaches.[6] Many people with mental health or substance use challenges have supportive families of origin or families of choice who wish to be engaged in both their care and their lives. The families who come forward to be engaged often fit this profile and are enthusiastic contributors to our work. However, this profile is not representative of all people with mental health or substance use challenges. Indeed, family-based violence, trauma and family conflict are directly associated with mental illness. Conflictual versus nonconflictual family dynamics are not a binary concept, but rather a complex reality among the population in general, including people with mental health or substance use challenges. Researchers working clinically may be very aware of complex family histories among their patients and may therefore inadvertently bring bias and stigma into engagement spaces. The family members who come forward to be engaged can feel stigmatized, blamed, and shamed, despite their wish to help; after first experiencing this as they help their loved ones navigate the healthcare system, they can re-experience it in engagement processes. To avoid restigmatizing family members, researchers are called on to recognize them as supportive families who want to help, while acknowledging the stigma that comes with conflictual family dynamics. If supportive family dynamics are not representative of at least some of target population, family engagement might not be appropriate for a study.

FAMILY IS WELCOMED BY ALL STAKEHOLDERS

To experience research engagement as positive, family members need to be welcomed in the research space by all stakeholders. Researchers must be willing to establish equitable partnerships with them and a shared sense of purpose, using a family-centred approach to engagement. Researchers have to be trained in strong engagement practices and be open to family feedback on their research, even if it does not align with their immediate goals and perspectives; they also have to be willing to negotiate a shared understanding and perspective, all within the context of sometimes rigid scholarly, institutional, funding, and approval contexts. In addition, if the study team is engaging PWLE, it is important that the PWLE want families to be engaged and consider their input helpful. This might not always be the case, for example, in contexts of family violence and conflict, or in key developmental stages such as adolescence. Despite the caregiving burden, PWLE may not always wish for family input. PWLE may sometimes feel that family voices overshadow their own, undermining their contributions to the research and their sense of autonomy in their own lives. To create a safe engagement space for family members, it is important that all team members, including research teams and PWLE, reflect on any biases they have that may be a barrier to authentic family engagement, that they truly want and need families around the table to address study issues relevant to them, that they welcome them there, and that they value their direct contributions to the relevant aspects of the study.

CONCLUSION

In a climate of increasing emphasis on engaging PWLE/F in research, some researchers may embark on family engagement processes because they believe family engagement is generally considered desirable. This can occur without due consideration of the circumstances and context of their specific research project and of the PWLE and family members they plan to engage. However, it is important to conceptualize this engagement in a thoughtful manner.[3] When engagement is not thoughtful and reflective, there is a high risk of tokenization, leaving family members wondering why they are present and what their contributions might be. This can create unequal power dynamics and limited capacity for meaningful change, reflecting tokenistic engagement that advances neither the research nor the goal of authentic and antioppressive practice. Unauthentic engagement stands the risk of restigmatizing and retraumatizing families, creating environments that detract from authentic engagement and losing family members in the engagement process. By reflecting on the aim, purpose and goals of family engagement, as well as the engagement context, researchers can avoid engaging tokenistically and move towards the authentic, meaningful engagement of families, in the appropriate studies, enhancing research and creating positive experiences for all involved.

AUTHOR CONTRIBUTIONS

Lisa D. Hawke conceptualized and drafted the paper. Connie Putterman further conceptualized the paper, edited the content, and approved the final version. Nathan Dawthorne, Shannon Pascoe and Shaylene Pind contributed to the content of the discussion, edited the manuscript, and approved the final version [Correction added on 14 August 2023, after first online publication: The preceding sentence has been corrected in this version.]

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Conceptualising community engagement as an infinite game implemented through finite games of 'research', 'community organising' and 'knowledge mobilisation'

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ABSTRACT (ENGLISH)

Meaningful community engagement process involves focusing on the community needs, building community capacity and employing culturally tailored and community-specific strategies. In the current practices of community-engaged health and wellness research, generally, community engagement activities commence with the beginning of a particular research project on a specific topic and end with the completion of the project. The outcomes of the community engagement, including the trust, partnership and contribution of the community to research, thus remain limited to that specific project and are not generally transferred and fostered further to the following project on a different topic. In this viewpoint article, we discussed a philosophical approach to community engagement that proposes to juxtapose community engagement for the specific short-term research project and the overarching long-term programme of research with the finite game and infinite game concepts, respectively. A finite game is a concept of a game where the players are known, rules are fixed and when the agreed-upon goal is achieved, the game ends. On the other hand, in infinite games, the players may be both known and unknown, have no externally fixed rules and have the objective of continuing the game beyond a particular research project. We believe community engagement needs to be conducted as an infinite game that is, at the programme of research level, where the goal of the respective activities is not to complete a research project but to successfully engage the community itself is the goal. While conducting various research projects, that is, finite games, the researchers need to keep an infinite game mindset throughout, which includes working with the community for a just cause, building trust and community capacity to maximise their contribution to research, prioritising community needs and having the courage to lead the community if need be.

Patient or Public Contribution: While preparing this manuscript, we have partnered actively with community champions, activists, community scholars and citizen researchers at the community level from the very beginning. We had regular interactions with them to get their valuable and insightful inputs in shaping our reflections. Their involvement as coauthors in this paper also provided a learning opportunity for them and facilitated them to gain insight on knowledge engagement. All authors support greater community/citizen/public involvement in research in an equitable manner.

FULL TEXT

INTRODUCTION

Community engagement is an umbrella term that encompasses a wide range of definitions. However, in simplistic terminology, community engagement seeks to collaborate with the community in an equitable and empowering manner to achieve sustainable outcomes.[1] There is a multitude of benefits when it comes to community engagement. This process empowers the community to participate in the decision-making process around different aspects of research, directly contributing to the concern at hand from their lived experience and relevant expertise. This promotes personal agency, well-being and self-confidence for the members of the community and opens up opportunities to act as community enablers for public health, injustice or indeed any other concern that is of importance to the community.[2,3] The fundamental approach to community engagement is to allow the fostering of impactful relationships between different stakeholders including with the community to where they belong. As community researchers, we encountered challenges when attempting to configure community engagement solely within the confines of a single research project. We found that our efforts to foster desired engagement and relationship building were falling short. However, once we shifted our perspective and began conceptualising community engagement as an integral part of a broader programme of research encompassing multiple projects, we started to experience greater success in terms of community trust, buy-in and involvement. In this viewpoint article, we discussed a logical approach to community engagement that proposes juxtaposing community engagement for specific short-term research projects and overarching long-term programmes of research.

PRINCIPLES OF COMMUNITY ENGAGEMENT

The engagement process with the community is a continuous and long-term endeavour. Atlee et al.[4] identified seven principles as a way to govern community engagement. 'Openness and Learning' allows stakeholders to engage with the community by actively listening to their concerns, feedback and ideas. The principle of 'Careful Planning and

Preparation' embodies the concept of creating a model of community engagement that is inclusive and has a clearly defined shared purpose. Actively involving members of the diverse community is another principle that Atlee et al.[4] termed 'Inclusion and Demographic Diversity'. Community engagement by definition is a collaborative process, however, the principle—'Collaboration and Shared Purpose' ensures that the collaboration is built on a purpose that interests and benefits both researchers and the communities. This is also key to the sustainability of the engagement; which was further reinforced by the 'Sustained Engagement and Participatory Culture' principle. Transparency is a crucial element between partners to establish a long, enriching and trusting relationship between the organisations, researchers and participants of the community—coined the 'Transparency and Trust' principle. Finally, the 'Impact and Action' principle underscores the importance of translating community engagement and the associated research into action to create real change and have an impact on the community in a positive manner.

COMMUNITY ENGAGEMENT THROUGH A STRATEGIC APPROACH

There are a number of community engagement strategies proposed and applied through various studies.[2,5] For meaningful community engagement, it has been universally emphasised to focus on developing equitable partnerships with the community, taking a community-centred approach and employing culturally sensitive and community-specific strategies.[6] In health and wellness research, which is commonly driven by a time-bound and target-focused culture,[7] developing a meaningful and long-term research partnership with the community through continuous community engagement is often not stressed and therefore overlooked. This drives the researchers to focus on specific project-based community member involvement strategies to have community representation in the projects. The participation ends with the duration of the research project.[8] The success of the reach of community engagement remains limited to those participants who are probably only interested in a particular topic, incentives or other personal/professional gain as opposed to developing a genuine interest in engaging in the research. In addition, the funding and resources for community engagement are also mostly limited to a specific research project, thereby restraining researchers and the community from continuing the engagement beyond the project. Therefore, a strategy for community engagement needs to be tailored to the programme of research. A programme of research encompasses multiple interlinked research projects that cover a wide range of issues and concerns of the involved community. This approach enables the researchers and the community in question to carry out the achieved community engagement, outreach and outcomes over another related project.

TOWARD A COMMUNITY-ENGAGED PROGRAMME OF RESEARCH

In the context of research, community engagement can be seen as a fundamental step toward community-based participatory research or community-engaged research (CEnR) because it builds the basis of a mutual partnership between researchers, organisations and members of the community.[5,9–11] This process provides a window for researchers to truly understand the community context and ecosystem, leading to research that is relevant and appropriate to the community. Researchers are able to strive toward an approach that best serves the needs and wants of the community and inspires citizen research, thus empowering members of the community in a collaborative manner. In this way, participants can shift the power dynamics in the researcher–participant relationship from observed to engaged.

We conducted a number of research projects on equitable access to care,[12–15] community health and wellness,[16,17] as well as job market integration and resettlement issues[18–20] as part of our CEnR programme for immigrant/ethnic–minority communities in Canada. This research examined the barriers to healthcare access and unmet healthcare needs encountered by Bangladeshi Canadians.[12,13] Through our community conversations,[14] we investigated potential solutions to these barriers and challenges that the community struggles with when accessing care. We also sought community input for issue prioritisation[15] which guided our research approach and strategies and led us to focus on health literacy.[21] We interacted with a variety of community groups and organisations during these studies and recognised that each community group and organisation has its own viewpoints, expectations, advantages and constraints. We developed plans for the purposeful and active participation of community members and organisations serving immigrant/ethnic-minority groups in research, priority-setting, cocreation of knowledge products and knowledge translation or mobilisation activities.

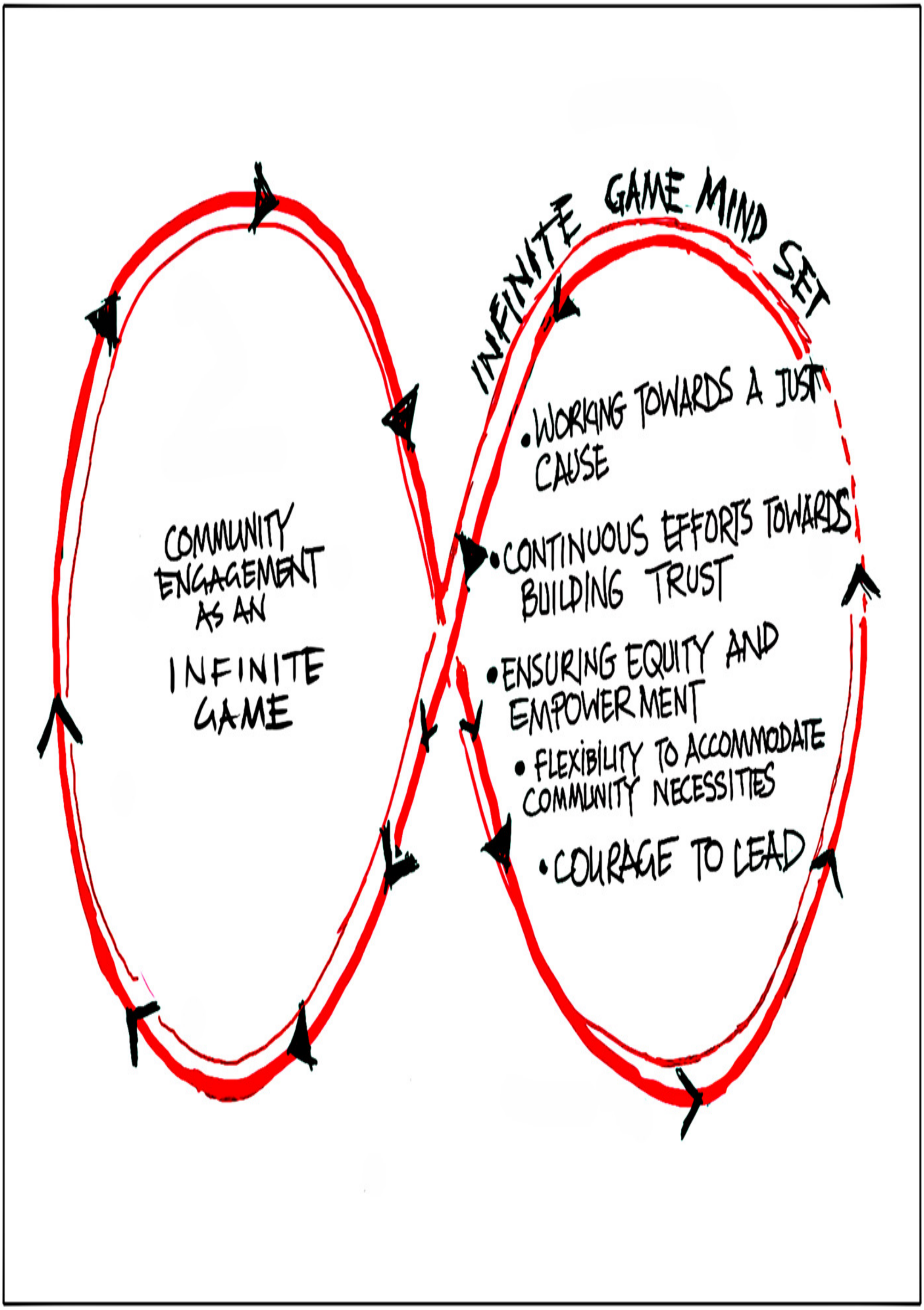
As our work progressed, we realised that we need to conceptualise community engagement at the programme level, not at the project level. Community engagement needs to be strategized as an approach to doing things inside the community and to explain the nature of our work to a wide range of the public and/or community members. It should not be conceptualised at a single research project level, because a single project level approach might lead to a parachute in and out scenario rather than maintaining a consistent presence. Our research programme-level community engagement efforts paid off by achieving the participation of members of the community in our research projects (both problem identification and solution development). Our community engagement efforts contributed to building interpersonal trust and led to active collaboration across all the steps of the research process of brainstorming, planning, executing and disseminating results.

INFINITE AND FINITE GAME

For a better comprehension of our community engagement strategy, we draw on the concept of ‘infinite and finite games’.[22] According to this concept, there are two types of games we engage in that are applicable in many aspects of our lives. These include education and career goals, work, business and essentially any social situation and activity where there are multiple participants and social, individual and systemic factors involved. Individuals need to follow certain rules, make decisions based on interactions with other individuals and consider multiple factors while striving to obtain certain outcomes. Finite games are set by specific objectives, timeframes, rules and boundaries. Finite players can either win or lose in this type of game.[22,23] On the other hand, infinite games are continuous activities without any designated beginning or end. In infinite games, the players are always learning and growing to advance a cause through building trusting teams while experiencing flexible growth.[22,23] The objective of the players in finite games is to win, and the winning or losing ends the game. In infinite games, the objective is not winning but rather ensuring the continuation of play, thus the game never ends. Similar to this concept, our community engagement efforts are centred around building trusting and collaborative relationships with communities.[22,23] An infinite player is motivated to keep the game going for as long as possible rather than looking for any immediate ‘win’.[23] As such, community engagement needs to be seen as an infinite game and therefore needs to be played with an infinite mindset. When infinite games are approached by using a finite mindset, the outcomes lead to decreased participation, trust, innovation and engagement which is not the goal of community engagement efforts. This, ultimately, leads to increased frustration from both the research and community sides.

FACTORS SHAPING AN INFINITE MINDSET FOR COMMUNITY ENGAGEMENT

As mentioned earlier, we need to conceptualise community engagement at the programme level, not at the project level. When meaningful community engagement for a programme of research is achieved, specific research projects requiring active participation of the community subsequently follow. Hence, we need to approach community engagement through an infinite game mindset,[24] as illustrated in Figure 1.



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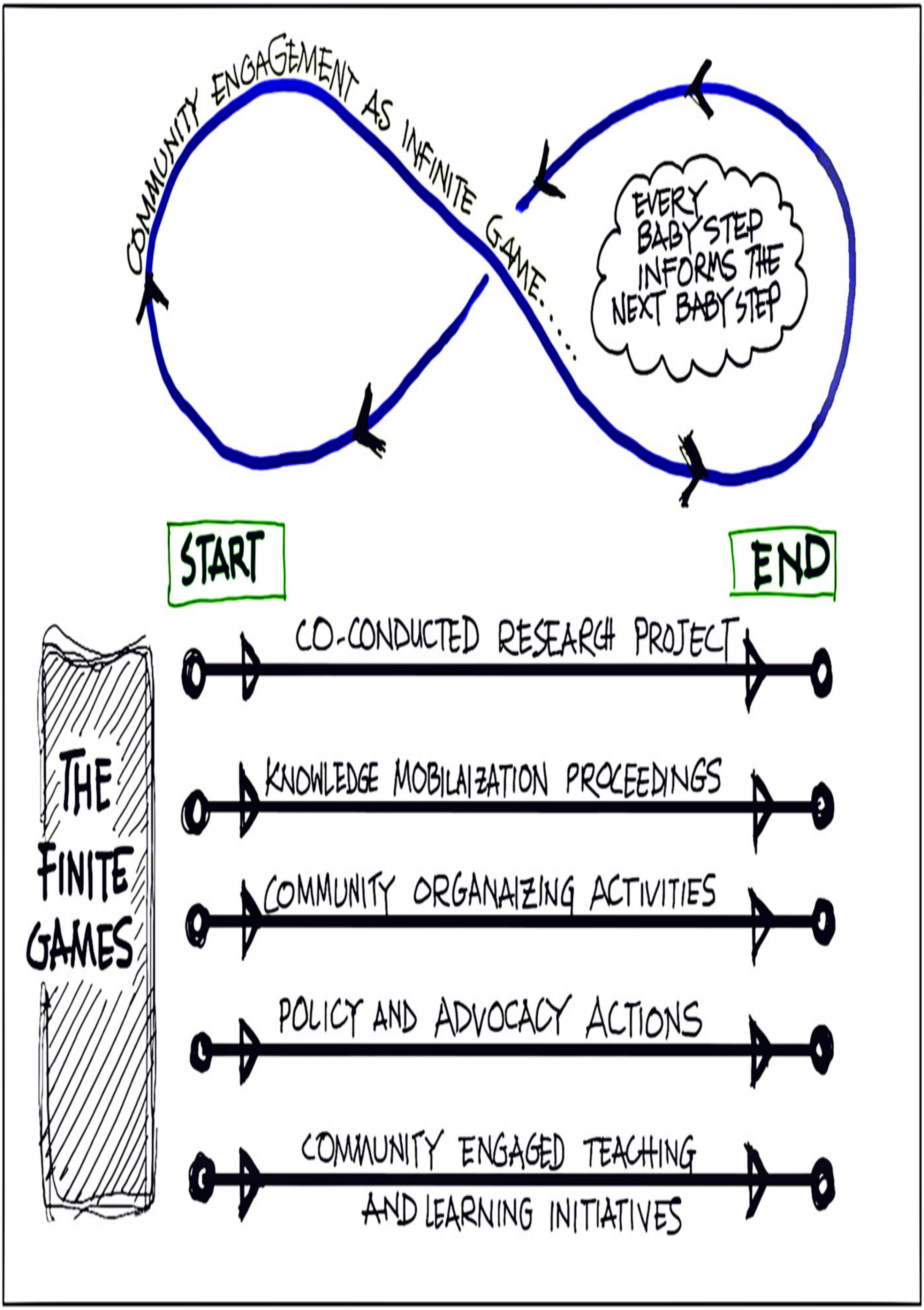
Community engagement toward a just cause, such as ensuring equity for immigrant/ethnic-minority communities, needs an infinite mindset. Community engagement thrives where there is a vision worth pursuing wholeheartedly when the vision is bigger than the researchers or the research projects. To advance the cause, the community needs to be on the side of the vision. This can be achieved through creating a relationship built on mutual trust, nonjudgement and shared benefit. The commitment to ensuring equitable and empowered involvement of the community in the process is another element that we always need to strive for. Without this approach, community engagement fails to mobilise the mass of people in the community. An infinite game approach also needs to ensure flexibility to accommodate the community's needs. This may warrant a change in the research focus based on experiential learning gained through community engagement. It calls for the fluidity of the researchers to be guided by the community regarding the focus of the programme of research. This approach ensures the community's long-term engagement and contributes to long-lasting trust. The courage to lead community engagement in these ways allows for innovation and the creation of new avenues of opportunity, thus perpetuating the infinite game.

SERIES OF FINITE GAMES CONTRIBUTING TO THE OVERARCHING INFINITE GAME

An infinite game does not exclude finite games. Rather, an infinite game is a context within which we can have a series of finite games (Figure 2). Finite games may exist within the infinite game, acting as checkpoints along the journey.[24] However, these games should not dictate the endpoint of the journey and should not derail the focus of the main mission. For example, within the infinite game of keeping up the health of community members, we can employ finite games such as playing indoor soccer in winter, outdoor cricket in summer or mall walking during bad weather days.



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We conceptualised that our individual research projects can be considered as a finite game. A research project has a start and an end with a number of possible tangible outputs. Furthermore, dissemination activities can be planned to take the findings and knowledge to the community. Also, we approached our research projects for not only knowledge creation but also to employ as a tool for engagement. Moreover, within our infinite game of community engagement, our finite game research projects have been acting as our milestones through completing a manuscript or conducting dissemination sessions. Table 1 shows the concurrence of the concept of infinite and finite games with respect to our programme of research.

Table 1 The juxtaposition of the concept of infinite and finite games with respect to our programme of research.

The infinite game	The finite games	Example of finite games
Community engagement with racialized/ethnic-minority communities for community health and wellness.	Co-conducted research projects.	Equitable access to primary care.
		Health and wellness literacy and determinants in the community.
		Mental wellness needs of nonhealth essential workers.
		Addressing digital inequity and the digital divide
		Job market integration of internationally trained health professionals.
		Community-based knowledge engagement hub.
	Knowledge dissemination activities.	Preparing and copresenting research results.
		Cowriting and publishing manuscripts.
		Writing articles for ethnic media.
		Arranging health and wellness workshops.
		Teaching and mentoring different levels of learners.
	Community organising actions.	Youth summer programme.
		Community scholar and citizen researcher programme.

		Newcomer research network.
		Alternative career mentoring.
		Coaching for professional development.
		Community Advisory Board or Community Advisory Group for research projects.
	Policy and advocacy.	Codeveloping and disseminating policy briefs, reports, white papers, or concept notes.
		Coadvocating for the cause through insider ownership and/or through outsider championship, as appropriate.
		Contributing to provincial and national level working groups.

CONCLUSION

The article refers to the principles and importance of community engagement in research. Drawing on the experience with multiple communities during our programme of research, we point out the need for strategic change in the community engagement process. Specifically, we refer to the concept of infinite and finite games in our community engagement strategy. We juxtapose short-term specific project-focused community engagement with the finite games where the players (e.g., smaller community subgroup and a few stakeholders of the project) are known, rules are fixed (e.g., community help in the recruitment or share lived experience and researchers design and lead the process, required performance measurement metrics to report, etc.), and when the agreed upon goal (e.g., completion of a research project or intervention) is achieved, the game ends. We advocate for a community engagement strategy for a programme of research instead of limiting it to one project. We do this by drawing on the infinite game concept where the players may be both known and unknown (e.g., research partners/collaborators, political/civil personalities, etc.), have no externally fixed rules (e.g., the researchers and community engage each other in multiple ways and beyond the methodological element of a study), and have the objective of continuing the game (i.e., the engagement) beyond a particular research project. The essence of this approach lies not in simply accomplishing a research project or paper, but rather in persistently pursuing research, community organising and knowledge mobilisation efforts that endure and contribute to the cause over time. It emphasises the ongoing commitment to community in a sustainable manner, beyond mere project completions. This transformative switch enhances the application and implementation of the principles of community engagement, thereby perpetuating the benefits to the community.

AUTHOR CONTRIBUTIONS

Tanvir C. Turin, Nahid Rumana and Mohammad A. A. Lasker conceived the paper. Tanvir C. Turin, Mashrur Kazi and Nashit Chowdhury drafted the paper. All authors provided critical input for multiple drafts. Nahid Rumana and Mohammad A. A. Lasker critically reviewed the manuscript. Nahid Rumana and Mohammad A. A. Lasker provided important perspectives as community member researchers. Tanvir C. Turin acts as guarantor to this article.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

This is a viewpoint article, thus there is no data viable with this article.

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The impact of adding cost information to a conversation aid to support shared decision making about low-risk prostate cancer treatment: Results of a stepped-wedge cluster randomised trial

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ABSTRACT (ENGLISH)

Background

Decision aids help patients consider the benefits and drawbacks of care options but rarely include cost information. We assessed the impact of a conversation-based decision aid containing information about low-risk prostate cancer management options and their relative costs.

Methods

We conducted a stepped-wedge cluster randomised trial in outpatient urology practices within a US-based academic medical center. We randomised five clinicians to four intervention sequences and enroled patients newly diagnosed with low-risk prostate cancer. Primary patient-reported outcomes collected postvisit included the frequency of cost conversations and referrals to address costs. Other patient-reported outcomes included: decisional conflict postvisit and at 3 months, decision regret at 3 months, shared decision-making postvisit, financial toxicity postvisit and at 3 months. Clinicians reported their attitudes about shared decision-making pre- and poststudy, and the intervention's feasibility and acceptability. We used hierarchical regression analysis to assess patient outcomes. The clinician was included as a random effect; fixed effects included education, employment, telehealth versus in-person visit, visit date, and enrolment period.

Results

Between April 2020 and March 2022, we screened 513 patients, contacted 217 eligible patients, and enroled 117/217 (54%) (51 in usual care, 66 in the intervention group). In adjusted analyses, the intervention was not associated with cost conversations ($\beta = .82$, $p = .27$), referrals to cost-related resources ($\beta = -0.36$, $p = .81$), shared decision-making ($\beta = -0.79$, $p = .32$), decisional conflict postvisit ($\beta = -0.34$, $p = .70$), or at follow-up ($\beta = -2.19$, $p = .16$), decision regret at follow-up ($\beta = -9.76$, $p = .11$), or financial toxicity postvisit ($\beta = -1.32$, $p = .63$) or at follow-up ($\beta = -2.41$, $p = .23$). Most clinicians and patients had positive attitudes about the intervention and shared decision-making. In exploratory unadjusted analyses, patients in the intervention group experienced more transient indecision ($p < .02$) suggesting increased deliberation between visit and follow-up.

Discussion

Despite enthusiasm from clinicians, the intervention was not significantly associated with hypothesised outcomes, though we were unable to robustly test outcomes due to recruitment challenges. Recruitment at the start of the COVID-19 pandemic impacted eligibility, sample size/power, study procedures, and increased telehealth visits and financial worry, independent of the intervention. Future work should explore ways to support shared decision-making, cost conversations, and choice deliberation with a larger sample. Such work could involve additional members of the care team, and consider the detail, quality, and timing of addressing these issues.

Patient or Public Contribution

Patients and clinicians were engaged as stakeholder advisors meeting monthly throughout the duration of the project to advise on the study design, measures selected, data interpretation, and dissemination of study findings.

FULL TEXT

INTRODUCTION

Healthcare costs are rising substantially in the United States and internationally,[1–7] leading to psychological, social, behavioural, and health-related challenges for patients. The associated cost-related hardship, often called *financial toxicity*, can result in delayed or forgone care[8,9] and is even associated with an increased risk of mortality.[10,11] In addition to the direct costs of healthcare, patients experience indirect cost burdens such as lost wages from missing work for appointments or illness-related disability. Communicating the relative or specific costs of options is an important part of patient-centred decision-making.[12] Patients want to know about cost information[13,14] and clinicians acknowledge its importance and impact on patients' choices and adherence to care.[15] Yet clinician communication and patient decision aids rarely include costs of treatment options to support decisions.[16]

Although financial toxicity affects patients with cancer worldwide,[1–5] it is particularly a problem for patients in the United States. The United States has a healthcare system that requires patients to use insurance to share the cost of care, and each insurance option in the private sector can vary in terms of the amount of cost-sharing provided.[6,7] In addition, more than 30 million people in the United States are uninsured and struggle to identify ways to pay for care through hospital billing options, the government, or social service agencies.[17–19] As many as 18% of patients in the United States have medical debt as a result,[19] and it is the most common form of debt in the United States.[20] Even patients who have adequate insurance coverage for cancer treatment receive out-of-pocket bills for copayments, medications, and support services. They also have indirect costs of care from lost wages or time off work, payment for transportation to/from health visits, and disruption to their daily routine.

In the context of early-stage, favourable risk prostate cancer,[21] there are several reasonable treatment options for patients to consider including active surveillance, radiation (external beam or brachytherapy) and prostatectomy (typically robotic). Each choice is similarly effective in preventing prostate cancer-related mortality but carries different tradeoffs and costs,[22] especially to patients with varying insurance coverage.[23] For example, prostatectomy and radiation therapy cost more than active surveillance both in terms of out-of-pocket health expenses and downstream indirect costs from time off work and recovery.[22–25] However, some patients prefer to intervene with surgery or radiation rather than actively monitor a known cancer, even if it is low-risk or favourable risk, because they worry about the cancer growing or spreading.[26] Others might choose active surveillance even with the increased risk of repeat biopsies and imaging because they want to avoid the possible side effects of surgery or radiation such as incontinence and erectile dysfunction.[27,28] The complexity of trade-offs, preferences, and difficulty estimating costs to patients can complicate shared decision-making.

We previously developed a conversation-based decision aid (called an Option Grid [OG]) containing information about low-risk prostate cancer management options. OGs are brief tabular comparisons of options that activate patients before clinical visits and facilitate efficient conversations during visits.[29] They can increase shared decision-making across diverse contexts.[30–32] by promoting deliberation and dialogue, while providing evidence-based information.[33] We added a prompt to consider the relative costs of prostate cancer management options. In past work, this approach increased the frequency of cost conversations about early-stage breast cancer decisions.[34] No such intervention has been developed and evaluated for prostate cancer.

In this study, we aimed to assess the impact of a conversation-based decision aid (OG) containing cost information about low-risk prostate cancer management options, combined with a brief training session for urologic surgeons, on the frequency and quality of patient-urologic surgeon cost conversations. We hypothesised that:

1.1: Urologic surgeons assigned to training and use of the decision aid would engage in more frequent cost conversations than urologic surgeons in usual care.

1.2: Urologic surgeons assigned to training and use of the decision aid would be more likely to make a referral (e.g., to social service organisations, billing representatives, social workers or financial navigators) to address specific cost details than urologic surgeons in usual care.

1.3 (Exploratory): Patients of urologic surgeons assigned to training and use of the decision aid would have lower financial toxicity at 3 months follow-up than patients of urologic surgeons in usual care.

We also aimed to examine the impact of the conversation-based decision aid and surgeon training on decision quality, including measures of decisional conflict, decision regret, and shared decision-making. We hypothesised that:

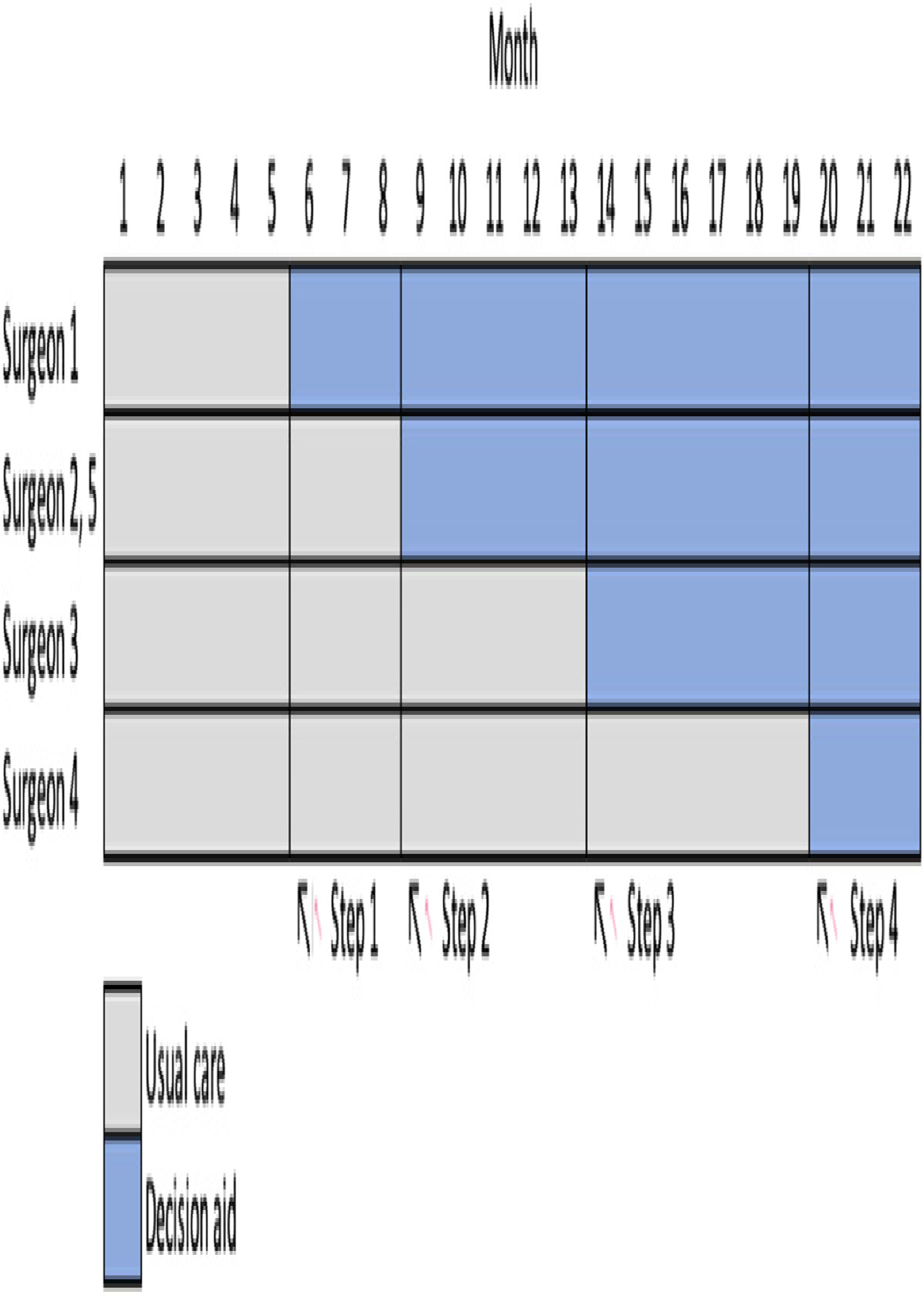
2.1: Patients of urologic surgeons assigned to training and use of the decision aid would report less decisional conflict, less decisional regret at 3 months follow-up, and more shared decision-making than patients in usual care.

METHODS

Detailed methods are described in a published protocol.[35] Reporting follows the 2018 CONSORT extension for stepped wedge randomised controlled trials.[36]

Design

We conducted a stepped-wedge cluster randomised controlled trial with urologic surgeons as clusters, four sequences, and at least one cluster assigned to each sequence (Figure 1). A stepped-wedge design involves delivering an intervention at regular intervals, or steps, following a baseline period with no intervention. In this type of design, studies often need fewer clusters to achieve the same statistical power as a larger cluster randomised trial, and each can act as their own control due to the baseline period.[37] In addition, because of the learning effects of a clinician-focused intervention such as a conversation-based decision aid, the stepped-wedge design limits contamination in the control group. Five 3-month periods were planned; we extended the length of some periods after trial initiation due to few eligible patients during the onset of the COVID-19 pandemic, resulting in five periods of 5, 3, 5, 6, and 3 months, respectively. We enroled independent eligible patients in each period.



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Settings

We conducted the study in outpatient urology clinics affiliated with a large academic medical center in the Midwest region of the United States.

Participants

We included five urologic surgeons who practiced at a participating clinic and routinely discussed management options for low-risk prostate cancer with patients.

We included English-speaking adult patients scheduled to visit a participating urologic surgeon to discuss a new diagnosis of low-risk prostate cancer. Eligible patients had at least one of the following: (1) a Gleason score of 6 or 7 (3 + 4); (2) a prostate-specific antigen level less than 10 ng/mL; (3) a surgeon's referral for study eligibility. We excluded patients unable to give informed consent due to cognitive or emotional barriers and those discussing recurrent or ongoing prostate cancer management. A research coordinator screened potentially eligible patients based on inclusion criteria and confirmed eligibility with the surgeon before arranging to contact the patient to gain consent to enrol in the study; surgeons could also refer patients directly to the study if they used the intervention with a patient during clinical care.

Patient and stakeholder engagement

At the start of the study, a patient and stakeholder advisory board was formed consisting of a survivor of prostate cancer, a patient advocate and leader of a local prostate cancer advocacy and education group, a urologist, a community engagement leader at the cancer center and expert on prostate cancer disparities, and an oncologist with expertise in financial toxicity. This team met monthly throughout the duration of the project to advise on the study design, intervention adaptation to include cost-related information, outcome measures selected, social service organisations and personnel for cost-related referrals, data interpretation, and dissemination of study findings.

Intervention and comparator

The intervention comprised an OG conversation-based decision aid comparing management options for low-risk prostate cancer, with relative cost information included for each option in addition to referral information for general and local resources for navigating care costs (Appendix A). OGs are brief, tabular comparisons of options written at an accessible reading level and organised by common patient questions.[29] OGs are used collaboratively by clinicians and patients to facilitate conversations and decision dialogue, while providing evidence-based information.[38] They are particularly useful in situations when patients might not have had time to prepare for a decision discussion, such as low-risk prostate cancer when patients often receive biopsy results from a clinician immediately before discussing management options. At the study start, we merged previously developed and tested OG information into a research version of an OG to compare active surveillance, surgical treatment and radiation treatment for low-risk prostate cancer. The cost information was added to the common questions about trade-offs between options and was generated from the literature available at the time of the study start.[24,25,39] To display comparative cost-related information, we included a visual icon to represent relative costs to patients ($–$$, $$–$$$, $$$) across options. We reviewed intervention adaptations with our stakeholder advisors, clinical partners, and study team members for clarity, feasibility, acceptability and appropriateness, and tracked adaptations systematically based on standards in implementation science.[40] Future work is ongoing to quantify more precise cost-level estimates across treatment options, but in this work, we encouraged clinicians and patients to weigh relative costs, and then refer patients to discuss more precise, personalised costs or resources with social workers, financial navigators, billing specialists or social service organisations. The study coordinator (K. P.), clinician, or administrative clinic personnel delivered the intervention to individual patients before or during a first discussion of management options following a new diagnosis of low-risk prostate cancer as defined above. After trial initiation, we adapted to allow clinicians who forgot to introduce the intervention before or during the initial patient visit to send the intervention to a patient postvisit, tracking adaptations using a standard framework.[40] The comparator was usual care.

Before study initiation, participating clinicians were trained in the study protocol. At the step initiating their entry into the intervention arm, each clinician attended a 30 min virtual training session in shared decision-making, use of the intervention, and cost-related resource and referral information.

OutcomesPrimary outcomes

We measured patient reports of cost conversations and whether or not a referral was made to discuss costs in a questionnaire collected immediately postvisit (T1).

Soon after trial initiation and before any observational data were collected, we discontinued planned observational data collection using an observer-reported cost conversation checklist.[41] This change occurred because of the COVID-19 pandemic which prompted mostly telehealth visits at participating clinics during the early months of the study and compromised the feasibility of having study team members audio record clinic visits in person for any in-person consultations. We attempted to have clinicians record the consultations using the telehealth software, but the new and changing software, combined with the challenges and pressures of the COVID-19 pandemic, and patients' hesitation to be recorded in their own homes with family members often present (even if clinicians were only to save the audio recordings, the recordings had to be created with video to start if patients were having a consultation with video turned on) made this process cumbersome. Instead, we decided to rely on the patient-reported questionnaire to simplify the process for all stakeholders.

Secondary outcomes

In the postvisit (T1) questionnaire, we measured patient-reported decisional conflict (SURE[42]), shared decision-making (collaboRATE[43]), and treatment choice preferred. We measured financial toxicity (COST[44,45]) as an exploratory outcome.

At 3-month follow-up (T2), we measured decisional conflict (SURE[42]), decision regret (decision regret scale[46]), treatment choice received, and financial toxicity (COST[44,45]) in a questionnaire distributed to participants by email or telephone.

Exploratory implementation outcomes

Among clinician participants, we measured feasibility, appropriateness, and acceptability of sustained intervention use with the Feasibility of Implementation Measure, Appropriateness of Implementation Measure, and Acceptability of Implementation Measure.[47] These four-item validated measures use a five-point ordinal scale, ranging from ‘completely disagree’ (score = 1) to ‘completely agree’ (score = 5). Higher scores indicate greater feasibility, appropriateness, and acceptability. We also measured clinicians' attitudes toward shared decision-making and cost conversations using the ADOPT scale[48] which lists words to describe using an intervention (e.g., CostTalk) and asks people how they feel about it.

Among patient participants, we assessed preferences for having cost conversations, with whom they prefer having cost conversations using an adapted validated measure on a five-point ordinal scale.[14] We assessed their confidence having cost conversations using a four-item measure on a four-point ordinal scale.[49] Among patient participants who received the CostTalk intervention, we measured acceptability of the intervention using the Acceptability of Implementation Measure.[47] These exploratory outcomes were added after study initiation.

Sample size. We assumed an intraclass correlation coefficient (ICC) value of 0.05 and a feasible total sample size of 200 patients across the five participating urologic surgeons. We estimated power directly for a stepped-wedge design by solving for its value given the specified ICC of 0.05 and the within-cluster variance of a Bernoulli (binary-valued) random variable (conservatively assumed to be its maximum value of 0.25. We based effect size assumptions on a prior study demonstrating a significant effect when comparing the impact of a decision aid with comparative cost information to a decision aid without cost information or usual care on cost conversation frequency (66.7% vs. 33.3%).[34] Using a two-sided test, the power to detect a difference in our primary outcome of cost conversation frequency was estimated to be 0.804.

Randomisation

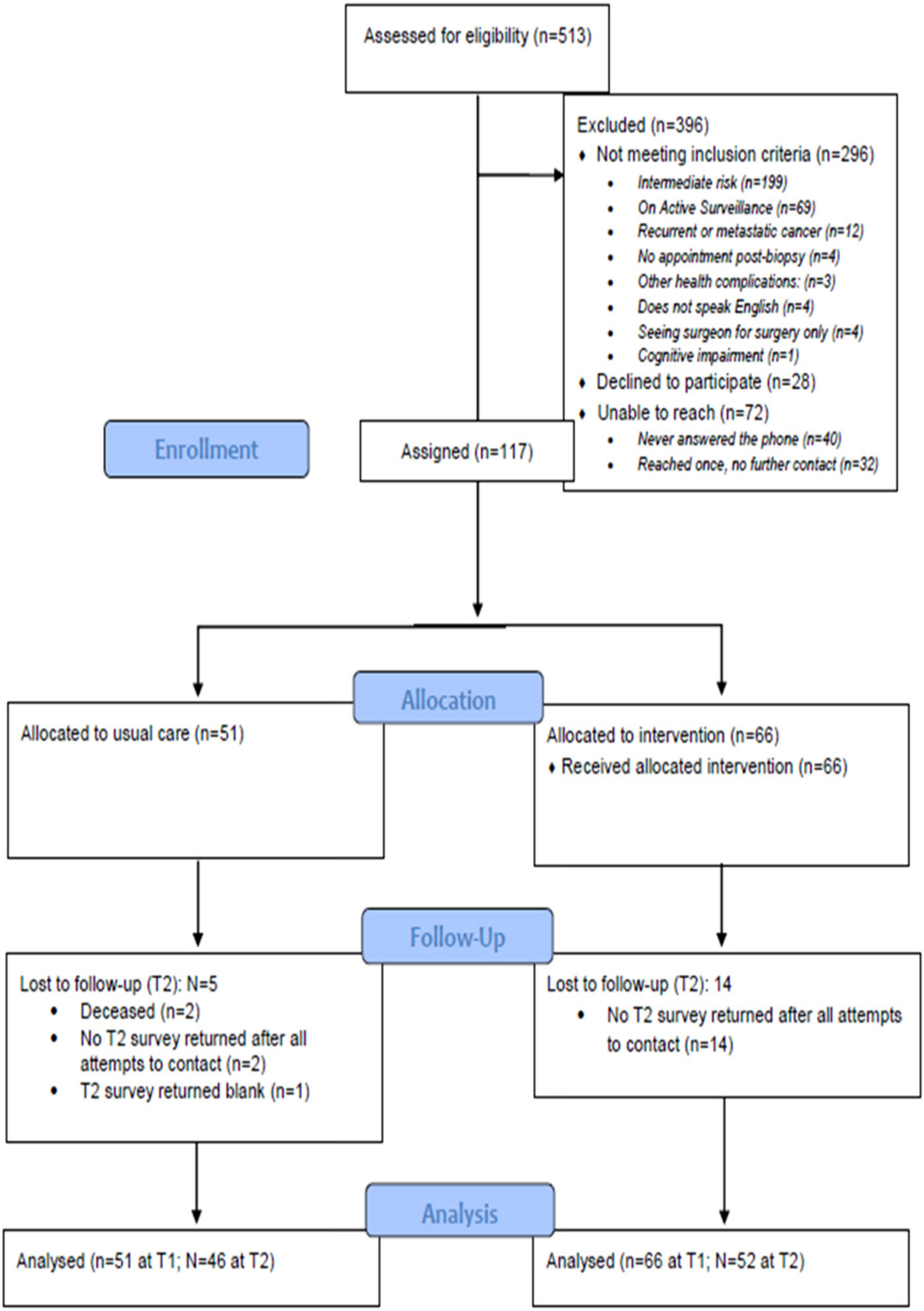
The principal investigator (M. P.) and study coordinator (K. P.) enroled clusters. The study statistician (A. J. O.), masked to cluster identity, generated the randomisation schedule and randomly allocated clusters (urologic surgeons) to the intervention sequences with a simple randomisation approach using R statistical software. Across the control and intervention arms, the study coordinator (K. P.) enroled consecutive eligible patients who provided informed consent to participate.

Statistical analysis

We first performed unadjusted bivariate comparisons of outcomes and predictors across intervention groups using *t*-tests for continuous variables and χ^2 or Fisher's exact tests (where indicated due to small sample sizes) for categorical variables. For primary and secondary binary-valued outcomes (e.g., cost conversations), we conducted logistic mixed-effectss regression analysis adjusting for patient educational attainment (less than college degree vs. college degree or more), patient employment status (full-time work vs. other), telehealth versus in-person visit, visit date, and the binary indicator variables of the study time period when the patient began follow-up as fixed effects, and clinician random effects to account for clustering of patient participants by urologic surgeon. We use analogous linear mixed-effect regression models to analyse outcomes with multilevel scales (e.g., decision regret scale[46]). In both types of models, we accounted for the stepped-wedge study design as well as the above-mentioned patient covariates. Formerly, let Yijt denote an outcome measured on the *i*th patient of the *j*th surgeon in time period *t*, OGjt indicate whether surgeon *j* has transitioned from usual care to the OG by time period *t*, and Xijt denotes a vector of covariates on the *i*th patient of the *j*th surgeon in time period *t*. The logistic and linear mixed-effect regression using models have the general form: [Image Omitted. See PDF]and [Image Omitted. See PDF]where in both models {λt}t= 2:5 adjusts for time periods 2 through 5 (time period 1 is the baseline period) and θj is a random effect specific to surgeon *j* assumed to be drawn from a normal distribution with mean 0 and an unknown variance. For the linear regression model only, ∈ijt is an idiosyncratic error term assumed to be drawn from a normal distribution with mean 0 and an unknown variance. In checking for outliers, we identified a few erroneously coded variables that we corrected. While we were prepared to use multiple imputation methods if the missing data was extensive, because drop-out only occurred at time period 2 (i.e., there was no dropout up to time period 1) and most outcomes were analysed at time period 1, we favoured the use of complete-case analyses for all analyses.

RESULTS

Participant flow: Between April 2020 and March 2022, 513 patients were assessed for eligibility. 296 did not meet inclusion criteria; 79 had a Gleason 6 or 7 intermediate risk, 120 had a Gleason score greater than or equal to 8, 69 were on active surveillance, 6 had recurrent cancer, 6 had metastatic cancer, 4 did not have an appointment postbiopsy, 3 had additional health complications, 4 did not speak English, 4 were seeing the surgeon for surgery only, and 1 patient was cognitively impaired. A total of 28 patients declined to participate and 72 patients were unable to be reached (40 patients never answered the phone and 32 patients were reached once with no additional contact). Of the 217 eligible patients that were contacted, 117 provided informed consent to participate. Figure 2 shows participant flow details.



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Patient participant characteristics

We enroled 117 patients total, of which 51 were randomised to usual care and 66 to the intervention condition. Most participants were White (84%), non-Hispanic (88%), and had a college degree or more education (56%). Reflecting the onset and progression of the COVID-19 pandemic, 49% of patient visits in the usual care arm were conducted via telehealth; 15% of patient visits in the intervention arm were telehealth. Table 1 displays participant characteristics.

Table 1 Enroled patient participant characteristics.

Abbreviation: IQR, interquartile range. **Aim 1: Cost conversation outcomes**

Table 2 presents summary statistics for the cost conversation outcomes at postvisit (T1). Full regression results are reported in Appendix C.

Table 2 Postvisit (T1) cost conversation summary statistics.

Cost conversation frequency: Unadjusted comparisons showed no increase in cost conversation frequency between usual care (47.1%) and intervention (43.9%) arms (χ^2 = 0.11, p = .74). In adjusted logistic regression analysis, the intervention was not significantly associated with more frequent cost conversations (β = .82, odds ratio [OR] = 2.27, p = .27).

Cost conversation referrals: In unadjusted comparisons, there were no significant differences in rates of referral to cost-related resources between usual care (5.9%) and intervention (7.6%) arms (χ^2 = 0.22, p = .90). In adjusted logistic regression analysis, the intervention was not significantly associated with referrals to cost-related resources (β = −.36, OR = 0.70, p = .81).

Financial toxicity: Financial toxicity, defined as the material and psychosocial burden of care costs on patients, was measured using a validated scale from 0 to 44, with higher scores representing more financial toxicity. It was consistent across usual care and intervention arms and across timepoints. Mean postvisit (T1) financial toxicity scores were 10.9 (SD: 7.7) in usual care and 11.1 (SD: 8.1) in the intervention arm. In adjusted linear regression analysis, the intervention was not significantly associated with financial toxicity scores postvisit (β = −1.32, p = .63). Financial toxicity scores at 3-month follow-up (T2) averaged 10.9 (SD: 9.2) in usual care compared to 10.5 (SD: 7.9) in the intervention. In adjusted linear regression analysis, the intervention was not significantly associated with financial toxicity at follow-up (β = −2.41, p = .23).

Aim 2: Decision outcomes

Table 3 summarises decision-related outcomes collected postvisit (T1). Table 4 summarises outcomes collected at 3-month follow-up (T2). Full regression results are reported in Appendix D.

Table 3 Postvisit (T1) decision outcome summary statistics.

	Usual care (*n* = 51)	Intervention (*n* = 66)	Adjusted *p*-value
Treatment choice preferred			
Monitor with tests (active surveillance)	25.5% (13)	15.2% (10)	
Surgery	45.1% (23)	31.8% (21)	
Radiation	2.0% (1)	6.1% (4)	
Other (cryotherapy or cryoablation)	3.9% (2)	3.0% (2)	
Not yet decided	23.5% (12)	39.4% (26)	.43
CollaboRATE	*n* = 48	*n* = 61	.32

Top box	52.9% (27)	54.5% (36)	
Communication preferencesa—% *Agree* or *Strongly Agree*		*n* = 51	
I would like my doctor to talk with me about my out-of-pocket costs when s/he recommends a test or treatment.		66.7% (34)	.80
I would prefer to talk about the cost of my care with someone other than my doctor, such as a nurse, social worker, or financial counsellor.		27.5% (14)	
I prefer to know about the out-of-pocket costs for my treatment before I am treated.		74% (37)	
My doctor should consider my out-of-pocket costs as s/he makes a medical decision.		31.4% (16)	
I consider my out-of-pocket costs when I make a decision about my care.		25.5% (13)	
SURE	*n* = 48	*n* = 62	.70
Decisional conflict	25.0% (12)	29.0% (18)	
No decisional conflict	75.0% (36)	71.0% (44)	

a

Measure was added after study initiation.

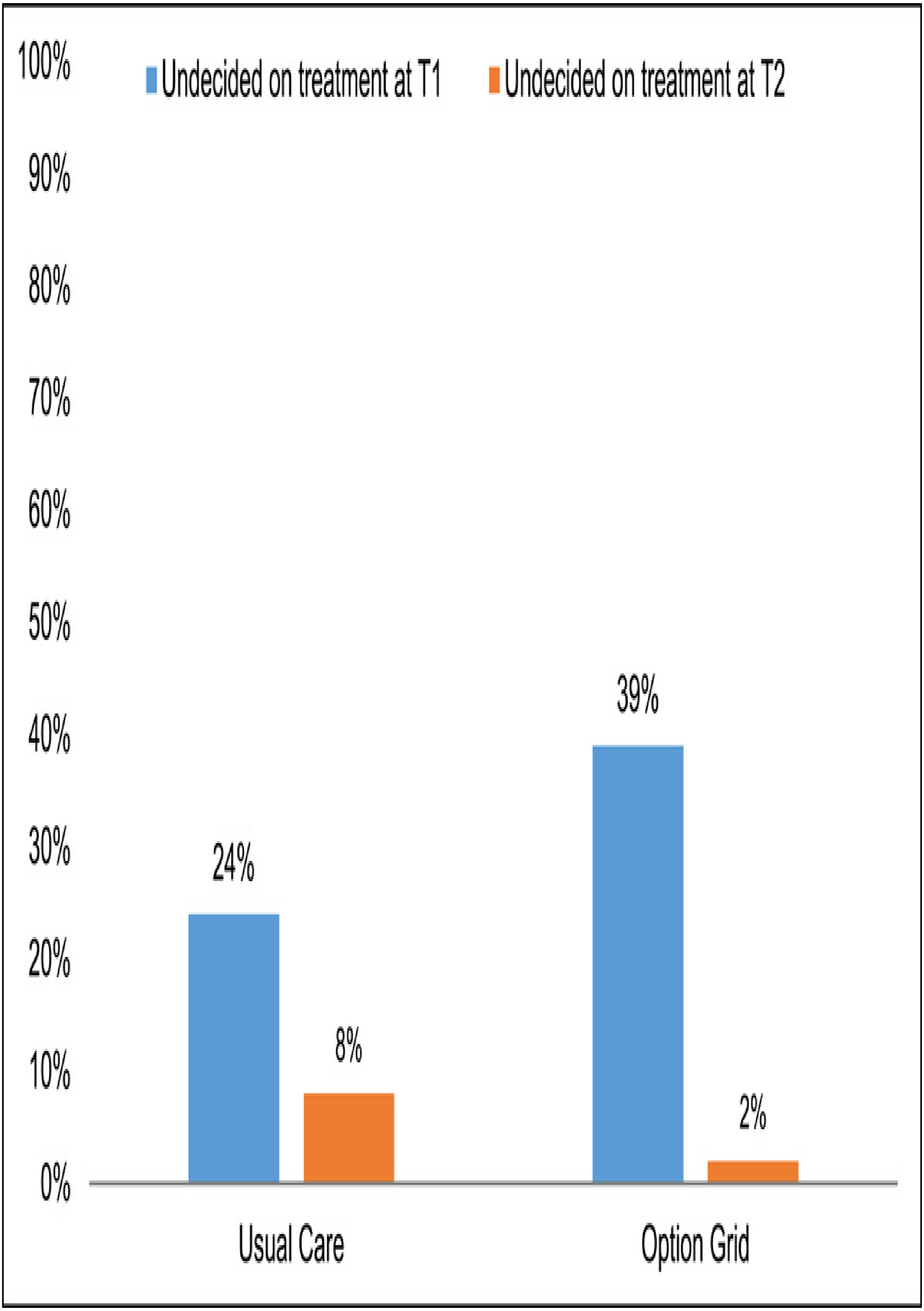
Table 4 3-Month follow-up (T2) summary statistics.

	Usual care 3 months follow-up (*n* = 46)	Intervention 3 months follow-up (*n* = 52)	Adjusted *p*-value
Treatment choice received			
Monitor with tests (active surveillance)	34.8% (16)	26.9% (14)	
Surgery	50.0% (23)	69.2% (36)	
Radiation	10.9% (5)	7.7% (4)	
Other (cryotherapy or cryoablation)	2.2% (1)	–	
Not yet decided	8.7% (4)	1.9% (1)	.62

SURE	*n* = 46	*n* = 51	.16
Decisional conflict	17.4% (8)	9.8% (5)	
No decisional conflict	82.6% (38)	90.2% (46)	
Decision regret	*n* = 46	*n* = 50	.11
Mean (SD)	12.6 (SD: 17.5)	11.2 (SD: 13.8)	
Median	2.5	5	
Range (possible range 0–100)	0–50	0–50	
COST financial toxicity	*n* = 44	*n*=48	.23
Mean	10.9 (SD: 9.2)	10.5 (SD: 7.9)	
Median	9	8	
Range (possible range 0–44)	0–36	0–36	

Shared decision-making: Unadjusted comparisons of collaboRATE shared decision-making scores showed no significant differences between usual care and intervention arms. In usual care, 52.9% of patients reported top box shared decision-making scores compared to 54.5% of patients in the intervention arm (χ^2 = 0.03, *p* = .87). In adjusted logistic regression analysis, the intervention was not significantly associated with shared decision-making scores (β = −.79, OR = 0.45, *p* = .32).

Treatment choice and deliberation: In unadjusted analyses, participants in the intervention arm appeared less likely to have decided on a treatment plan postvisit (T1) than participants in usual care (39.4% vs. 23.5% undecided; χ^2 = 3.30, *p* = .07; Figure 3). This reversed at 3 months follow-up (T2), where participants in the intervention arm appeared slightly more likely to have decided on a treatment plan than participants in usual care (1.9% vs. 8.7% undecided; χ^2 = 2.82, *p* = .09; Figure 3). In adjusted logistic regression analysis of those undecided versus decided on any treatment, the intervention was not significantly associated with treatment indecision postvisit (β = .64, OR = 1.90, *p* = .43) or at 3 months follow-up (β = −1.39, OR = 0.25, *p* = .62). However, among those undecided on treatment at T1 and who had not decided on treatment by T1 (usual care *n* = 12, OG *n* = 26), the OG was associated with improved resolution of treatment indecision by 3 months follow-up compared to usual care (unadjusted Fisher's exact test, *p* <.03). Due to the small sample size available for this analysis (*n* = 38) and the high conversion of patients to treatment resolution in the intervention arm, our ability to estimate models that adjusted for study time-period, other patient covariates, and physician random-effects was compromised with the effects of most such variables being inestimable. However, the one variable whose effect could be adjusted for was visit date and we found minimal evidence that it was associated with the resolution of treatment indecision.



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Decisional conflict: At T1, 25.0% of participants in usual care and 29.0% of participants in the intervention arm reported decisional conflict immediately postvisit ($\chi^2 = 0.22$, $p = .64$). At T2 3 months later, 17.4% of participants in usual care and 9.8% of participants in the intervention arm reported decisional conflict (χ^2 = 1.20, p = .27). In adjusted logistic regression analyses, the intervention was not significantly associated with decisional conflict postvisit (β = −.34, p = .70) or at 3 months follow-up (β = −2.19, p = .16).

Decision regret: In unadjusted comparisons of the decision regret score (0–100 scale), there were no significant differences in decision regret reported in usual care (m = 12.6, SD = 17.5) and intervention (m = 11.2, SD = 13.8) arms at 3 months follow-up (t = 0.44, p = .66). Adjusted linear regression analysis showed no significant association between the intervention and decision regret scores (β = −9.76, p = .11).

Implementation outcomes

Most clinicians had positive views on using the intervention. Regarding acceptability, all clinicians stated that they approved of the intervention (100% agreed or strongly agreed; mean = 4.2 [SD: 0.4], range: 4–5), and 4/5 (80%) said they welcomed using the intervention in practice moving forward (mean = 3.8 [SD: 0.4], range: 3–4). The majority of clinicians found the intervention fitting, suitable, and applicable for their practice (80% agreed or completely agreed; mean = 3.8 [SD: 0.4], range: 3–4), highlighting the appropriateness. Regarding feasibility, 80% agreed or completely agreed that it seems implementable in their practice and seems easy to use. However, a little more than half (3/5 or 60%) of clinicians described using it as easy and effective, only 2/5 (40%) described it as timesaving and collaborative, and 1/5 (20%) described it as necessary. One clinician (20%) described it as inefficient and laborious.

Patients stated that they preferred having cost discussions with a doctor (68% agreed or strongly agreed; mean = 3.9 [SD: 1.0], range: 2–5), compared with a social worker or financial counsellor (only 28% agreed or strongly agreed; mean = 3.0 [SD: 1.1], range: 1–5). Additionally, patients wanted to know their out-of-pocket costs before they were treated (75% agreed or strongly agreed; mean = 4.0 [SD: 1.0], range: 2–5), but were mixed in terms of whether they consider out-of-pocket costs when making treatment decisions (28% agreed or strongly agreed; mean = 2.8 [SD: 1.2]).

The majority of patients who received the intervention approved of their doctor using the intervention (70% agreed or strongly agreed; mean = 3.9 [SD: 0.7], range: 3–5). Additionally, most patients found the intervention appealing and welcomed their doctor using it (mean = 3.7 [SD: 0.8], range 2–5 and mean = 3.8 [SD: 0.8], 3–5, respectively).

DISCUSSION

This study evaluated an intervention to improve cost discussions between urologic surgeons and patients when deciding how to manage low-risk prostate cancer. Most decision aids and decision aid standards do not include cost information,[9,50] even though patients report that costs impact their choices and the implementation of those choices.[12,51,52] Despite extensive engagement with the clinical teams and high enthusiasm from both clinicians and patients using the intervention, the intervention was not significantly associated with the hypothesised outcomes, though we were unable to robustly test outcomes due to recruitment challenges. There were early indicators of a positive association between the intervention and cost conversation frequency in adjusted analyses, though these results were not statistically significant. In addition, it appeared that the decision aid-based intervention supported active deliberation based on the number of people undecided after their appointment, which resolved at their 3 months follow-up; this analysis was supported by a small sample size and did not allow for a fully adjusted model to be estimated, thus is presented as an exploratory finding worthy of future study. When adjusting for patient education, employment, telehealth versus in-person visit, visit date, and the enrolment time period as fixed effects, and clinician as random effects, results did not show significant associations with cost conversations or decision outcomes.

It is possible that those enroled in the study early in the recruitment period had higher financial toxicity and financial uncertainty due to the onset of the COVID-19 pandemic. We did note that more participants early in the study reported lower incomes and higher financial toxicity scores; these challenges were faced by many individuals in 2020 as jobs required individuals to stay home to avoid spreading illness, and the economy suffered from widespread shutdowns which were necessary but placed financial strain on individuals and businesses. It is also possible that the use of telehealth (which was more common early in the study, common in 2020 for those with nonurgent needs and those who did not need in-person care) impacted the way in which clinicians and patients discussed options and costs openly. In our study's regression analyses adjusting for these factors, neither visit type (telehealth or in-person) nor visit date were significantly associated with our outcomes. It was important to adjust for these factors in our analyses, but we might not have been able to detect intervention effects above and beyond these differences.

In addition, it is possible that clinicians need more than a conversation-based decision aid and brief training to encourage cost conversations. Clinicians were enthusiastic about the intervention, but it is difficult to change typical conversational flow and content. Perhaps more documented impact on patient outcomes and more in-depth role-playing interventions could serve as stronger motivators and increase self-efficacy for discussing costs. Alternatively, perhaps the patients in our study were less concerned about costs because many were employed with relatively high incomes. A larger study could engage a more socioeconomically diverse group of patients.

It is interesting to note that the intervention might not have encouraged cost-related referrals. The conversation-based decision aid listed resources for patients to contact for assistance or questions with financial aspects of care (e.g., social workers, financial navigators, hospital billing representatives and community organisations). It also listed questions patients could ask if they wanted to learn more about their costs. Perhaps clinicians using the intervention felt that the conversation-based decision aid covered this information without having to bring it up directly, or that many patients in this study did not need additional referrals to discuss costs.

Despite the limited impact on cost conversations and decision outcomes as measured, clinicians reported that they approved of the intervention and most wanted to use it beyond the study period. Some noted verbally that patients appreciated the intervention and even referenced it over time at subsequent visits. Clinicians provided suggestions for ways to improve the cost-related information in the decision aid that might help future work. For example, some clinicians commented that while active surveillance may cost less to the patient up front, the cost of repeated biopsies and imaging over time adds to these costs and could make active surveillance equivalent to surgery/radiation costs in 5–10 years. In addition, although the cost to patients between surgery or radiation might be equivalent or close to it, the cost to the healthcare system might be much higher for those who choose external beam radiation. We looked into the literature to clarify these questions raised by clinicians, and the data were limited or outdated on actual costs to patients and to the healthcare system. Future studies could explore more precise costs to patients and the healthcare system over time.

Finally, the number of people in the intervention arm who deliberated about options—remaining undecided upfront and resolving their uncertainty over time—warrants further investigation. One of the main goals of shared decision-making is to encourage patients to choose a treatment that aligns with preferences, taking the time they need to think through options. Most people in the control group (75%) made decisions upfront at the time of their appointment, while almost 40% were undecided in the intervention arm at the time of their appointment. At the 3 months follow-up, however, this uncertainty resolved, and only 2% remained undecided in the intervention arm. Perhaps those assigned to use the OG spent more time weighing their options. Future work could explore the process of shared decision-making and deliberation with and without a decision aid.

Strengths of the study included the highly engaged clinical team, many of whom thanked the research staff during and after the study for the intervention and resources. Some reported anecdotally that patients were bringing the intervention back to the clinic at their follow-up visit(s) months or even a year later. In addition, adding exact costs to decision aids is resource-intensive and often varies widely by patient. We used relative cost information and referrals to incorporate costs into an existing, previously tested conversation aid. The engagement of patient and stakeholder advisors also allowed us to adapt an intervention and develop a study flow that met the needs of end users even during difficult times such as the onset of the COVID-19 pandemic. The intervention was rated feasible and acceptable, and some plan to continue using even beyond the study period.

However, limitations included the small sample size (of about 60% of that planned) and heterogeneity of the number of patients by clinician, which impacted our statistical power to detect differences between groups. In addition, the timing of early recruitment began during the early stages of the COVID-19 pandemic limiting our ability to identify patients in-person and audio-record conversations. In addition, COVID-related delays in seeking care could have impacted the representativeness of our sample based on our inclusion criteria that men had to have low-risk prostate cancer. Low-risk prostate cancer is generally less commonly diagnosed among Black men, and Black men often delayed seeking care for prostate cancer during 2020.[53] Moreover, changes in clinical staffing led to smaller sample sizes than anticipated overall, and smaller cluster sample sizes. One clinician stopped treating patients with prostate cancer just before the clinician's randomised assignment to the intervention. This clinician often treated a more socioeconomically and racially diverse patient group at a satellite hospital facility. Across the analyses, the intervention was among the stronger of the associations despite being nonsignificant. Therefore, the sample size limitation, the heterogeneity of the number of patients by clinician, and a smaller than anticipated effect size on our primary outcome (47.1% discussing costs in usual care vs. 43.9% in intervention) affected our ability to detect differences between groups.

Future work should explore ways to engage clinicians and patients in shared decision-making and cost conversations during or after the clinical visit. Such work could involve additional member(s) of the care team, explore the best time to address these important issues, consider the amount, specificity and quality of cost information presented, directly ask about deliberation, and record or observe visits to assess outcomes.

AUTHOR CONTRIBUTIONS

Dr. Mary C. Politi led all aspects of the work including the design of the work, analysis and interpretation of data, and writing and revising the manuscript. Dr. Rachel C. Forcino contributed to the analysis and interpretation of data and writing and revising the manuscript. Ms. Katelyn Parrish contributed to the acquisition of the data and revising the manuscript. Dr. Marie-Anne Durand contributed to the design of the work, analysis and interpretation of data, and revising the manuscript. Dr. A. James O'Malley led the analysis and interpretation of data, and contributed to writing and revising the manuscript. Dr. Rachel Moses contributed to the analysis and interpretation of data and revising the manuscript. Ms. Krista Cooksey contributed to the analysis of data and revising the manuscript. Dr. Glyn Elwyn co-led the design of the work, analysis and interpretation of data, and writing and revising the manuscript. All authors have approved the final version.

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CONFLICT OF INTEREST STATEMENT

Dr. Mary C. Politi was a consultant for UCB Biopharma 2022–2023 on a topic unrelated to this manuscript. Drs. Glyn Elwyn and Marie-Anne Durand have developed Option Grid patient decision aids, which are licensed to EBSCO Health; they receive consulting income from EBSCO Health and may receive royalties in the future.

DATA AVAILABILITY STATEMENT

The datasets generated during and/or analysed during the current study are available from the corresponding author on request.

ETHICS STATEMENT

The study was reviewed and approved by the Washington University in St. Louis Human Research Protection Office (project #202004249). All participants provided informed consent to participate. This study was registered at ClinicalTrials.gov on 21 May 2020, (https://clinicaltrials.gov/ct2/show/NCT04397016).

AAppendixOPTION GRID INTERVENTION

[IMAGE OMITTED. SEE PDF.]

[IMAGE OMITTED. SEE PDF.]

BAppendixADDITIONAL POSTVISIT (T1) DECISION OUTCOME SUMMARY STATISTICS

	Usual care (n = 51)	Intervention (n = 66)	Adjusted *p*-value

Consumer assessment of healthcare providers and systems (CAHPS) communication measure (%) 'Yes, definitely'	*n* = 48	*n* = 62	.33
During your most recent visit, did your urologist explain things in a way that was easy to understand?	92.2% (47)	90.9% (60)	
During your most recent visit, did your urologist listen carefully to you?	92.2% (47)	92.4% (61)	
During your most recent visit, did your urologist show respect for what you had to say?	94.1% (48)	92.4% (61)	
During your most recent visit, did your urologist spend enough time with you?	90.2% (46)	89.4% (59)	
Perceived efficacy in patient–physician interactions[a]		*n* = 38	.85
Mean		13.8 (SD: 3.5)	
Median		16	
Range (possible range 0–16)		4–16	

a

Measure was added after study initiation.

C**AppendixPRIMARY OUTCOME REGRESSION RESULTS**

	Cost conversations	Cost strategies	Cost referrals
	Coefficient	Coefficient	Coefficient
Study step 1	(Reference)	(Reference)	(Reference)
Study step 2	−0.197	0.337	−0.81
Study step 3	0.461	−24.07	−29.78
Study step 4	0.261	0.783	−0.04
Option Grid	0.822	0.620	−0.04
Education	0.048	0.169	−31.00
Employment	0.305	0.045	−1.30

Telehealth	0.643	1.269	0.87
Visit date	−0.003	−0.002	<0.01
	Variance	Variance	Variance
Clinician	<0.001	0	0

DAppendixSECONDARY OUTCOME REGRESSION RESULTS

	Undecided on treatment (T1)	Undecided on treatment (T2)	CollaboRATE (T1)	SURE (T1)	Decision regret (T2)
	Coefficient	Coefficient	Coefficient	Coefficient	Coefficient
Study step 1	(Reference)	(Reference)	(Reference)	(Reference)	(Reference)
Study step 2	−0.23	19.03	0.43	0.77	−2.49
Study step 3	−0.30	−8185.0	1.12	−0.36	−6.33
Study step 4	−0.98	−4215.0	−0.02	−0.31	−10.13
Option Grid	−0.64	−1.39	−0.79	−0.34	−9.76
Education	−17.10	−2217.0	−0.24	0.54	14.66
Employment	−0.09	22.71	−0.85	−15.98	3.99
Telehealth	−0.41	−2565.0	−0.68	0.09	−8.07
Visit date	<0.01	<0.01	<0.01	<0.01	0.03
	Variance	Variance	Variance	Variance	Variance
Clinician	0.43 (SD: 0.65)	0	0	0.35 (SD: 0.59)	6.09 (SD: 2.47)

DETAILS

Subject:	Intervention; Toxicity; Surgeons; Prostate cancer; Professional attitudes; Mortality; Enrollments; Data interpretation; Regression analysis; COVID-19; Clusters; Prostate; Risk; Radiation; Medical referrals; Health care facilities; Decision analysis; Positive thought; Cost analysis; Feasibility; Regret; Recruitment; Decision making; Teamwork; Group decision making; Surveillance; Patients; Employment; Random effects; Telemedicine; Social services; Health risks; Pandemics; Newly diagnosed; Urology; Costs; Verbal communication; Cancer therapies; Disease management; Sequences; Insurance coverage; Clinical outcomes; Medical decision making; Cancer; Advisors; Referrals; Attitudes; Dissemination; Timing; Information; Conflict
Business indexing term:	Subject: Insurance coverage Costs
Location:	United States--US
Identifier / keyword:	conversation aid; costs of care; decision aid; financial toxicity; stepped-wedge cluster randomised design
Publication title:	Health Expectations; Oxford
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A Community of Practice to increase education and collaboration in dementia and ageing research and care: The Liverpool Dementia &Ageing Research Forum

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ProQuest document link

ABSTRACT (ENGLISH)

Background

Too often, dementia research is conducted in research silos without thorough integration and the involvement of people with lived experiences, care professionals and the Third Sector. Research can also get lost in academic publications, without reaching those benefiting most from the evidence. The aim of this methods and evaluation paper was to outline the aims, components and evaluation of the public-facing and -engaging Liverpool Dementia &Ageing Research Forum, to provide a blueprint for setting up similar communities of practice.

Methods

The Forum was set up in 2019 with the aim to (a) connect different stakeholders in dementia and ageing and co-produce research and to (b) inform and educate. This paper provides an account of the Forum model and evaluates the following key elements: (1) engagement; (2) experiences of the Forum and its impact (via an online evaluation survey and three reflections). All Forum members and attendees were asked to complete a brief evaluation survey about their experiences from October to November 2022. Three regular Forum attendees provided a case study about their involvement and its impact.

Findings

The Forum has reached out to diverse stakeholders and the general public, generating growing interest and engagement since its initiation. Forty-four members and attendees completed the survey. Most attendees completing the evaluation survey have so far engaged in between 5 and 20 activities (47.8%), and 91% felt the aims of the Forum have been met. Engaging in the Forum has produced various benefits for attendees, including increased research capacity and knowledge, as well as improved connectivity with other stakeholders. Eleven percent of respondents, 39% of lived experts, stated they experienced improved access to postdiagnostic care.

Conclusions

This is the first reported multistakeholder Community of Practice (CoP) on dementia and ageing. We make key recommendations for setting up and running similar dementia CoP, as they provide a noninterventional format for raising awareness, capacity and access to dementia care.

Patient and Public Involvement

This paper reports on the involvement and engagement of people with dementia, unpaid carers, health and social care providers and Third Sector organisations in a CoP.

FULL TEXT

INTRODUCTION

Patient and public involvement and engagement (PPIE) in dementia research are increasingly reported.[1,2] PPIE is critical to engaging people with diverse nonacademic work, voluntary and lived experiences in the field of research. To ensure that the voices of nonacademic team members in the design, conduct and dissemination stages are truly heard and recognised, stakeholders need to be integrated equitably in any research—this includes providing support to conduct some qualitative analysis and code transcripts, co-design topic guides and surveys and be co-authors in publications and nonacademic outputs, such as lay summaries.[3,4] With some research involving specifically recruited individual public advisers,[5–7] other research engages with dementia and carer stakeholder groups such as the Dementia Engagement and Empowerment Project[8] and the European Working Group of People With Dementia.[9,10] A broader approach to involving lived and professional experts in the co-design of research, and also empowering and advancing their knowledge, is by creating a Community of Practice (CoP). Communities of Practice can help facilitate wider and more in-depth social learning and knowledge exchange compared to individual learning.[11] Specifically, communities of practice bring together peers and professionals and experts from similar backgrounds, such as dementia, and enable learning through social engagement and joint participation in social practices, such as attending topic-specific group events and activities and engaging in topical discourse and discussion. Developed by Wenger,[12–14] this social theory has been employed in various settings outside of the educational sector, and in dementia, for example, has been found to effectively bring together a diagnostic clinical network[15] and primary care memory clinics.[16] However, it appears that no CoP, to date and reported in the literature, has been brought together to share knowledge about dementia care and to jointly generate research ideas for collaborative delivery, with diverse stakeholders from academia, health and social care, the voluntary and community sector and lived experience.

The Liverpool Dementia &Ageing Research Forum was set up in September 2019 with two underpinning aims: (1) to educate and inform about the latest dementia research and services to anyone with a professional or personal interest in the topic; and (2) to build an interdisciplinary wide network of stakeholders from academic, care provider, policy, Third Sector (voluntary services/charities) and lived experiences backgrounds to co-produce research together. The Forum provides a range of activities to network and collaborate across different stakeholder groups, generate research ideas, jointly apply for research funding and inform and connect members about the latest research, care services and related opportunities.

The aim of this methods and evaluation paper was to outline the aims, components, and evaluation of the public-facing and -engaging Liverpool Dementia &Ageing Research Forum, to provide a blueprint for setting up similar Communities of Practice. For this purpose, we have conducted a mixed-methods evaluation of the Forum, involving an online survey to all previous attendees and ongoing members, as well as three case studies on different stakeholders who have been involved in the Forum (one carer, one service provider, one clinician turned academic).

METHODSThe Liverpool Dementia &Ageing Research Forum

The international Forum, which is based in Liverpool, comprises four regular activities, which address each or both aims of the Forum to different degrees, enabling as large an engagement and skill-building of attendees and members as possible: (1) bimonthly public seminars/webinars; (2) monthly journal clubs; (3) biannual regional networking meetings and (4) an annual conference. Public seminars turned into webinars during the COVID-19 pandemic and have remained so. Seminars are free to the public and open to anyone with an interest in dementia and ageing. At each webinar, a different speaker shares their research or overview of care provision, which is then discussed with the audience via a moderator. Previous topics included carer resilience, dementia in South Asian minority groups, innovative long-term care for dementia, falls in older adults, Dementia Care Navigation and Admiral Nurses, as well as social and spatial inequalities in healthcare use for people living with dementia.

Monthly journal clubs are open to members interested in discussing the latest dementia research in the field and are normally attended by postgraduate students, academics, clinicians and Third Sector providers. To date, these have been held remotely to enable people outside the University of Liverpool to join easily.

Regional networking meetings are taking place twice a year, virtually to date, and last up to 90 min. Each meeting involves two regional speakers presenting their care services or initiatives, followed by a discussion and a virtual roundtable update and discussion on ongoing services, initiatives and research. This provides a more open platform for networking and collaboration.

The annual conference originally started face-to-face and has returned to face-to-face delivery after 2 years of remote delivery. Based on the continued growth of membership and attendees, the fourth annual conference was the first to invite open abstract submissions from academics, students, care providers and people with lived experiences of dementia and ageing.

How is it maintained?

The Forum was set up by C. G., as a result of recognising diverse expertise in the dementia care field across the region, despite a lack of a coherent network or Forum to engage with and learn from one another. The Forum is thus led and organised by C. G., with additional logistical and planning support provided for the annual conference and regional networking meetings (abstract submissions, venues and room bookings and refreshment orders). The Forum is advertised via email and word of mouth to the National Health Service (NHS) Trusts, Third Sector organisations, unpaid carers, as well as via social media, the University of Liverpool and National Institute for Health and Care Research Applied Research Collaboration North West Coast (NIHR ARC NWC) news, Eventbrite and its own webpage.

Forum members receive a monthly newsletter about event information and research and engagement opportunities, and anyone can join as a Forum member. An accompanying webpage provides additional news updates, and people can register for events via Eventbrite.

Data collection

Four different sources of data were collected: (1) registration and attendance numbers; (2) co-produced research and publications; (3) evaluation survey and (4) three case studies on engagement, experiences and impact. Registration and attendance numbers were taken from Eventbrite and Microsoft teams/Zoom/in-person events. Data on funded grant applications and publications were recorded continuously on an Excel spreadsheet. The evaluation survey was designed by the Forum organiser (C. G.) and piloted with a senior healthcare professional and academic. The survey was set up on google forms, and all survey questions are listed in Table A1. Three purposefully varied stakeholders and lived experts were approached about their engagement, experiences of involvement and the impact this has had on themselves as a person and within their professional/caring role.

No ethics approval was required as the feedback and evaluation survey on engagement and experiences of the activities of the Forum involved registered Forum members, and no participants were recruited for this feedback.

Data analysis for evaluation

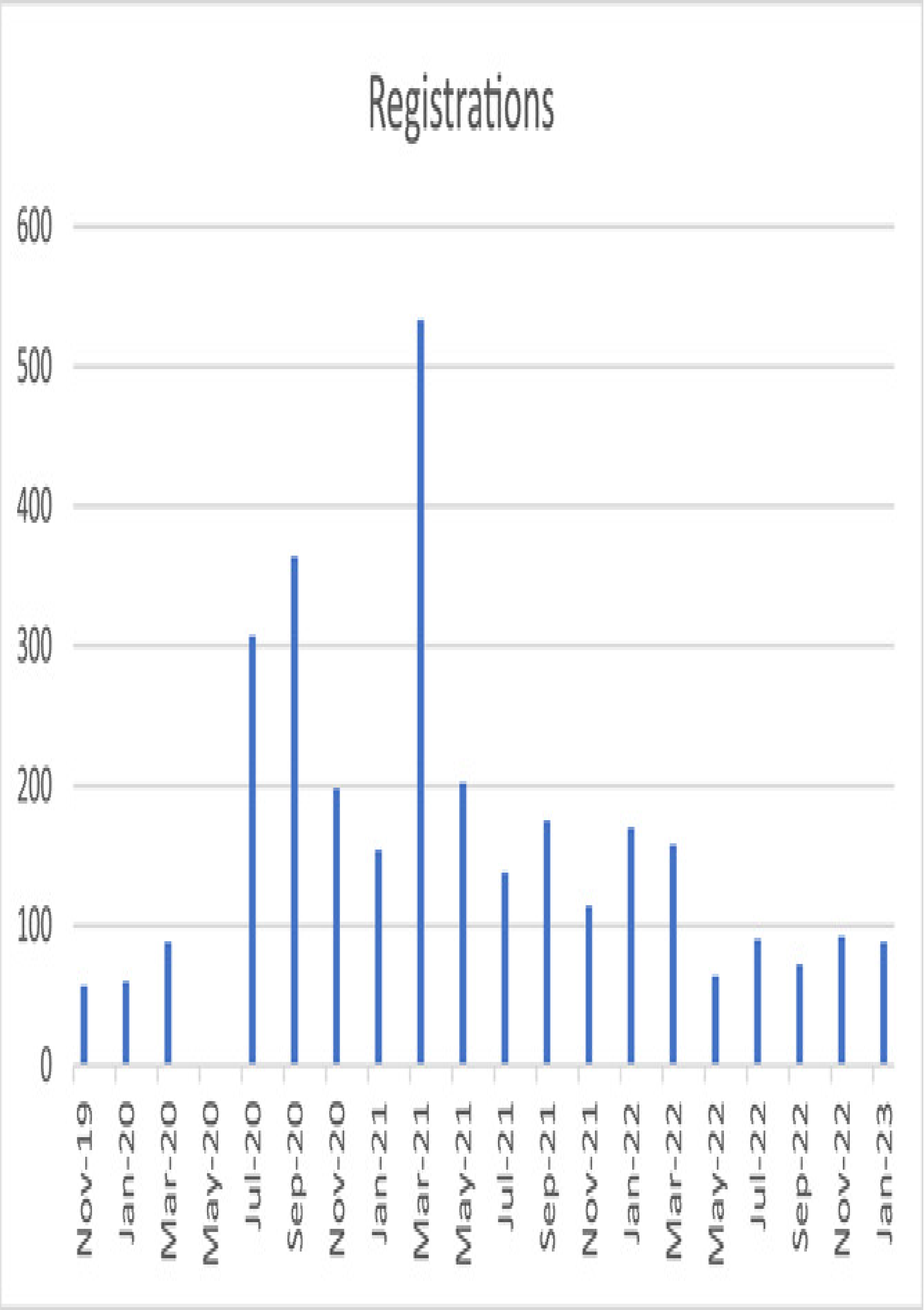
Data (survey responses) were analysed by google forms automatically, generating frequencies of responses for each question, graphs and diagrams.

Recommendations for similar CoPs

Based on the host's experiences of running the Forum, and on the member's experiences of engaging with the Forum, this paper provides key recommendations for setting up and running a similar CoP.

RESULTSThe Forum in numbersParticipation and engagement

Registration numbers for the bimonthly seminar/webinar series are shown in Figure 1. The first three seminars took place face-to-face, with the format moved online due to COVID-19 after the March webinar series. As shown, this enabled a large increase in people registering for the webinar series, resulting in increased attendance numbers. The greatest level of interest was reported for a webinar on a dementia core outcome set (*n* = 533),[17] the impact of COVID-19 on dementia care (*n* = 364)[6,18] and caring for a parent with dementia from a distance (*n* = 307).



Enlarge this image.

Co-produced research and publications

The Forum has generated a number of different co-produced research ideas, with 10 funded projects focusing on the impact of COVID-19 on dementia social care in the community, the impact of COVID-19 on care home visitation experiences and the care home workforce, global research into dementia care with Colombia, India and Uganda, as well as the unmet mental health needs of paid and unpaid carers, inequalities in accessing and using dementia care and inequalities in social care needs assessments. These were, to date, funded by the NIHR, the University of Liverpool ODA Seedfund and the Policy Support Fund, The Pandemic Institute, Geoffrey and Pauline Martin Trust. We are also having NIHR ARC NWC funded PhD students with topics generated as a result of the Forum connections, as well as NIHR ARC NWC research interns who are health and social care practitioners, conducting linked Forum research into dementia. Examples of internship projects include the experience of driving assessments in dementia and evaluating the impact of singing and dancing groups for people living with dementia and their carers.

To date, co-produced Forum research has resulted in 23 publications and policy briefings.[18,19]

Embedding within existing infrastructure

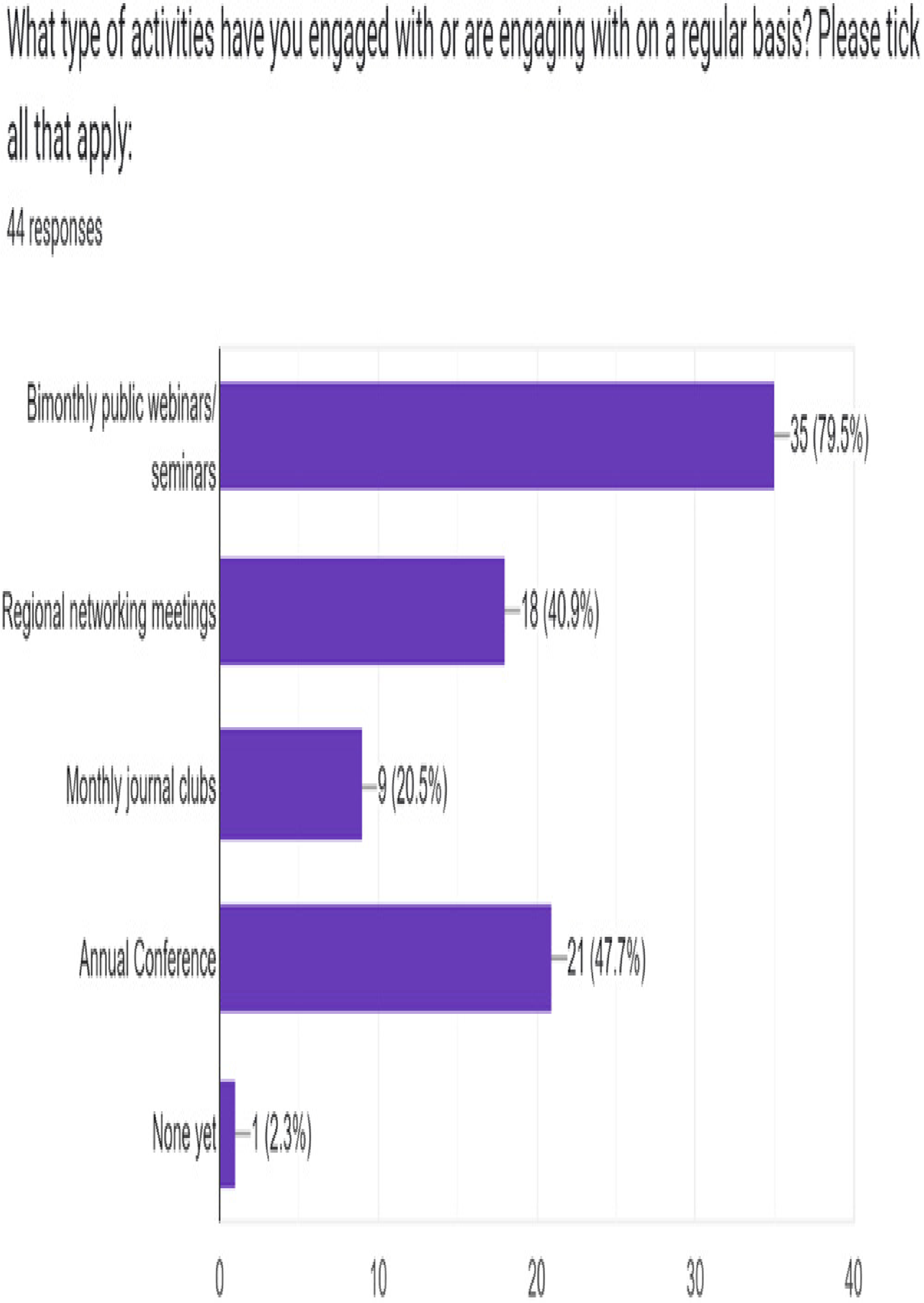
The Forum emerged from the NIHR ARC NWC which involves 60 diverse member organisations. The Forum drew upon the ethos of the equitable and collaborative ARC to set up a dementia and ageing-specific network of lived and professional experts. While the Forum started in the North West Coast region, it grew to become a national and international Forum, facilitated by remote webinars and events. When required, the ARC NWC provides minimal administrative support for hosting the annual conference and room bookings for face-to-face networking meetings, and support with public adviser fee payments for those lived experts who become actively involved in specific grant applications.

Evaluation surveyDemographics

Forty-four Forum members and users completed the evaluation survey between October and November 2022. Survey responders comprised a mix of academics, health and social care professionals, postgraduate students and lived experts, and from a mix of within the Liverpool region (*n* = 24, 54.5%), UK-residing outside Liverpool (n = 14; 31.8%) and from outside the United Kingdom (*n* = 6; 13.7%).

Engagement with activities

Engagement with activities ranged from ‘0’ to date to over 20, with the majority of respondents having participated in between 1–5 (45.5%) and 5–10 (34.1%) activities. The most commonly engaged activity of all four was bimonthly public webinars/seminars (*n* = 35; 79.5%), with one respondent not having participated in an activity yet as a newly added member (see Figure 2).



What type of activities have you engaged with or are engaging with on a regular basis? Please tick all that apply:

44 responses

Enlarge this image.

Feedback

The vast majority of responders stated that the aims of the Forum were met (91%), with 7% stating ‘maybe’ and one person stating ‘no’. When asked why responders were attending Forum events, 88% stated ‘to find out more about the latest evidence research and evidence’, with 64% stating ‘to meet peers and connect with different stakeholders and experts in the field. Over a third wanted ‘to jointly develop and apply for research funding and get involved in research’. As a result of the Forum, two-thirds of responders have met experts in the field and learned about different services, with nearly half of the responders having engaged in research by co-producing research. Eleven percent (*n* = 5) also noted improved access to support services. Of all lived experts who shared their views (*n* = 13), this equates to 38.5% who reported positive impacts on access to care.

All responders had positive to very positive (93%), or neither negative nor positive experiences of the Forum.

Three member reflectionsReflection 1—Unpaid carer and support service providerBackground

As a former Consultant in Fashion Merchandising, I gave up my company to look after my mother who had developed Alzheimer's and she died peacefully at home. I also looked after her brother who had vascular dementia and their half-sister who had vascular dementia. They all had long lives between their late 80s and 90s when they died, and it is from them that I get my belief in giving back to the community.

I am active in Merseyside and beyond in the following, to name some of my key involvement roles: Deputy Lead governor of Mersey Care NHS Foundation Trust and have been a governor since it became a Foundation Trust; a founding member, co-chair and treasurer of SURF (Service Users Reference Forum) for people and carers of people with dementia working together to try to make changes in attitudes and services; on the Liverpool Dementia Action Alliance co-ordinating group; involved in the patient engagement and experience group of Liverpool Place; Founder member of Together in Dementia Everyday (TIDE) carers involvement network supported by The National Lottery; Chair of the Liverpool Experts by Experience of the Doctorate in Clinical Psychology and a Public Advisor for the NIHR Applied Research Collaboration North West Coast.

I have spoken at conferences and helped run conferences. Set up and run groups for people with dementia and carers, I will take part in anything where I can promote awareness of dementia and the importance of listening to experts by experience.

My engagement and experiences with the forum

I have worked tirelessly with C. G. [Forum organiser] on research projects, especially during Covid-19 as it had disastrous results on both carers and people with dementia, and with all my contacts with carers and people with dementia, I know what is happening in the community. From the start of any research project when it had almost nothing more than a title, C. G. would ask if I wanted to be involved as a public advisor and as a carer then at the first meetings with the full research group, we hone down the project and apply for funding. If funding is granted through the information gathering, we check what information is coming through against what I and usually another carer are hearing from our grassroots information this is especially important as it acts as a check. This is the area where my knowledge is invaluable to the research project.

Impact

Being involved with the Forum and research has enabled me to understand my worth and not be backward in coming forward that what I must contribute is as important and valid as the professionals in the research and specialist field. I get much out of the Forum as I get to hear of research that I had no idea was/is happening. It also has provided me with the speaker to come to SURF and talk to our group that can run to 30 people, but our notes go to over 100. The skills I have developed during this time really are to do with the knowledge I have developed plus not to sit quietly in discussions but to take part as I have as much knowledge as any of the experts.

Reflection 2—Charity representative

As the Chair of the Board of Trustees for TIDE—I want to keep in touch with emerging research in the dementia world to inform our campaigning and influencing activities. We believe that carers and former carers have the experience and knowledge to improve health and social care, research and policy development throughout the UK. A social worker by profession, my background is in health and social care, having worked in local government, the Department of Health in England and as an independent consultant. I have been a Board member for Wales and West Housing Association for the last 8 years and have also previously chaired the Parkhaven Trust, a Merseyside charity providing residential and day services for older people and people with dementia.

I have a strong interest in research and represent TIDE in several research advisory groups, recruiting and mentoring unpaid carers to participate as experts by experience, to ensure their voices are heard in shaping and monitoring programmes. Membership of the Forum has led to TIDE's participation in several research programmes and I have co-authored subsequent publications.

It can be hard to keep up to date with wider research findings, so the Forum provides a great opportunity to find out about current work. Also important is the opportunity to network with colleagues from the research world. Ensuring that research findings are disseminated and applied is a constant challenge and the Forum plays an important role in this regard. Recent research by Forum members into the impact of COVID on older people, people with dementia and unpaid carers has provided important evidence for TIDE in our campaigning work. Membership in the Forum has given me greater insight into the research world as well as enhanced my knowledge about ethics, methodology and data analysis.

The recent annual Forum conference held in Liverpool gave TIDE the opportunity to promote the importance of involving unpaid carers in research and some practical examples of projects we have undertaken that involve carers as equal partners.

Reflection 3—Trainee clinician turned researcherBackground

I am based in Southport and have worked in mental health for around 14 years. This experience has covered acquired brain injury and adult mental health, and in my current role of 7 years as an assistant psychologist in older adult mental health. It was through my current role that I began supporting families affected by dementia. My role has involved delivering individual and group support around postdiagnostic support, carers and mild cognitive impairment.

Through working as an assistant psychologist, I regularly heard in-depth accounts from people on their experiences of living with dementia and adjusting to a diagnosis. I have also developed an appreciation for the huge challenges faced by people and families living with dementia, as well as an understanding of the limitations of the health service in providing quality care, particularly for people with young-onset dementia.

Over time, I began to request opportunities to develop research or evaluations on where services could improve for people using them. Unfortunately, time and resources are often limited when working in the NHS, and it was often difficult to conduct research.

Experiences with the Forum

I initially got involved with the Forum through a research internship with the National Institute of Health Research, which was led by C. G. For this I produced a qualitative project which is now being processed for publication. The completion of this internship has given me the opportunity to lead a research project including the designing, analysis and writing up. I have also had the opportunity to present at an international conference and display a poster at the Research and Forum conference in Liverpool.

Every month I attended a virtual meeting called a Journal Club in which a mixture of academics, clinical workers and other researchers discuss research that is presented by an attendee. I have found these meetings particularly helpful, and it has been interesting to listen to interpretations from a variety of perspectives. The meetings are less than an hour long and the virtual aspect ensures they are highly accessible. I feel these meetings are highly valuable for someone like myself who is looking to increase my academic competencies while working in a clinical setting. I feel that my attendance at these meetings has increased my ability and confidence to critically review research articles, as well as the educational aspect from the content of the studies.

Finally, the Research Forum is hugely valuable for community networking. There are regular webinars and virtual events, as well as an annual conference. These have allowed me easy access to recent research, as well as making it very easy to develop connections with local and national charities. Community support can often be dynamic, experiencing lots of change regarding locations and personnel and it is important to be able to keep up with its new initiatives and research. I have found the research forum to be a vital method of dementia networking in the North West as I see the positive difference in community inclusion that is present in Liverpool, but not in the area I currently work in.

Key recommendations for setting up and running a dementia CoP

Based on the experiences of the Liverpool Dementia &Ageing Research Forum, and challenges encountered (primarily the COVID-19 pandemic restricting face-to-face meetings, and at times staff time issues), we have five key recommendations for setting up and running a dementia CoP:

- 1.

  Have a supportive infrastructure to launch the CoP from: In the case of our Forum, this included the NIHR ARC NWC. When setting up a new dementia CoP, it is beneficial to link in with existing supportive academic, health or social care infrastructures, as it will also enable growing the CoP.

- 2.

  Involve members to help run different activities: While all activities are organised by one Forum lead, larger events such as the annual conference or the regional networking meetings require additional support in terms of content and logistics planning. By involving local members from diverse backgrounds to support the planning of the annual conference or sourcing refreshments and rooms for the regional networking meetings, the Forum can draw on the existing expertise of its members and attendees and also allow wider buy-in and attendance at Forum events.

- 3.

  Engage with people via different complementary activities and communication streams and platforms on a regular basis: In the present case, this includes providing four regular different activities and events, as well as monthly email updates, and newsletters and engagement via social media platforms. These activities emerged from growing discussions and facilitation opportunities within the Forum.

- 4.

  Enable equitable access and ensure everyone can contribute and get heard: As part of the Forum, we ensure that people with lived experiences as well as professionals, and academics and students can attend and share their views and contribute to the Forum (including via providing talks, shaping research ideas or leading research). This also involves a flexible approach by offering both face-to-face and remote events, as not all attendees may wish to attend face-to-face (especially when living in other regions of the country or other countries altogether) or to attend remotely (due to digital difficulties). This flexible approach particularly emerged from the COVID-19 pandemic and related face-to-face restrictions.

- 5.

  Evaluate the CoP and ask what works and what may not work so well, to increase engagement and feelings of building the CoP together: The brief anonymised online evaluation of the Forum as well as the three reflections enabled members to express their views about the Forum. This was the first thorough evaluation of the Forum, with ongoing verbal feedback provided by attendees and members at different Forum events. For example, the fact that regional networking meetings are now taking place face-to-face again was based on Forum feedback at the event of the last regional networking meeting.

DISCUSSION

This paper provides a methodological overview of setting up and running a public-facing, inclusive and collaborative research and engagement forum into dementia and ageing. Since initiation, the Forum has engaged with diverse stakeholders in the field and members of the general public, bringing together academic and care professionals, students, decision-makers and lived experts in the field to jointly shape and develop research and share new evidence into care, thus successfully meeting its aims.

As a result of engaging with the Forum, this CoP has led to diverse research involvement and co-production by involving various nonacademic stakeholders in grant submissions and thus research projects. Stakeholders and experts without previous connections were brought together based on their shared lived and professional expertise in dementia and ageing, evidencing how a CoP can generate new connections between experts to facilitate shared learning, engagement, and research development. Public and patient involvement is key to creating meaningful research that addresses the real-life difficulties for those living with, caring for someone with, or working with someone with a condition, and a growing body of evidence focuses solely on PPI or reports PPI involvement within its research.[1,5,20,21] However, the Liverpool Dementia &Ageing Research Forum appears to be the first CoP into dementia and ageing which advances individual types of public involvement and engagement, such as involving stakeholders in grant developments or dissemination, to forming a coherent Forum. This approach not only equitably involves people with personal and professional experiences in research, but also offers a platform to connect and share learnings with one another. Based on Wenger's[12] original theory of Communities of Practice, this evidenced approach further adds to two reported monostakeholder-specific dementia Communities of Practice[15,16] by reporting the benefits of multistakeholder involvement.

This increased involvement in research as one benefit of the Forum has led to improved capacity building, as evidenced in the reflections. One healthcare professional, working as an assistant psychologist supporting people with dementia and carers, has been actively involved in journal clubs, webinars, and other events and networking opportunities, which has raised his research capacity. Similarly, one unpaid carer has been strongly involved in various regular activities, whilst also being involved in different grant applications and funded research projects, all as a result of the Forum. While these are reflections, they illustrate how members of the Forum, from different backgrounds, can benefit from a topic-specific CoP that enables equitable involvement. With a dearth of evidence on how Communities of Practice can raise research capacity, there is some evidence reporting on the impact of meaningful public involvement of people with dementia and improved skillsets as a result. Beresford-Dent et al.[8] reported improved skills in people with dementia and unpaid carers through their strategic involvement as public advisers in a randomised controlled trial. The authors also highlight though that improving research capacity required significant time and effort from the academic research team members. Further research needs to be conducted on the impact of PPIE activities and overarching or linked Communities of Practice on capacity building.

In addition to increased research capacity, responders also noted the impacts of the Forum on improving wider knowledge about dementia and latest research, with some respondents reporting improved access to support services as a result. Communities of Practice are known to enable knowledge exchange among members.[11,16] With a dearth of evidence into Communities of Practice in dementia and ageing, specifically in diverse stakeholder communities, this evaluation appears to be the first to showcase the positive impacts of the Forum on knowledge exchange. This is particularly important given the mix of members and attendees, as people with lived experiences of dementia are generally little able to easily connect with care providers and ask questions and discuss issues. The improved connectivity between different stakeholders, as well as the public talks about different services and research evidence, appear to have led some respondents to experience improved access to support services. Whilst only 11% (*n* = 5) of respondents reported this, from the pool of possible respondents to have experienced this outcome (*n* = 13 lived experts), this is an important finding. Considering the myriad of inequalities that most people with dementia and carers face when trying to access care,[22–24] this evaluation provides the first and exploratory evidence as to how a public-facing CoP into dementia, which offers a durable network built on quality relationships and trust and enables sharing of knowledge and awareness, has enhanced the skills and expertise of stakeholders, leading to changes in how people (i.e., carers and people with dementia) are able to access care.

CONCLUSIONS

The Liverpool Dementia &Ageing Research Forum is the first reported dementia-specific CoP bringing together diverse stakeholders in the field. Setting up a dementia-specific CoP can help raise knowledge and education, as well as awareness about the condition and care pathways, as well as enable research capacity, meaningful co-produced research and improved access to care. While the Liverpool Dementia &Ageing Research Forum focuses on dementia, such a dementia-specific CoP can be adapted to encompass or refocus on more medical aspects surrounding dementia. A future in-depth evaluation is required to explore the experiences of engaging with the Forum and its impacts via qualitative interviews or focus groups with a larger group of attendees. This methods paper provides an approach to setting up and running dementia Communities of Practice elsewhere, and what to consider when doing so, representing a non-interventional avenue to support those with lived and professional experiences in the field.

AUTHOR CONTRIBUTIONS

Clarissa Giebel designed and set up the Liverpool Dementia &Ageing Research Forum, and designed the evaluation. Clarissa Giebel drafted the manuscript and analysed the survey responses. Ruth Eley, Hilary Tetlow and Thomas Faulkner wrote their sections in the Methods section, and jointly interpreted the findings and made recommendations with Clarissa Giebel. All authors approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

Clarissa Giebel is an Associate Editor of the journal and was not involved in any decision-making surrounding this manuscript assessment. The remaining authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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

AAppendix

Table A1 Evaluation survey.

#	Question	Possible answers

1	What is your background?	•Academic •Healthcare professional •Social care professional •Charity •Local council/policy representative •Student •Lived expert (person with dementia/current or former carer) •General public
2	Where are you from/do you work?	•Liverpool region •United Kingdom •International
3	What type of activities have you engaged with or are engaging with on a regular basis?	•Bimonthly public seminars/webinars •Monthly journal clubs •Regional networking meetings •Annual conference
4	Approximately how many events have you participated into date?	•1–5 •5–10 •10–20 •20+
5	The aims of the Forum are twofold: (1) to raise awareness and inform and discuss the latest research and evidence in dementia and ageing; and (2) to connect professionals, students, volunteers and lived experts in the field to jointly generate ideas for research and improve dementia care. Do you feel these aims are met with the activities provided?	•Yes •No
6	Why do you attend the Forum events? Please tick all that apply	•To find out more about the latest research and evidence •To meet peers and connect with different stakeholders and experts in the field

7	Overall, what are your experiences of the Forum?	•Very negative •Negative •Neutral •Positive •Very positive
8	Can you write a brief summary of your experiences and what the Forum has offered to you?	

DETAILS

Subject:	Citizen participation; Public involvement; Stakeholders; Aging; Health care; Collaboration; Social care; Community; Dementia disorders; Patients; Communities of practice; Surveys; Medical personnel; Polls &surveys; Seminars; Integrated services; Dementia; Evaluation; Access; Unpaid; COVID-19
Company / organization:	Name: University of Liverpool; NAICS: 611310
Identifier / keyword:	carers; Community of Practice; dementia; public and patient involvement and engagement
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Supporting carers to improve patient safety and maintain their well-being in transitions from mental health hospitals to the community: A prioritisation nominal group technique

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ProQuest document link

ABSTRACT (ENGLISH)

Introduction

Carers of people with mental illness may face distinct challenges, including navigating fragmented health and social services during discharge from mental health hospitals. Currently, limited examples of interventions that support carers of people with mental illness in improving patient safety during transitions of care exist. We aimed to identify problems and solutions to inform future carer-led discharge interventions, which is imperative for ensuring patient safety and the well-being of carers.

Methods

The nominal group technique was used which combines both qualitative and quantitative data collection methods in four distinct phases: (1) problem identification, (2) solution generation, (3) decision making and (4) prioritisation. The aim was to combine expertise from different stakeholder groups (patients, carers and academics with expertise in primary/secondary care, social care or public health) to identify problems and generate solutions.

Results

Twenty-eight participants generated potential solutions that were grouped into four themes. The most acceptable solution for each was as follows: (1) 'Carer Involvement and Improving Carer Experience' a dedicated family liaison worker, (2) 'Patient Wellness and Education' adapting and implementing existing approaches to help implement the patient care plan, (3) 'Carer Wellness and Education' peer/social support interventions for carers and (4) 'Policy and System Improvements' understanding the co-ordination of care.

Conclusion

The stakeholder group concurred that the transition from mental health hospitals to the community is a distressing period, where patients and carers are particularly vulnerable to safety and well-being risks. We identified numerous feasible/acceptable solutions to enable carers to improve patient safety and maintain their own mental wellbeing.

Patient and Public Contribution

Patient and public contributors were represented in the workshop and the focus of the workshop was to identify the problems they faced and co-design potential solutions. Patient and public contributors were involved in the funding application and study design.

FULL TEXT

BACKGROUND

Informal carers provide unpaid help to a friend or family member needing support. According to the 2021 census, more than 5.7 million people are estimated to be informal carers in the United Kingdom.[1] Carers Week in their 2022 report have estimated that the number of informal carers in the United Kingdom could be as high as 10.6 million.[2] A total of 1.5 million people care for someone with a mental illness.[3] Patient safety policies increasingly encourage carer involvement in reducing patient harm. One recent study found that carers who intensively engaged during hospital care provided patients with greater protection, but typically experienced negative consequences for themselves. The authors concluded that carer involvement in patient safety needs to be better understood, especially from the carers' perspective and negative consequences for carers need to be mitigated by practice improvements that value their contributions.[4]

This is especially true for carers of people with mental illness who may face distinct challenges because mental health problems are not seen. They might experience what is called ‘hidden caring’ where family carers may not recognise themselves as carers due to which they are less likely to access support.[5] However, they might be providing all sorts of help including emotional support, encouragement, practical help with daily tasks and advocacy.[6] Carers may have serious concerns about the safety of the people that they care for and experience stigma. They may feel responsible/guilty when the patient's health deteriorates or when patient safety incidents occur.[7] These feelings are especially heightened when they care for people with mental illness.[8] Thus, it is not surprising that caring is seen as a chronic stress experience.[9] Carers often experience psychological distress symptoms, including anxiety and depression, and may fail to meet their own health needs or make unhealthy lifestyle choices.[7]

All these challenges and especially those related to patient and carer safety, might worsen during the transition from inpatient mental health services to the community.[10] Inpatient mental health settings pose unique challenges for patient safety which also influence the discharge process including interpersonal violence, coercive interventions, safety culture, harm to self and safety of the physical environment.[11] Discharge is often described as a chaotic time with multiple threats to patient safety. For example, the weeks after discharge have been associated with numerous adverse outcomes, including self-harm, medication safety incidents, suicide and violence.[8] Adverse social outcomes which include loneliness and homelessness have also been reported.[12] Systems feel fragmented to many carers whereby social and clinical services seem funded and operated separately and miscommunication is common.[13] Carers must coordinate and navigate fragmented health and social services when their loved one is discharged from mental health hospitals.[7] They are often the individuals that must advocate for the patient and act as a ‘boundary spanner’ between fragmented services.[14] Fragmented services can be defined as a lack of coordinated care between health and social care for patients and carers.[15] Fragmentation of services is linked to the quality of care provided and poor clinical and social care outcomes.[16] Carers transfer important information between services and are sometimes the only constant in the patients' health and social care network.[17] Having effective social support (often provided by carers) is thought to reduce the likelihood of adverse events, such as suicide postdischarge.[18] The important role of carers during transitions of care has been highlighted during the pandemic.[19] This was because large numbers of patients were discharged from inpatient mental health services while access to community services was limited.[20]

A recent systematic review found only 12 carer involvement interventions to improve patient outcomes (e.g., readmissions) during mental health transitions.[21] From the 12 interventions, the interventions which supported carers across the full care pathway were the most promising.[21] A recent study involving patient engagement activities found that many carers had concerns about the safety of the person they cared for and their own mental health and safety during care transitions.[8] They described feeling unsupported, lonely and depressed in the community, and were unable to optimally support their loved ones.[8] Moreover, carers for those with mental illness felt they were not involved in discussions and decisions around discharge and had insufficient information about available support services in the community. These feelings were amplified during the Covid-19 crisis.[22] Another study found that competence and listening skills of staff members, concerns about waiting times, staffing levels and overall resourcing of services were key safety issues for mental health service users, carers and professionals. However, that study did not identify solutions and did not focus specifically on care transitions.[23]

Supporting carers of people with mental illness during transitions of care is imperative for ensuring patient safety and the well-being of carers themselves.[24] Patient safety and carer wellbeing challenges during discharge from mental health hospitals span social care, primary care, secondary care and public health with carers being expected to skillfully interact with the multiple professionals across diverse disciplines who are involved in the care of their loved ones. Therefore, interdisciplinary lenses are needed to develop multiagency solutions.[8] To address this, in the present study, we conducted a workshop that brought together patients and carers as well as expertise academics (some with clinical/social care backgrounds) within primary care, mental health, social care and public health. The work aimed to identify problems and solutions to inform future carer-led patient safety interventions after hospital discharge as well as interventions to support the carer's well-being during this challenging time.

METHODSStudy design

The widely used nominal group technique (NGT) was used which combines both qualitative and quantitative data collection methods.[25] Delbecq et al. proposed the initial model for NGTs and set out four distinct phases: (1) problem identification, (2) solution generation, (3) decision making and (4) prioritisation, implementation and intervention development.[26] Phases 1–3 were conducted as one online workshop event and phase 4 was conducted separately using online survey technology. The study team brought together stakeholders from health services and the community to identify problems and coproduce solutions for feasible interventions.[27]

Phase 1 problem identification

Participants were asked first in smaller breakout rooms to broadly identify problems that affect safety of people discharged from mental health services and the well-being of carers. The results of each breakout room were fed back to the full group.

Phase 2 solution generation

Participants within each breakout room were asked what services could do to solve the problems initially highlighted in phase 1. All solutions identified within each breakout room were then discussed with all participants as one group.

Phase 3 decision making

Participants decided which of the potential solutions should be prioritised considering also their feasibility (*the possibility that can be achieved is reasonable*) and acceptability (how much they like the idea) leading to a reduction to the list generated in phase 2.

Phase 4: Prioritisation, implementation and intervention development

The study team reviewed and merged solutions to create a list that is manageable for participants to understand and rank. A Qualtrics survey[28] was designed for the ranking exercise. Each solution was classified into four main themes, this was done through discussion between the immediate project team (S. M., M. P. and N. T.) highlighting and discussing what each intervention primarily addresses. Participants were asked to rank each solution (from the least to the most important) within each theme by feasibility and acceptability. Cumulative scores were generated by reversing the ranking scores and adding them together across participants. The focus of the analysis was on the top three solutions ranked. The survey was sent to participants by email after the workshop.

Phases 1–3 of the workshop took place as one online session via Zoom hosted by the lead researcher (N. T.). The workshop started with an introduction to the project scope including the background, layout of the session and prompt questions. Twenty-eight participants took part in the workshop and were split into four breakout rooms. Each breakout room had a facilitator from the University of Manchester with experience in facilitating NGTs. All four groups were evenly distributed and included patients, carers, academics and professionals. As a part of the phase 4 ranking exercise on Qualtrics, participants were asked to fill out their demographic data: age, ethnicity, gender, stakeholder group (patient, carer, practitioner, academic, other), professional role/job title and the number of breakout room (1, 2, 3, 4).

Participants' recruitment and eligibility

Participants were recruited via already established contacts within the study team and through social media. Links with relevant universities and third-party groups were also established. To help recruit people from underserved communities and maximise the relevance of the findings to the community, the recruitment approach was carefully designed to be inclusive (format/type/language used on adverts) of patients/carers with diverse backgrounds to capture the voices of research underserved groups.

The eligibility criteria were broad so that patients/carers were not excluded based on demographic factors, social and economic factors, and factors related to health status and health conditions as described in the NIHR-INCLUDE guidance.[29]

The eligibility criteria for the NGT were the following:

- 1. 18 years and older AND
- 2. past mental health inpatients OR
- 3. carers, such as relatives OR
- 4. academics (with primary care, social care or public health background).

The eligibility of interested participants was further confirmed by the study team using the following screening questions. To take part in the workshop participants would have to return a completed screening pro-forma with the following items:

- 1. Your primary stakeholder group (are you a patient, informal carer, professional-state job title).
- 2. Do you have direct experience of discharge from inpatient mental health services (Yes OR No).
- 3. Would you prefer to be in a patient-/carer-only group or a mixed group with other stakeholders (question presented only to carers).
- 4. Please provide 3–4 sentences about yourself and why you would like to take part in the workshop.

Once eligibility was confirmed, participants were sent the information sheet, topic guide (outlining the itinerary for the workshop and discussions) and a consent form to sign and return to the study team. Once the consent form was signed and returned, participants were sent the Zoom link for the workshop. The NGT workshop took place on 15 June 2022 and was approximately 3 h long with scheduled breaks. Participants received £25 per hour for taking part in the workshop, in line with the INVOLVE guidelines.[30]

Data sources

Relevant data from phases 1–3 were collected by the host and breakout room facilitators in the form of hand-written notes. Further to this, the whole workshop including the breakout rooms was audio recorded. For phase 3, anonymous rankings were collected using Qualtrics and were analysed independently by the two researchers within the study team (S. M., N. T.). Handwritten notes collected during phases 2 and 3 (solution generation) were used to provide context towards the ranking exercise (phase 4).

Analysis

For the analysis, we used the Qualtrics data generated in the survey. We asked participants to rank the solutions within each theme by feasibility and acceptability (1 being the most feasible/acceptable and the last as the least). We reverse-coded the data which gave us the cumulative ranking from the most acceptable/feasible solution (highest number) to the least (lowest number).

RESULTSDemographics

Twenty-eight participants took part in the workshop and 17 of them (61.8%) also completed the ranking survey on Qualtrics sent by email after the workshop. During phases 1 and 2 of the workshop (Zoom event), breakout rooms one to three were an equally distributed mix of stakeholder groups. Breakout room four consisted only of carers because some carers had stated that they would prefer to be in a separate group during the screening stage. Table 1 describes the demographics of the 17 participants who took part in the workshop and completed the online survey. We did not collect demographic data from participants who did not complete the survey. Participants were a mixed group of patients (29.4%, *n* = 5), carers (35.2%, *n* = 6) and academics (35.2%, *n* = 6), many academics also had a clinical/social mental health professional background. Two social care professionals and one academic also had lived experience as a carer. The mean age was 43 years (26–55) exact age was reported; however, we presented it categorically to increase anonymity. Eleven participants were female (64.7%), 10 participants identified as White British (White or British) ethnicity (58.8%), 2 (11.8%) Mixed and 1 person (5.9%) identified as Black Caribbean, Greek, Asian British and British Pakistani, 1 (5.9%) did not disclose.

Table 1 Demographics data of all participants taking part in phase 1, phase 2 and phase 3 of the workshop.

Age group	Ethnicity	Gender	Stakeholder group	Professional role/job title
26–35	White British	Female	Informal Carer	
36–45	Asian British	Female	Patient	
36–45	White British	Male	Academic	Academic in Pharmacy
46–55	British Pakistani	Female	Informal Carer	
46–55	Mixed	Female	Patient	
46–55	White British	Female	Informal Carer	
26–35	White British	Male	Informal Carer	
26–35	White	Female	Patient	
46–55	British	Female	Patient	
46–55	British	Female	Patient	
36–45	Greek	Male	Academic	Research Associate
36–45	Mixed	Male	Academic	Expert by Experience
46–55		Male	Academic	Carers Lead
36–45	White British	Female	Academic	Lecturer

46–55	White British	Female	Informal Carer	
46–55	Black Caribbean	Male	Informal Carer	
36–45	White British	Female	Academic	Research Fellow

Phase 1: Problem identification

Several distinct patient safety and carer well-being concerns were identified by the four breakout rooms. One commonly identified concern across the breakout rooms was a lack of support for carers with regard to their mental health and difficulties navigating the discharge process (such as a lack of awareness on how to best support the patient). Table 2 lists the highlighted safety concerns for patients discharged from mental health services and carer well-being concerns by all four groups.

Table 2 Problems identified by participants during phase 1.

•1. *Difficulty navigating discharge process*: The discharge process is difficult for carers to know how to support patients (e.g., confidentiality)
•2. *Difficulty navigating the transition between CAMHS and adult services*: Carers feel they are expected to take responsibility
•3. *Difficulties if carers aren't family*: If not family members, this might affect the way carers are seen by mental health professionals—creates confusion with professionals (uncertainty and delays and the involvement)
•4. *Carers guilt*: Periods of deterioration (close to section)—when the patient has no insight of becoming more unwell, if a carers is involved in this, they can feel very guilty
•5. Lack of immediate support during recovery
•6. *Carers have insufficient knowledge about illnesses*: Carers need to be educated about the specific illness/diagnosis
•7. *Carers difficulty managing work and caring repsonsibilties*: Carers who work are feeling stressed to leave people with mental illness alone and risk their safety/people might feel abandoned
•8. *Strain on the family dynamic*: A child might put a strain on the whole family, and it is difficult to support with the whole family and the relationship

•9. *Difficulties faced by people without carers*: People without carers, e.g., widowed or have no contact with family
•10. *Insufficient carer involvement preadmission*: Not much involvement of carers very early on before admission
•11. *Carer's own mental health and wellbeing are affected*: For example, higher levels of stress, anxiety, depression and other mental health effects are common
•12. *Patients health deterioration waiting for service availability*: Health deterioration due to lack of resources, beds, carer staff at the hospitals.
•13. *Emotional impact of improper hospital discharge* for patient and carers (stress, anxiety, anger)
•14. *Lack of carer engagement policies at the hospitals*, e.g., carer charter, carer strategy, MH strategy at the NHS acute trust.
•15. Risk of self-harm—suicide and risk management
•16. Human resource shortages
•17. Carers feeling isolated
•18. *Insufficient co-ordination of care with primary care and wider community services* (which could include families)
•19. *Insufficient access to wider services and support* (such as community assets to support wellbeing, work, etc.), especially in the context of people who may face major barriers to accessing services themselves

Abbreviations: CAMHS, child and adolescent mental health services; MH, mental health.

Phase 2: Solution generation

There were many potential ideas generated across the four breakout rooms. These ranged from specialist teams to support patients and carers when they are transitioning back into their home, to family therapy and training techniques for patients and carers. Techniques suggested included behavioural activation and problem-solving skills to manage everyday stressors.

Phase 3: Decision making

After a group discussion with regard to the potential solutions highlighted in phase 2, the list was combined (solutions that were very similar grouped together) into 34 potential solutions generated across the four breakout rooms. Potential solutions ranged from improving access to services to family therapy and carer wellness interventions. Table 3 lists the 34 potential solutions generated.

Table 3 Potential solutions were generated during phase 3 of the workshop.

•(1) Improving access to services
•2) Quick access to therapies
•(3) *Dedicated family liaison worker*: To act as a bridge between hospital and home, including checking the safety of home to return to, etc.
•(4) Working with carers to develop *a full pathway of mental health support*, from emotional support and prevention to everyone stepping up to more intensive support for those who need it. Perhaps delivered by carers champions within services like IAPT.
•(5) Having *collaborative discharge planning* from the hospital with the patient, family worker (as suggested above) and carer. Perhaps adapting existing approaches such as activity scheduling/BA type approach to help the patient plan what they need to do and what they need help with and plan where that help will come from, e.g., cooking, bills, cleaning, medication, etc.
•(6) More *education for families* on conditions
•(7) Tailored *peer support intervention* for carers, in a format that is convenient to the people involved, that may be face to face, remotely, telephone, etc.
•(8) *Ring-fenced time* at the end of appointments for staff to speak to carers
•(9) *Home environment check* at admission/predischarge
•(10) *Financial grants for travel expenses* for carers
•(11) *Improving inpatient experience for carers*, i.e., carers resource pack, open communication and consistent feedback between acute staff and carers

•(12) *Practical risk management guidance* for acute to community transition
•(13) Carers' needs assessments assessing the needs of carers at discharge
•(14) *More clarity on co-ordination of care*: Who should be doing it, what works, what models are more or less effective
•(15) *Practical approaches to enable the delivery of person-centred care*: Person-centred care is something that is well recognised and understood but remains extremely difficult to actually deliver, an intervention that provides a practical way of delivering this would be useful
•(16) *Better implementation of existing solutions*: A lot of the issues flagged are areas where there is quite a good understanding of what needs to happen, but less in terms of how we ensure it is delivered in an effective and efficient way
•(17) *Package of support* based on both carer (if there is one) and the patient's needs
•(18) *Self-care and coping strategy training for patients*: Patients being educated and receiving basic training in self-care and important coping strategies, including behavioural activation and problem-solving skills which can help them manage their everyday stressors
•(19) *Psychoeducation around mindset*: The risks of being focused only on the negatives; learn techniques to switch off to positives
•(20) Mindfulness-based meditation, and relaxation techniques for carers
•(21) *Carers illness education*: Carers receive basic training about specific illnesses and being educated about the importance of more generic stressors that other people may face
•(22) *Transitional discharge model*: Peer support to individuals who are looking for additional support following a discharge.
•(23) *The process to improve communication between carers and staff*: Carer staff/leads at hospitals to engage and involve carers in discharge and carer pathways

•(24) *Joined up services working in conjunction* not ringfencing funding
•(25) *Specialist MDT discharge team*: Team of doctors, nurses and care staff, etc., who handle discharge for patients and carers till they are discharged and settled in the home.
•(26) *Postdischarge follow-up*: Weekly check-in with both patient and carer for the 12 weeks following discharge to ensure things are going well
•(27) *Carers wellbeing support*: Support for carers so they don't become unwell themselves inc. advice on support groups, etc.
•(28) Carers discharge planning involvement involving carers in discharge planning
•(29) *Start support planning/information capture at admission*: Identify who the support network is for the patient, and how much involvement can be provided and this can then help with the discharge
•(30) *Improvement of CAMHS—adult transition*: Make the transition from CAMHS to adult services age later or the services to work together for some time
•(31) *Family therapy*: An evidence-based approach to treating adolescents that focuses on intervening directly with family members to repair relationships and addressing challenges encountered by adolescents and caregivers in key extrafamilial systems
•(32) *Talking services for carers*: Having people that carers can speak too. Patient to talk to someone when a carer is not there
•(33) *Improving the importance of carer support in policy and practice*: NHS services and hospital trusts are to elevate supporting carers to the same importance as safeguarding
•(34) *Improving peer communication between carers*: Carers need to connect with each other and recognise their role. Time for self-care for patient

Abbreviations: BA, behavioural activation; CAMHS, child and adolescent mental health services; IAPT, improving access to psychological therapies; MDT, multidisciplinary team. **Phase 4: Prioritization, implementation and intervention development**

The list of 34 potential solutions was reduced to 20 solutions by the research team, many of the potential solutions were similar so were combined. Workshop participants were then sent a Qualtrics survey which comprised four main themes and were asked to rank each of the solutions within each theme by feasibility and acceptability. The four main themes (carer involvement and improving carer experience, patient wellness and education, carer wellness and education, policy and systems improvements) and the solutions within these themes were derived from the discussions in phase 3. Participants felt it too difficult to rank such a large list of solutions, we collectively so decided to create four smaller themes, based on the primary problem the solutions aim to address. Table 4 lists out the four themes and the solutions within each theme including the cumulative ranking (by reversing the ranks and adding them together across participants) for each solution within the themes, Figure 1 outlines the most feasible (*the possibility that can be achieved is reasonable*) and acceptable (how much they like the idea) and acceptable solutions within each theme.

Table 4 Themes and solutions for participant cumulative ranking by feasibility (F) and acceptability (A) (phase 3).

Theme 1: Carer Involvement and Improving Carer Experience	A	F	Theme 2: Patient Wellness and Education	A	F	Theme 3: Carer Wellness and Education	A	F	Theme 4: Policy and System Improvements	A	F
Dedicated family liaison worker or team for discharge to act as a bridge between the hospital and home, including checking the safety of the home when the patient returns. Weekly check-in with both patient and carer for the 12 weeks following discharge to ensure things are going well.	46	30	Adapting and implementing existing approaches such as activity scheduling to help the patient plan from, e.g., cooking to bills, etc. Ensuring person-centred care is delivered in an effective and efficient way.	50	55	Basic training/education for carers and patient families about specific illnesses and being educated about the importance of more generic stressors that other people may face.	40	38	Checking the home environment is checked at admission/predischarge.	51	58
Start at admission: identify who the support network is for the patient, and how much involvement can be provided and this can then help with the discharge.	44	51	Patients should receive basic training in self-care and important coping strategies to manage their everyday stressors.	42	58	Carers needs assessment and mindfulness-based meditation, and relaxation techniques for carers.	32	31	All services working together in conjunction not ring-fencing funding.	54	62

Improving inpatient experience for carers, i.e., carers and service users resource pack, open communication and consistent feedback between acute staff and carers.	32	43	Family therapy—patients and their family members (including their carers) receive therapy together.	48	48	NHS services should elevate supporting carers to the same importance as safeguarding.	27	31	Financial grants for travel expenses for carers.	28	25
Staff/leads at hospitals involving and working with carers to develop a full pathway of mental health support. A carers discharge planning involvement and transitional discharge model. Maybe it can be delivered by carers champions within services like IAPT.	41	23	Patient to talk to someone when a carer is not there.	32	33	Tailored peer/social support intervention for carers. Provided in a format that is convenient to the people involved, so they do not become unwell themselves.	41	30	Practical guidance acute, community around risk management.	38	49
More time is needed at the end of appointments for staff to speak to carers.	17	33	Basic training/education for patients about specific illnesses and being educated about the importance of more generic stressors that other people may face.	23	31				Understanding co-ordination of care—who should be doing it, what works, what models are more or less effective.	59	59
									Improving access to therapies for patients.	43	42

Abbreviation: IAPT, improving access to psychological therapies.

Carer Involvement and Improving Carer Experience’	Patient Wellness and Education	Carer Wellness and Education	Policy and System Improvements
- Most Acceptable: Dedicated family liaison worker/team - Most Feasible: Support planning at admission	- Most Acceptable: Adapting and implementing existing approaches - Most Feasible: Education about illness	- Most Acceptable: peer/social support intervention for carers - Most Feasible: Carer education about illness	- Most Acceptable: improving carer understanding around co-ordination of care - Most Feasible: Joined-up working between services

Enlarge this image.

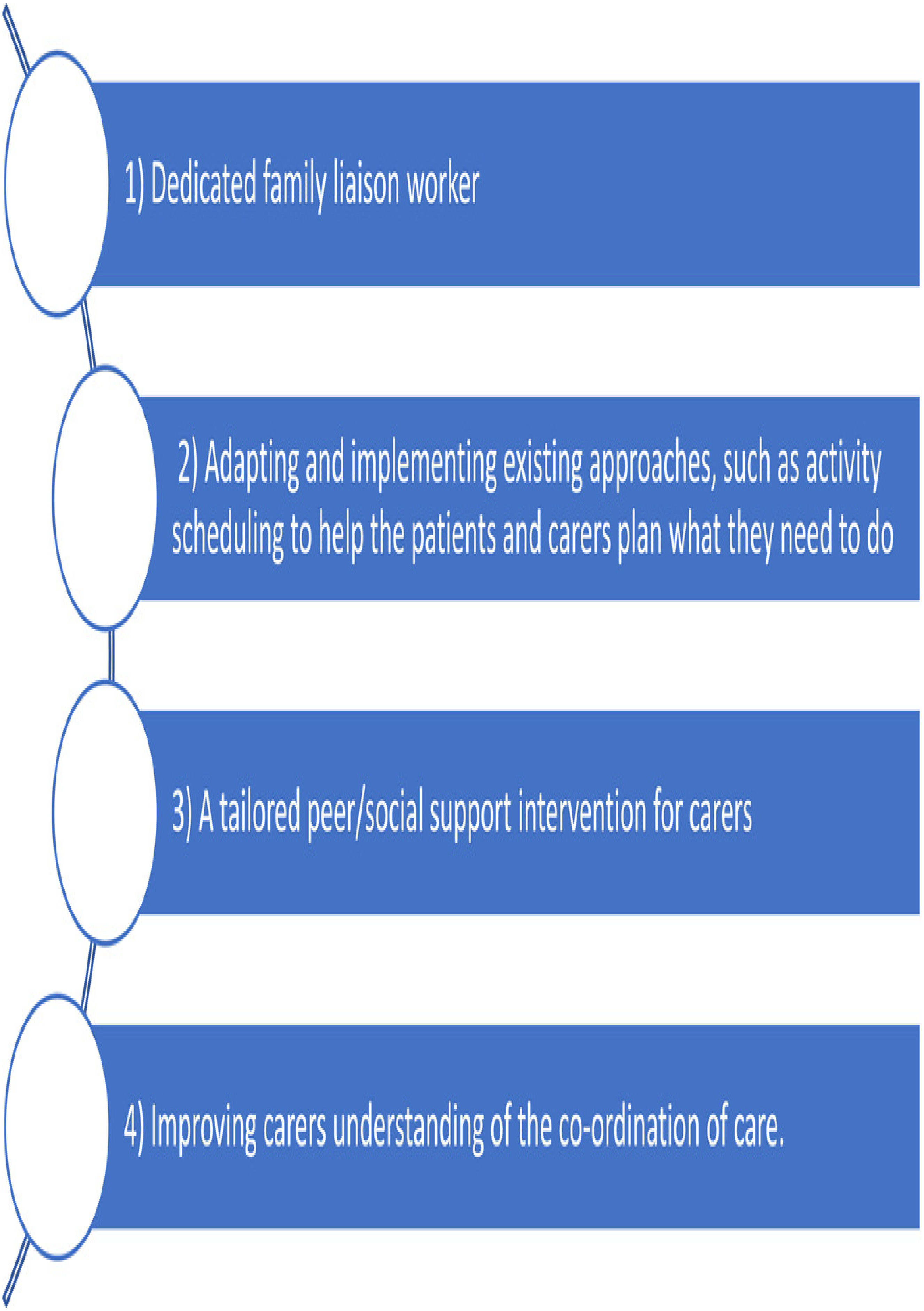
For theme 1 ‘Carer Involvement and Improving Carer Experience’, the top three ‘most acceptable’ solutions were (1) having a dedicated family liaison worker or a specialist team to act as a bridge between the hospital and home, (2) starting at admission and identifying the support network for the patient and (3) staff leaders at hospitals working with carers to co-develop a full pathway of support. The top three most feasible solutions were (1) starting at admission and identifying the support network for the patient, (2) improving inpatient experience for carers, that is, carers and patients resource pack, open communication and consistent feedback between acute staff and carers and (3) more time at the end of appointments for staff to speak to carers.

For theme 2 ‘Patient Wellness and Education’ the top three most acceptable solutions were (1) adapting and implementing existing approaches such as activity scheduling to help patients implement their care plan, (2) patients receiving basic training in self-care and important coping strategies and (3) basic training/education for patients about specific illnesses as well as generic stressors. The top three most feasible solutions were (1) basic training/education for patients about specific illnesses and being educated about the importance of more generic stressors that other people may face, (2) adapting and implementing existing approaches such as activity scheduling to help the patients plan what they need to do and (3) patients receiving basic training in self-care and important coping strategies, as the top three, respectively. There is an overlap between the top three solutions for acceptability and feasibility however the order is different.

For theme 3 ‘Carer Wellness and Education’, the top three most acceptable solutions were (1) tailored peer/social support intervention for carers, (2) basic training/education for carers and patient families about specific illnesses and generic stressors and (3) carers needs assessment and mindfulness-based meditation, and relaxation techniques for carers. The top three most feasible solutions were (1) basic training/education for carers and patient families about specific illnesses and generic stressors; (2a) carers needs assessment and mindfulness-based meditation, and relaxation techniques for carers; (2b) NHS services and hospital trusts elevating support for carers to the same importance as safeguarding, was ranked as a joint second and (3) tailored peer/social support intervention for carers.

For theme 4 ‘Policy and System Improvements’, the top three most acceptable solutions were (1) improving carer understanding of the co-ordination of care, (2) all services working together in conjunction not ring-fencing funding and (3) checking the home environment at admission/predischarge. The top three most feasible solutions were (1) all services working together in conjunction not ring-fencing funding, (2) improving carer understanding of the co-ordination of care and (3) checking the home environment at admission/predischarge. Like theme 2, there is an overlap between the top three solutions for acceptability and feasibility however the order is different.

Across all themes, the top four feasible and acceptable solutions identified by the group were (1) having a dedicated family liaison worker, (2) adapting and implementing existing approaches, such as activity scheduling to help the patients and carers plan what they need to do, (3) a tailored peer/social support intervention for carers and (4) enabling carers to understand the co-ordination of care (Figure 2).



1) Dedicated family liaison worker

2) Adapting and implementing existing approaches, such as activity scheduling to help the patients and carers plan what they need to do

3) A tailored peer/social support intervention for carers

4) Improving carers understanding of the co-ordination of care.

Enlarge this image.

DISCUSSION

This study involving a diverse stakeholder group identified many patient safety concerns and carer well-being risks during care transitions from inpatient mental health hospitals to the community. These include lack of information and support, distress and isolation. Multiple solutions were generated based on the collective knowledge of the diverse stakeholder group; the most highly ranked feasible and acceptable solutions were naming a dedicated family liaison worker and adapting better implementing existing approaches. Four broad themes of solutions were uncovered based on their nature and purpose: carer involvement in improving patient experience, patient wellness and education, carer wellness and education, policy and system improvements.

Our findings are consistent with previous research which highlighted that carers are concerned for their own mental wellbeing and patient safety during this precarious time.[13] The outcomes of this prioritisation exercise echo previous findings about key problems in relation to patient safety carer wellbeing at transition care points and advance the existing knowledge by identifying stakeholder-led solutions to these problems. The group felt that providing support to carers of people discharged from mental health hospitals, through intervention development or systems/process/policy change, has the potential to improve patient safety at this particularly distressing time. In line with our findings, carers have previously suggested that there are numerous ways that services could support them.[7] First, by improving access to information and knowledge about services, systems and medication as well as care plans and self-care practices. Second, by providing practical support and advocacy support to carers in social/community care services (e.g., through case managers). Third, through promoting self-awareness, wellbeing and awareness amongst others about the role of carers and patient safety behaviours.[7]

The evidence base on which interventions can effectively improve patient safety and carer well-being is relatively limited. This is despite carer-led suggestions and the gradually growing awareness of the need to consistently include carers in care quality and safety improvement programmes for people with mental illness and in parallel support their mental well-being. A recent systematic review of interventions involving carers in transitions between inpatient mental health hospitals and outpatient care found that three intervention components with increasing levels of complexity have been tested.[21] They involved psychoeducational sessions in the hospital, structured involvement of carers in discharge planning and follow-up sessions with patients and carers in community services after discharge, or combinations of these three components in the most complex scenarios of these interventions. Interventions, which included carer participation in discharge planning, appeared to be beneficial in relapse reduction, which is a highly relevant outcome, both clinically and in terms of health care costs.

Evidence suggests that interventions involving carers improved the experience of caring and quality of life amongst people with severe mental illness and reduced the psychological distress of carers[31] and that intervention components for carers should be considered as part of integrated services for people with severe mental health problems.

Hence, our stakeholder-led solutions combined with the findings of previous systematic reviews suggest that there is a pressing need for mental health hospitals and community services to adopt strategies to facilitate the implementation of carer involvement for ensuring safe transitional care. We encourage the co-design of novel carer-inclusive transitional care interventions informed by the solutions proposed in the current study. In the face of growing evidence showing that the voices of the most vulnerable patients with mental ill health and their carers are often not considered while designing service improvements, we strongly recommend consulting published guidance such as the NIHR quality, diversity, and inclusion strategy while coproducing and testing these solutions as interventions/service improvements. A factorial trial design to test these interventions is recommended to better understand the benefits of individual intervention components on different patient and carer outcomes. The use of this design will also allow for flexible implementation and ensure feasibility within busy services.

Strengths and limitations

One strength of the study was the promotion of open dialogue between diverse stakeholders including carers, academics with different perspectives and health professionals. We also provided the option of a carers-only group to reduce any potential negative power dynamics and promote inclusivity. As a result, we generated a series of potential intervention ideas that were agreed upon by this diverse group of stakeholders.

However, this study had also some key limitations. The most important limitation is that the attrition rate between the online workshop (phases 1–3) and the final online questionnaire to rank solutions (phase 4) was considerable. We originally planned to complete phase 4 during the workshop, but as there were so many solutions generated the task became too complicated to manage in one session. We, therefore, arranged a follow-up exercise, which resulted in a moderate attrition rate and incomplete collection of the demographic information of the participants in the workshop. Furthermore, the online nature of the workshop could have resulted in digital exclusion for some carers (especially those who are lacking e-literacy).

The sampling decision to use established contacts within the study team and social media enabled us to access academic expertise across the three academic fields of knowledge we hoped to combine expertise (Primary Care, Social Care and Public Health). However, in the future, including a greater number of patients and carers and using techniques to access more diverse groups would be beneficial.

Implications and conclusions

The members of our stakeholder group concurred that the transition from mental health hospitals to the community is a particularly distressing period of the care pathway, where patients and carers are particularly vulnerable to safety and well-being risks. This study identified several feasible and acceptable solutions to enable carers of people transitioning from mental health hospitals into the community to improve patient safety and maintain their own mental wellbeing. Clear policies and financial investments are required to convert these feasible and acceptable solutions into intervention components using a comprehensive co-production approach. Once co-produced, these intervention components could be evaluated preferably as a care bundle using a factorial trial design to better understand which components work best for which patient and carer outcomes. This coproduction and evaluation approach would generate crucial knowledge to ensure the longevity and cost-effectiveness of care-inclusive transitional care interventions.

AUTHOR CONTRIBUTIONS

Natasha Tyler and Maria Panagioti devised the design of the study and lead the funding application, lead the workshop and oversaw the project. Sarah McMullen drafted the manuscript, conducted analysis and data collection and planned the logistics of the workshops. Sally Giles and Claire Planner facilitated breakout rooms in the workshop. Ioannis Angelakis applied for ethical approval for the project and devised study documents. Richard N. Keers, Catherine Robinson, Yu Fu and Judith Johnson contributed towards the design of the study and attended the workshop. All authors revised and contributed to the writing of the manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data available within the article or its Supporting Information: Materials.

ETHICS STATEMENT

This study was approved by the University of Manchester Proportionate Ethical Review Panel, reference 2022-14187-23633. Informed consent was gained from all participants.

DETAILS

Subject:	Hospitals; Intervention; Mental health; Public health; Patients; Mental health care; Mental disorders; Expertise; Discharge; Social services; Mental health services; Conferences; Qualitative analysis; Liaison; Stakeholders; Patient safety; Well being; Social care; Hospitalization; Education; Ordination; Illnesses; Decision making; Workshops; Health education; Professionals; Safety; Caregivers; Educational systems; Data collection; Nominal group technique; Academic staff; Community hospitals; Data; Social support; Co-design; Prioritizing; Primary care; Social interactions; Health services; Loneliness
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How do (false) positively screened patients experience a screening programme for liver cirrhosis or fibrosis in Germany? A qualitative study

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ABSTRACT (ENGLISH)

Objective

This study aimed to explore psychosocial consequences of (false) positive liver screening results and to identify influencing factors for perceived strain within a multistage screening programme for liver cirrhosis and fibrosis in Germany.

Methods

Between June 2018 and May 2019, all positively screened patients were asked to participate in the study ($n = 158$). $N = 11$ telephone interviews and $n = 4$ follow-up interviews were conducted. Semi-structured telephone interviews were carried out. The analysis followed a structuring content analysis approach. Thereby, categories were first defined deductively. Second, the categories were revised inductively based on the data.

Results

The main themes found regarding the consequences of the screening were categorised in emotional reactions and behavioural reactions. Few respondents described negative emotional consequences related to screening. Those seem to be mostly driven by suboptimal patient–provider communication and might be worsened when transparent information transfer fails to happen. As a result, patients sought information and support in their social environment. All patients reported positive attitudes towards liver screening.

Conclusion

To reduce the potential occurrence of psychosocial consequences during the screening process, medical screening should be performed in the context of transparent information. Regular health communication on the side of health professionals and increasing patients' health literacy might contribute to avoiding negative emotions in line with screening.

Patient or Public Contribution

This study recognises the wide-ranging patients' perspectives regarding the consequences of liver screening which should be taken into consideration when implementing a new screening programme to ensure a patient-centred approach.

FULL TEXT

INTRODUCTION

Medical screening aims at identifying diseases in their preclinical phase to prevent severe progression.[1] Typically, screening is used to detect diseases before symptoms are present and thus, before patients seek medical advice for a specific problem.[2] Therefore, screening has the potential to move patients from a state of supposing themselves as healthy to the state of having a medical disorder. Reception of a positive test result represents a stress factor and can have severe psychosocial consequences.[3] This is especially an ethical problem, if screening results are false positive.[4–8] Besides the benefits of early detection of diseases, such as early treatment and potential prevention of progression, those negative effects should also be taken into consideration when evaluating new forms of screenings.[9,10] It is known from various studies on different screenings for cancer, that (false positive) abnormal findings in screening can lead to sleeping disorders,[4] increased anxiety,[4,11] psychological distress,[12,13] sadness,[12] restlessness,[12] fears[14] and considerations on future participation in screening.[15] However, those consequences do not occur consistently. It is important to differentiate between long-term and short-term effects[5,13] as well as between disease-specific and general outcomes.[8]

In addition to false-positive results, intensive surveillance during the screening process itself can produce unfavourable side effects on psychological well-being and health-related quality of life due to the confrontation with a potential threat.[16]

The majority of studies reporting on psychosocial effects of screening refer to different types of cancer screening programmes such as breast,[8] colorectal,[17] anal[18] and skin cancer.[19] Little is known about the impact of other medical screenings, for example, for advanced liver fibrosis or cirrhosis.

Cirrhosis is the common end stage of a chronic liver disease that often develops unnoticed over the years and thus is most often diagnosed in a late phase when complications occur.[20] In many cases, the transition between advanced liver fibrosis and cirrhosis is fluid. In this stage, causative treatment is less successful or impossible.[21] Furthermore, it constitutes a risk factor for the onset of liver cancer. Even in highly developed health care systems, cirrhosis is diagnosed in an asymptomatic early stage only in about 25% of patients.[22]

In January 2018, the SEAL programme (structural early-detection of asymptomatic liver cirrhosis or fibrosis) was implemented for 39 months in two German federal states (Rhineland-Palatinate and Saarland) aiming to investigate the feasibility, effectiveness and cost-effectiveness of a general screening programme for liver fibrosis and cirrhosis in primary care.[21] Within this programme, patients who were members of the statutory health insurance (Allgemeine Ortskrankenkasse Rhineland-Palatinate/Saarland—AOK) and who were eligible for participation (inclusion criteria: signed informed consent, no prior diagnosis of liver cirrhosis, minimum age of 35 years, eligible for health check-up [every 2 years, since April 2019 every 3 years]) were screened for cirrhosis and fibrosis. The screening procedure itself consisted of the additional determination of two serum surrogate markers and the calculation of the aspartate aminotransferase to platelet ratio index (APRI) in primary care (first stage).

For the SEAL programme, a cut-off value of 0.5 was chosen. In the case of a higher APRI in combination with at least one pathological transaminase, patients were considered positively screened patients with conspicuous liver values. Thus, a positive screening rate of 3.5%–4.0% was expected for the SEAL cohort with a false-positive screening rate at the first stage of 70%–80%.[23,24] Positively screened patients were referred to gastroenterological specialist examination for further clarification (second and third stage).

Within the SEAL programme, the present study was designed to explore potential psychosocial consequences, as well as behavioural changes for positively screened patients within the screening process. Since these patterns are complex and highly individual, a qualitative approach represents the best design to systematically explore all potential reactions and processes related to liver screening within the subjective reality of the concerned. Furthermore, with this study, we want to focus on the patient's perspective, which is often given too little attention when implementing new medical interventions. The guiding research questions are as follows:

- 1. Are there negative psychosocial consequences in relation to the screening?
- 2. Which factors are related to psychosocial consequences?
- 3. Are there (behavioural) reactions in relation to the screening to cope with psychosocial consequences?
- 4. What are the attitudes towards screening after receiving a (false) positive test result, in general and specifically towards the SEAL programme?

MATERIALS AND METHODS

The methods and results in this article are reported using the consolidated criteria for reporting qualitative research (COREQ) checklist.[25]

Participants and procedures

To identify positively screened patients, an interface to the electronic case report form (eCRF) was installed. The eCRF served as a management tool within the SEAL programme to collect all relevant patient data. When a new referral of a patient to a specialist was documented in the eCRF, the study team received an e-mail information. Immediately afterwards, the patient was contacted by the first author via mail including a patient information and informed consent. He approached the interviewees with this information, including a statement that the study is independent of their medical treatment. The researchers were not in contact with the physicians or clinics of the patients and had no relationship before the study commencement. Incentives of €50 (in form of a transfer to a private account after the interview) were used to increase the response rate for this study since we received no responses within the first 4 months of recruiting. All patients, who were positively screened in the SEAL programme in the period between June 2018 and May 2019 were asked to take part in the study (n = 158). With a response rate of 7%, we could realise n = 11 telephone interviews. Initially, a purposeful sampling strategy based on the criteria sex, age, comorbidity level and federal state was planned. However, since the recruiting phase took more than 1 year and the response rate was unexpected low, recruiting stopped after reaching interviews with n = 11 patients. The resulting convenience sample was based on the researchers' considerations that this sample size is (a) sufficient to reach data saturation and (b) feasible to analyse within the available resources. This rationale is supported by a work of Guest et al.[26] concluding that most themes emerge after 6–12 interviews. In some cases, a recall appointment (second stage) at the specialist was already scheduled at the time of the interview, hence a second talk after the consultation could be realised (n = 4). This option was offered to include further patient experiences even after correction or confirmation of a preliminary screening result to receive a more holistic impression. To keep the recruiting period in limits, we did not offer this for patients, who had no follow-up consultation scheduled.

To explore short-term psychosocial consequences homogeneously, we tried to realise the interviews as soon as possible after the initial mail approach. However, due to delays in communication and documentation in the eCRF, the time between physician visit and realisation of each interview varied.

For data collection, an interview guideline was developed based on the research questions. The guidelines covered four main topics: information about the screening, reactions to the results, external information retrieval and attitudes towards screening (see Supporting Information Material). This guideline was consented within a team of field experts (psychology, sociology, health services research and gastroenterology) and was pilot tested in the first interview. During the interviews, field notes were made to complement the data.

The telephone interviews consisted of two parts. First, an open narrative part, semi-structured by the guidelines, covered the main topics enabling the patients to speak openly. The second part was a short standardised query of sociodemographics, for example, age, education and comorbidities.

Interview setting

All interviews were carried out by the first author (male), who has extensive experience in both qualitative and quantitative methods. He holds a Master of Science in Sociology and Empirical Social Sciences and was occupied as a research assistant at the University Hospital of Freiburg at the time of the interviews. At the beginning of each interview, the interviewer introduced himself, explained the goal of this study and repeated key information that was presented in the patient information sent out in advance. The interviewer emphasised that he has no medical profession and that this study is not related in any way to the medical treatment of the patients. All interviews were conducted by telephone while the respondents were at home. No presence of other cohabitants interfered with the interviews. Transcripts and findings were not returned to participants for comment and or correction; however, the respondents were encouraged to contact the researcher after the interview in case of any upcoming thoughts or supplementary requests as a consequence of the interview.

Data analysis

In sum, audio material of 4.5 h (approximately 19 min/call) was recorded. Audio data were transcribed verbatim by an external service provider and have been checked twice to ensure accuracy. The analysis was conducted by the first author and followed the structuring content analysis approach by Kuckartz[27] using MAXQDA PLUS 2020 software. Thereby, categories were first defined deductively based on the research questions and assigned as part of the first coding procedure. Second, the categories were revised inductively based on the data, subcategories were formed, and a subsequent coding procedure was applied. When topics were addressed multiple times, they were also coded multiple times as text passages. The coding tree is available as Supporting Information Material.

RESULTSAnalysis sample

In sum, nine women and two men were interviewed (see Table 1). One person was accidentally included in the SEAL programme, though she did not fit the inclusion criteria for the main study (35 years or older). However, since this was not an exclusion criteria for the qualitative study, we decided to keep the interview data in the sense of a holistic approach. The mean age of the respondents was 65 years, however, since the mean is biased by the minimum extreme of 30 years, the median age (72 years) provides a better impression. In comparison to the general SEAL population, our sample was, on average, 12 years older (median age of the whole SEAL population was 60 years) and less balanced regarding sex (SEAL population: 54.5% women). On average, three pre-existing conditions were mentioned with a minimum of one and a maximum of six. The majority of our sample reported to have low (54.5%) education (see Table 1) which is assumed to be associated with low health literacy.[28,29]

Table 1 Sample characteristics.

Sex	Age	Comorbidity/pre-existing conditions	Education
F	72	Neurological disorder	Low
M	55	Hypertension, respiratory organ disease, musculoskeletal disease, cancer	Low
F	72	Hypertension, liver/gall bladder disease, musculoskeletal disease, dejection	Medium
F	72	Hypertension, respiratory organ disease, liver/gall bladder disease, diabetes	Medium
F	74	Hypertension, circulatory/vascular disease, gastrointestinal disease, diabetes, neurological disorder	Medium
M	66	Heart attack, diabetes	Low
F	30	Respiratory organ disease, gastrointestinal disease	Low

F	59	Hypertension, kidney disease, musculoskeletal disease, cancer, dejection/anxiety	Medium
F	62	Hypertension, liver/gall bladder disease	High
F	77	Hypertension, circulatory/vascular disease, gastrointestinal disease, diabetes, musculoskeletal disease, cancer	Low
F	78	Heart attack	Low

Abbreviations: F, female; High, university-entrance diploma/vocational diploma; Low, no certificate or elementary/secondary school leaving certificate; M, male; Medium, general certificate of secondary education.

The following four sections refer to the four research questions step by step.

Perceived psychosocial consequences

Overall, the short-term negative consequences of screening were limited. With the exception of one patient (P 5), who reported that her liver values were good, each patient commented on their own emotions regarding excessively high liver values (see Table 2). Those were differentiated into negative and positive emotions, represented by two main categories.

Table 2 Reported emotions on liver screening results.

Patient	Pos (+)/neg (−)	Patient statement to the question: 'How do/did you feel with the screening result?'
1	+	'Normal, like normal, I'm quite honest. […] And I also feel comfortable and… that's why'.
2	+	'I didn't really worry about the liver. […] I'm fine, perfectly happy'.
3	−	'If there is still said (laughs), the values are so bad, if the doctor is already afraid, then you also get scared'.
4	−	'Oh God, then I say: O.k., then it's like this. I've lived my life, done, then it's just over. So let's put it this way, I don't have a strong will to live right now'.
5	/	/
6	+	'No, directly worried not. […] I thought, oh well, if he means in ten years, then it's not so bad (laughs)'.
7	+	'No, I mean, I can't do more than pay attention anyway'.
8	−	'So emotionally I was in a bad way, until they told me yesterday that I… that it is not liver cancer. […] Sometimes you think, well, it won't be anything, and other times you get carried away and think that you have more'.

9	–	‘I was already a bit… […] I thought: wait and see what he says first, but of course I was relieved when he then wrote: no signs’.
10	+	‘I'm not one to be afraid of anything. I think it's all good. […] Deep down, I knew it and now I've had that confirmed, and now I'm happy’.
11	–	‘So not so good. I was thinking, first the heart, now the liver is coming too’.

In sum, five patients reported negative emotions about the screening results and five patients reported positive or at least neutral emotions in relation to the screening results. The negative emotions can be described as fear and sorrow as well as resignation (P 3, 8 and 11). In one case, the emotion was expressed as reduced will to live (P 4). However, the latter should not be attributed solely to screening since the person explained other circumstances that altogether led to this state (e.g., recent death of a family member).

The positive emotions were characterised by comfort (P 1), happiness (P 2 and 10) and self-care (P 7). One patient used humour to answer the question (P 6).

Factors related to psychosocial consequences

Two patients explained in a follow-up interview when the screening results turned out to be false positive that their negative emotions were blown away after conclusive findings. This result points to the uncertainty periods during the waiting time between a preliminary screening result and the confirmatory/corrective diagnosis. On the one hand, time under uncertainty plays an important role with regard to the manifestation of negative emotions. On the other hand, functional patient–provider communication is the key to reduce the burden of uncertainty. Every interviewee who described negative emotions also reported about suboptimal physician–patient interaction including a lack of trust, regardless of whether the screening result was verified or not:

Oh well, I don't have any confidence. (P 3)

Nobody asked me about that. […] I have to go back there now, and then I will also address this. That's why I say I'm annoyed with myself that I didn't address it right away. (P 8)

I have to get myself very involved. Very strongly. (P 11)

On the other hand, patients who showed no negative emotions emphasised the good relationship to their health care providers, which were untouched by false-positive results:

I trust my doctor blindly. (P 2)

He's good. […] It's the family doctor. You only go to him if you are satisfied. (P 5)

Very great trust. (P 7)

It seems that a good information flow with transparent communication of comprehensive health information builds trustworthy patient-provider relationships and reduces the risk of developing negative emotions in the context of screening. Here, it is important that the educational level and cognitive capabilities, respectively, health literacy of the patients are taken into account.

I don't understand medicine at all. (P 3)

He told me that, but I couldn't remember it because, yes, there are always such special names. (P 7)

Behavioural reactions and coping

Patients were asked how they reacted to upcoming negative emotions or insufficient information concerning their screening results. The majority of the interviewees reported that they have searched for external information sources and resources of social support. Both were most often found in friends or acquaintances who were described as having general knowledge in the field of medicine.

This is my godchild, she's an occupational therapist: tell me what the liver values are, please. And she told me, then I knew. (P 1)

The pharmacist also told me not to worry, it wouldn't be that bad. (P 1)

I have a niece who works at the pharmacy. I thought when she came she would look at it (groans), but so far she hasn't come. (P 3)

My brother was a geriatric nurse, and he also had a bit of an idea. […] And then we talk about it from time to time . (P 6)

This result once again emphasises the need for a well-working patient–provider communication, since otherwise external information sources that might not be qualified are consulted to reduce the information gap.

Future screening attitudes

Overall, the majority of respondents were positive about screening procedures and especially about the SEAL programme. It was striking that even three of the participants who reported negative emotions during the screening process were clearly in favour of the screening programme. The decisive factor was a smooth and fast diagnosis process.

Yes, that's reassuring. So, I have to say, that was the best thing I could have done, to agree to the project here, because I do notice that it goes hand in hand, it goes quickly, and you're in good hands. (P 8)

After all, it doesn't hurt. And it's reassuring to know that nothing will change for the worse. (P 9)

And then that result afterwards with the better knowledge […] is absolutely an advantage in any case. (P 10)

Yes, I think that's a good thing, if you're in treatment there and you're being questioned. And, if it's nothing, it's also good. (P 11)

DISCUSSION

This study explored the experiences of patients who were screened (false) positive for cirrhosis or advanced fibrosis in Germany, including four patients who received a confirmatory diagnosis about hepatic liver injury present.

The results partly fit with previous work, as only some respondents described negative emotional consequences related to the screening itself. The latter seems to be mostly driven by insufficient informational support, which plays a key role in dealing with diagnoses, especially when health literacy is low.[30–33] Additionally, negative psychosocial consequences of screening might be worsened, when suboptimal patient–provider communication impedes the transfer of transparent information.[34] As a result, patients tend to ask for information in a low-threshold area, that is, their social environment. Even though the respondents reported that their social supporters were considered as having medical knowledge, they are no experts in gastrointestinal screening. Therefore, this informational support seeking behaviour might, on the one hand, have beneficial effects (e.g., bringing relief), but on the other hand, it might also carry a risk of misleading information and thus should be avoided by optimising the information flow and by strengthening confidence in the patient–provider relationship.[35]

The limitations of this study are that, due to unclear documentation and communication delays, it was not possible to control the duration between the screening of the participants and the interview. We have to assume that there is an indeterminable time offset between the check-up, the documentation in the eCRF and the initial approach, respectively the realisation of the interviews. Thus, recall bias might have occurred. Additionally, this leads to an unclear sample of participants who report about very recent reactions and individuals with larger narrative periods. Further bias in our results might be caused due to the low response rate of the sample (7%). A possible explanation for this could be that some participants were not aware of the name of the screening programme and were confused by our affiliation (Freiburg) since the programme was conducted in other Federal States of Germany.

Since we could not follow our initially planned purposeful sampling approach, we could not entirely influence the composition of our sample so that patients with higher education, as well as men, were underrepresented. As a consequence, we could also not explicitly integrate the views of vulnerable groups.[36]

In terms of sampling, a certain selectivity might have occurred, since patients with high psychosocial load might be not in the state to participate in a study.

Furthermore, it is important to state that this study does not focus on long-term psychosocial consequences and it is not clear whether some of the reported emotions persist or aggravate over time.

From a methodological point of view, face-to-face interviews might have gained deeper information about the situation of the patients. In telephone interviews, the information about the interlocutor is limited because no visual stimuli (e.g., gestures) are present to improve the relationship between the interviewer and the interviewee.

CONCLUSION

To reduce the potential occurrence of negative psychosocial consequences during the screening process, medical screening should always be performed in the context of well-communicated and transparent information. Our results emphasise that measures to improve health communication on the side of health professionals (organisational component) and measures to increase health literacy on the side of patients (individual component) might contribute to avoid negative emotions in line with the screening. This result also illustrates how important it is to foster health literacy from a public health perspective. Here, future studies from other countries might contribute to an international comparison of our results. In addition, our data indicate that the waiting time for clarification was perceived to be stressful. Thus, a smooth and fast diagnosis process not only may contribute to an overall positive attitude towards screening but also reduces burdensome periods.

This study revealed a key role of health communication for the evolution of negative emotions in relation to screening. Since health communication is a major problem in the context of health care for vulnerable groups, it is important to integrate the view of migrants, low-educated people and patients with cognitive deficits in further research on this topic.

AUTHOR CONTRIBUTIONS

Urs A. Fichtner and Erik Farin-Glattacker developed the interview guidelines, interviewed the patients, coded and analysed the data. Urs A. Fichtner drafted the paper. All authors contributed to subsequent drafts and the final version.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Due to ethical considerations and German data protection law, the individual patient data cannot be published.

ETHICS STATEMENT

This substudy of the SEAL programme was performed in line with the principles of the Declaration of Helsinki. The substudy has been granted by the Ethics Committees of Rhineland-Palatinate and Saarland (reference number 837.361.17 [11195]). Furthermore, it was reviewed and approved by the data security officer of the Medical Center of the University of Freiburg. The SEAL programme was registered at the German Registry for Clinical Studies

(DRKS) under the ID DRKS00013460. Data collection was based on written informed consent. For this purpose, we sent all respondents information material and a consent form via mail before the telephone interviews. Consent for publication is not applicable.

DETAILS

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'Just because we're younger doesn't mean our opinions should be any less valued': A qualitative study of youth perspectives on a Youth Advisory Council in a mental healthcare context

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ABSTRACT (ENGLISH)

Introduction

Recognition of the importance of youth engagement in youth mental health and/or addiction (MHA) service design and delivery is increasing. Youth Advisory Councils embedded in MHA organizations represent one strategy that allows youth to be involved in MHA at the individual, organization and systemic levels. This level of involvement can facilitate positive outcomes for both the youth and the organization. As these councils become more common, it is important that organizations are prepared to partner with the participating youth. This study uses a descriptive qualitative approach to understand the motivations and expectations of youth with lived experience with MHA concerns who were beginning to work on a Youth Advisory Council in an MHA setting in the Greater Toronto Area.

Methods

Semistructured interviews were conducted with each youth, ages 16–26, on the advisory council ($N=8$) to understand their motivations, expectations and goals coming into the work. Interviews were transcribed verbatim and analysed using a reflexive thematic analysis.

Results

Analysis resulted in five overarching themes: providing opportunities for youth learning and growth, platforming youth, empowering youth, embracing youth leadership and promoting youth-driven change. The findings illustrate that these youth came into the Youth Advisory Council motivated to create positive change in the mental health system, take on leadership roles and had high expectations for organizational support. Our analyses provide insight for organizations planning and implementing Youth Advisory Councils in the MHA sector with the goal of best supporting youth in driving positive change across the system.

Conclusion

Youth want to be provided authentic opportunities for their engagement to make a difference. MHA organizations must embrace youth leadership and move towards listening to youth experience and acting on youth recommendations to enhance service design and implementation to improve access and to better meet the needs of youth utilizing these services.

Patient or Public Contributions

This study incorporated service users, including youth ages 16–26 with lived experience of MHA concerns who served on the Youth Advisory Council at the Family Navigation Project, Sunnybrook. Youth Advisory Council members contributed to two relevant research activities: (1) youth reviewed the draft interview guide before data collection, and their feedback was prioritized in the final version and (2) youth contributed to knowledge translation through contributing to academic conference presentations.

FULL TEXT

INTRODUCTION

Mental health and/or addiction (MHA) issues impact an estimated 1.2 million Canadian children and youth.[1] In fact, youth mental health concerns make up the largest portion of the global health-related burden for youth.[2] The youth mental health crisis was exacerbated by the coronavirus disease 2019 (COVID-19) pandemic, with youth around the world reporting decreases in well-being and mental health deterioration.[3–6] Still, fewer than 20% of Canadian youth receive appropriate MHA treatment.[1] These figures are particularly concerning as early intervention is critical to reducing the burden of illness across the lifespan.[7] Youth engagement at the organizational level is an emerging strategy to combat the youth mental health crisis.[8–12]

Youth engagement has been described as the process of participation of youth at the community and organization level that is made meaningful through intentional consideration of youth strengths, interests and developmental needs.[13] Meaningful youth engagement draws on Article 12 of the United Nations Convention of the Rights of the Child, which stipulates that decision-makers must solicit youth input in matters that impact them.[14] Positive youth development (PYD) has been posited as a framework for meaningful youth engagement,[15] as it takes a strength-based view towards youth and stresses the importance of creating opportunities for youth to gain skills, build relationships, become leaders and to thrive in adulthood.[16,17]

There is increasing evidence of the benefits of youth engagement within healthcare organizations for both the youth and the organization through providing opportunities for participating youth to grow personally and professionally [15,18–20] and encouraging the development of community-specific and contextually relevant organizational programming.[9,21,22] Youth Advisory Councils (YACs), sometimes called Youth Advisory Boards, Committees, Coalitions or Groups, represent one way that healthcare organizations can structure youth engagement to lift youth voices within healthcare systems to identify youth priorities for the MHA sector.[18,23–26]

YACs have been increasing in popularity in the healthcare field over the last two decades.[27] YACs help organizations find ways to reduce barriers and create pathways to more meaningful client engagement.[25,27] Prior research on youth engagement in MHA has evaluated youth personal and professional growth,[28,29] experiences and required work of adult facilitators and organizations[18,30] and outcomes of youth engagement such as the development of youth-friendly resources.[10] Less is known about what motivates youth to get involved at the advisory level in MHA, and what expectations youth bring into the work. Our research objectives are to explore (1) why youth want to be involved in advisory roles in MHA and (2) what they expect from the experience through analysis of interviews with eight youth beginning their work on a YAC in the MHA sector. This understanding may help MHA organizations as they develop and grow their youth engagement strategies.

STUDY CONTEXT

The Family Navigation Project (FNP) at Sunnybrook is a nonprofit organization that provides MHA navigation support for youth aged 13–26 and their families.[31] MHA navigation programmes work through identifying pathways to and through the multitudes of MHA treatment options to help individuals and their families find appropriate care.[32–34] FNP is a free service where youth or caregivers of youth can connect with a navigator to receive individualized support to find and access appropriate and timely MHA care.[31]

Based on guidance from youth with lived experience with MHA concerns, and prior evidence from FNP's research pertaining to a youth engagement framework in MHA navigation services, FNP established their first YAC in February 2022.[35–37] The YAC was guided by PYD, encouraging opportunities for youth to gain skills to accomplish their goals, build on their established strengths and provide platforms for youth to share their insights and recommendations. The YAC meets monthly virtually via Zoom to guide the implementation of FNP's Youth Engagement Strategy[36] through providing feedback on content areas chosen by FNP and through the development of a youth-led project to increase youth engagement at FNP. Youth advisors are compensated for their participation and expertise. The first term of the YAC ran from February 2022 to September 2022.

METHODSStudy design

This qualitative study used a descriptive qualitative approach to explore the experiences of youth as they joined the FNP YAC. A descriptive qualitative approach encourages researchers to remain close to the qualitative data source to comprehensively describe events in the words of event participants.[38] Study methods and results are presented in accordance with the COREQ (COnsolidated criteria for REporting Qualitative research) checklist.[39] This study is part of a larger investigation into the facilitators and barriers to youth engagement through YACs in MHA system navigation. All study protocols were approved by Sunnybrook Health Sciences Research Centre Research Ethics Board (#5476).

Recruitment for YAC

At the time of the launch, FNP was working with four Youth Engagement Partners who informed the development of the YAC and joined as the first members. Youth Engagement Partners worked with FNPs in their first year to guide a participatory research study to develop a youth engagement framework.[37] FNP conducted outreach to attract additional youth through MHA agencies in the Greater Toronto Area, focusing on those who served equity-deserving groups. Applicants completed a written application and virtual interview to share their ideas about improving the MHA system, the importance of diversity, equity, inclusion and belonging, as well as their strengths for the role. Including the four former Youth Engagement Partners, a total of eight youths aged 16–26, from diverse backgrounds, with lived experience with MHA concerns and who lived in the Greater Toronto Area, were selected out of 55 applicants for the first term of the FNP YAC. Applicants with a strong commitment to equity and a desire to create positive change in the MHA system were chosen based on recommendations from the Youth Engagement Partners. The age range was set to 16–26, as at age 16, the youth could consent for themselves, and 26 is the age cap for FNP services. More demographic information about the members of the inaugural YAC is provided in Table 1.

Table 1 Demographic information of participants.

	All participants (*n* = 8)
Age	Average: 21.5
	Range: 16–26
Race/ethnicity	
South Asian	25%
White	25%
Mixed race (Black, White)	12.5%
Mixed race (Indigenous, White)	12.5%
Indo-Caribbean	12.5%
Southeast Asian	12.5%
Living with a disability	75%
2SLGBTQI+	50%
Student	62.5%
Previous professional experience	
MHA organization	37.5%
Youth engagement	50%

Abbreviations: 2SLGBTQI+, Two Spirit, Lesbian, Gay, Bisexual, Trans, Queer, Questioning, Intersex and more; MHA, mental health and/or addiction.

Data collection

Each youth advisor (*n* = 8) completed a single semistructured interview via Zoom. The interviewer (A. Y.), who served as the organization liaison for the YAC, has a masters in social work, identifies as female, mixed race (Indigenous, White) and was 28 years old at the time of the interviews. As organization liaison, she attended all YAC meetings, bridged communication between the organization and the YAC, provided administrative assistance and was available for support as requested by YAC members. The interviewer had a previous working relationship with half of the group (former Youth Engagement Partners, *n* = 4) at the time of the interviews.

Interviews were conducted at the start of the first term of the YAC with some participants having participated in the YAC orientation. Interviews were audio recorded and transcribed verbatim. Interview guides were developed by the organization liaison in partnership with youth and explored youth advisors' motivation to join the FNP YAC, their expectations coming into the work and their goals for the upcoming term. Sample questions can be seen in Table 2. Interviews lasted on average 38 min. The interviewer completed memos after each interview to facilitate a deeper exploration of data.[40]

Table 2 Sample interview questions.

Interview topic	Sample interview questions
Motivation	•What interested you about the YAC that made you want to get involved? •What excites you about this opportunity?
Expectations	•What are your expectations of FNP for this work? •What are your expectations of your fellow YAC members for this work? •How do you think organizations and the adults within them should prepare to work with youth for projects like these?
Goals	•Do you have a personal goal for yourself on this project? •Does this work support your larger career or life goals? •Are there things that you'd like to learn about or be trained in to better perform your role as a YAC member?

Abbreviations: FNP, Family Navigation Project; YAC, Youth Advisory Council.

Data analysis

Data were analysed using reflexive thematic analysis.[41,42] Consistent with Braun and Clarke,[41] the analysis included six phases. Two coders (A. Y. and R. M.) familiarized themselves with the data and coded independently in the first phase using MAXQDA. The codes were refined and reorganized through reflexive discussion between coders (A. Y. and R. M.), including resolving any disagreement, in virtual meetings until saturation was reached. Once all the transcripts had been coded, both coders (A. Y. and R. M.) reviewed the memo and codes together to search for themes, and sorted codes into corresponding overarching and subthemes. Coders (A. Y. and R. M.) sorted the 86 total codes into 17 subthemes. The 17 subthemes were then sorted into five overarching themes. Finally, coders (A. Y. and R. M.) defined and named the overarching themes.

RESULTS

The analysis results in five overarching themes. The themes include *providing opportunities for youth learning and growth*, *platforming youth*, *empowering youth*, *embracing youth leadership* and *promoting youth-driven change*. The themes and their corresponding subthemes and supporting quotes can be viewed in Table 3.

Table 3 Summary of themes and corresponding quotes.

Themes	Quotes
1. Providing opportunities for youth learning and growth	

1.1 Deeper understanding of the MHA system	Mostly my interest was the opportunity to collaborate with other youth that have also had lived experience [with MHA] and then also see kind of what opportunities I can gain from learning other people's experiences and then sharing my own and then what can come out of that. (Participant 5)
	I'm also really interested in system navigation. And, the problems of system navigation specifically for youth. So I thought that this would be a really good opportunity to see what's being done in the FNP and what's being done elsewhere in the Greater Toronto Area and try to connect with folks who are interested in you know, the same things that I'm passionate about. (Participant 7)
1.2 Personal and professional growth	I'm trying to figure out where I want to be, if I want to be more behind the scenes or if I want to be patient facing. (Participant 7)
2. Platforming youth	
2.1 Elevating youth voice	My expectation is that they [FNP] might just be willing to listen to the input that we provide and also I want to see them be receptive. (Participant 4)
2.2 Meaningful youth engagement	There's for sure a difference between someone talking to you and then talking with someone on a collaborative format and kind of bouncing off opinions with each other. Rather than someone just talking at you for 20 minutes and you writing notes on something, I think it's more engaging for youth to feel more connected and not only that they're listening to something, but that they're contributing on an equal basis to everyone else. (Participant 5)
	Youth engagement means youth being able to be actively a part of creating a solution. (Participant 6)
3. Empowering youth	
3.1 Expectations of the organization	I think that was a really important thing that the youth engagement, the youth involvement was carried along throughout the entirety of that process. (Participant 4)
	I think the vibe of the ice breaker really helped. Like the story about the boomerangs, it made it feel less we're kids talking to adults, it made it seem like we're friends or co-workers discussing fun things in our lives. (Participant 1)

3.2 Needed organizational support	I think there's a lot of new inclusive trainings that are out there, like some of the big ones are LGBQT2S+ trainings, other ones could be accessibility trainings and stuff like that, like universal design and things along that line. Because right now I feel like youth are at the forefront of a lot of these movements and are really strong advocates and having adults also being on the same page is really important, because then it shows that they're willing to prioritize youth in what they value first. Along that line, I think having trainings where youth voices are also heard is pretty important. (Participant 4)
3.3 Intentional adult interaction	If a youth said something that was unrealistic, instead of laughing and being like 'oh that's a good idea but you're kind of way off.' Being like, 'that's a really good idea, now when I think about it we don't necessarily have that much funding so how can we do this in a smaller manner. What are your ideas?' Instead of just, 'ha-ha that's funny or cute,' and not really encouraging the next step. (Participant 8)
3.4 Organizational culture	I think being understanding and compassionate, but not being condescending [is important]. Adults can be very judgmental when you're someone clearly struggling. So I think [they could try] suspending judgement. Especially because, the talk around mental health is different than it was, even 10 years ago. So, I think it's important to suspend judgement and [to] be understanding. (Participant 6)
	There's a lot of times, where in cultural instances or in terms of sexuality and gender, there can be a lot of disconnect between younger people and older people. Just because of the way they were raised. So I think it's important to start really tackling that so that the services are suitable for all youth. (Participant 8)
	I feel like when I work with people who are definitely a couple of generations different from me, it feels very rigid and I don't have the opportunity to really speak in the way that I would normally speak just because we're so used to putting on this front to follow suit. (Participant 4)
4. Embracing youth leadership	
4.1 Comfortable environment	I felt like at least for a lot of the questions about personal experience during the interview it felt like a safe place to talk about it which I thought was very important, especially for mental health subjects. (Participant 1)

4.2 Collaborative practices	I'm a big believer in if you want to turn your camera off, turn the camera off. Or use the chat function, so I think that's just a little bit like, yes it's a little bit more inconvenient for everyone else, but at least you still are having the person who can't use these functions be a part of the process. And so that's why I like it when we do things other than just us talking on the screen. If there's other engagement opportunities that's a little bit more universal design I think that's always a benefit. (Participant 4)
4.3 Informed by youth experience	I know at least in group projects for school …I feel really bad when one person has a lot of work compared to everyone else. So I feel like one major thing is that everyone gets an equal amount of base work, and then should they want they can take on more things. (Participant 1)
4.4 Virtual tools for participation	I've kind of tried to navigate it [the MHA system] all over the world, and I've had this newcomer experience in Canada, and I've had to really try to find my own way through this really complicated mental health system. (Participant 4)
	One thing that I think could be pretty useful is a maybe like a Google document that we could use with everyone together. A lot of my work is currently based off of that, and having the accessibility for everyone. or like other team members to come in and put their own opinions or their thought process on what they're doing, and seeing what we're working on. I think it's a good idea to make it accessible, right? So that's one thing that I would like to see. (Participant 3)
5. Promoting youth-driven change	
5.1 Youth impact	Especially after finding that help was really long, and just getting all that stuff sorted out was hard…that process is kind of daunting so I wanted to help out with it. (Participant 1)
	Having the youth's opinions and their thoughts is important for future decisions, they can't just let people decide what the world wants to make for them. (Participant 3)
5.2 Accountability	From this position you're seeing what happens with the navigators and what happens with that information, where does it go from there. And I found it really intriguing and helpful to understand what routes could be changed in the future, to be make it more beneficial and supportive to the individuals who are there. (Participant 3)

	If you want to create a space where youth feel like their contributions are valued, you need from the get go to establish that you genuinely care about their input. (Participant 4)
5.3 Outcomes	An opportunity for youth to have their say and have their voices be heard. I think that's really important, and so I really wanted to be a part of that. (Participant 4)

Providing opportunities for youth learning and growth

The youth shared their hopes for personal and professional learning through their participation in the YAC. This theme of providing opportunities for youth learning and growth included subthemes of *deeper understanding of MHA system* and *personal and professional growth*. This theme emphasized the importance of considering the benefits for youth joining a YAC in addition to the benefits organizations receive from establishing a YAC.

Deeper understanding of MHA system

Youth discussed how their personal experience in the MHA system led them to be interested in how the system operates, and how it can be improved for other youth. They shared they wanted to learn more about MHA including navigation, peer support and community-based organizations. Notably, the youth wanted to hear from peers about their experiences to inform their ideas and understanding of the MHA system. One youth shared,

I kind of just want to pick everyone's brain about what they've experienced [related to MHA] and what they've learned from it. Because I feel like what they've learned from, maybe I could apply to myself and then that could be applied to the broader community. (Participant 6)

In discussing their interest in learning more about the MHA system, youth identified hearing the experiences of peers seeking MHA care and the behind-the-scenes information from the service provider could help them to better determine where positive change could occur.

Personal and professional growth

Youth advisors also recognized how this work could benefit themselves both personally and professionally. One youth shared, ‘I'm hoping to get some experience working in the mental health space and better understanding of how it works through talking to people who've also been in it. I can see myself in it in the future as well’ (Participant 5). Youth shared their excitement about learning about the different careers within the MHA field, with some youth having a clear idea about their career goals, while others wanted to use the opportunity to identify what kind of MHA career they were interested in.

On the other hand, some youth were not interested in pursuing a career in MHA but noted how the experience could provide transferrable skills such as facilitation, group work, advocacy and research skills. For example, one youth shared their goal as, ‘definitely learning more about the research aspect of things. Like how these studies are used to implement new structures in mental health service’ (Participant 8). Youth noted that these skills were valuable to helping them get ahead in school, ranging from adding to their resumes for graduate school applications to offering opportunities for volunteer hours for their secondary school graduation requirements.

Platforming youth

Youth advisors shared expectations that organizations should provide platforms for YACs to be heard and for their recommendations to be meaningfully actioned. This theme included subthemes of *elevating youth voice* and *meaningful youth engagement*. This theme highlights the importance of authentic youth engagement, where organizations go beyond creating a seat at the table for youth and take steps to ensure youth feedback will have a meaningful impact on service design, delivery and evaluation.

Elevating youth voice

Youth advisors expressed that young people not only need MHA organizations to provide opportunities for them to share their ideas, opinions and feedback but that the organization must also be open to responding to it. Youth recognized the difference between being listened to and having their ideas impact programme direction. For these youth participants, being heard was just the first step, but having their voices result in meaningful change was their ultimate goal.

Meaningful youth engagement

To achieve this meaningful impact, youth shared that they believed they should have robust involvement and influence over YAC activities. They indicated that when youth have this kind of involvement, they can structure the work in a way that continuously elevates youth voice. One youth shared an example of this robust involvement:

I really like how youth-led everything is, I at first was a little bit hesitant. I thought it was going to be a little bit more passive. But then I think in the first meeting where we were talking about how if a youth is missing a meeting, how we were able to help catch them up, the idea of having another youth fill in that role. That was something that really stood out to me. (Participant 4)

In this example, the youth shared that it was important to them that the youth advisors be able to update their peers if they missed a meeting, so that the youth voice was not filtered through the adult lens of the organization liaison. Youth also discussed the importance of having a youth facilitate the YAC meetings. This allowed the youth to have control over their meetings and institute structures that helped their peers to feel engaged in the virtual setting, such as starting with an icebreaker. Involving youth at all stages of the project and giving them autonomy to choose how their participation was structured helped the youth to feel valued as they began their work on the YAC. Providing youth with a platform where the youth can have a meaningful impact and collaborate equally with adults in the space is critical for the authentic youth engagement required for YACs.

Empowering youth

Youth advisors shared their hopes and expectations that the organization would provide support to achieve their collective goal of uplifting youth voices within FNP. This theme of empowering youth included subthemes of *expectations of the organization*, *needed organizational support*, *intentional adult interaction* and *organizational culture*. This theme highlights that the organizational setting and adult support within it must empower youth to feel informed and valued, so that they are able to provide their feedback and embrace the importance of their role.

Expectations of the organization

Youth reported different ways that they believed the organization would support them, including reflecting that they had the backing of FNP leadership and the organization liaison. Youth valued that FNP leadership demonstrated their support to the YAC through writing welcome letters, attending initial meetings to meet youth, making themselves available for one-on-one meetings with youth and encouraging youth to share their expectations in the group charter. Youth identified organizational support as playing a major factor in the sustainability of the project. YAC members requested that FNP leadership be available to support them in their project goals as needed, such as consulting on project direction and providing relevant contact information as it pertained to the project.

Needed organizational support

Youth advisors reported that establishing relationships with FNP leadership and the organization liaison was critical to learn about organizational policies and practices to keep the YAC informed. One youth shared, ‘there has to be some kind of embedded staff support or otherwise it wouldn't work’ (Participant 2). Youth expected the organization liaison would provide necessary context in meeting discussion and allow for greater coordination between the YAC and FNP, which in turn would encourage organizational action on youth recommendations. Youth also shared the importance of administrative support, such as setting up the Zoom or emailing previous meeting notes, from the organization liaison to be able to make the most out of monthly meetings.

Intentional adult interaction

Youth advisors also noted the importance of interaction with other adults within the organization. Youth reported that willingness on the adult's side to embrace youth ideas would be a critical part of the success of the work. Youth understood that the generational divide between youth and adults complicated the work ahead, but shared that they felt through open communication they could overcome any barriers to being seen as equal partners in the work. One youth shared, ‘I guess I expect a level of respect. Just because we're younger, doesn't mean our opinions should be any less valued’ (Participant 6). Youth also suggested that YAC interaction with adults on the team should be constructive and that adults should take a positive approach when working with youth. Youth described the role for adults within the organization on the YAC was to use their professional expertise to provide support and guidance for YAC activities. One youth shared,

Obviously, as much as I have lived experience, we [the YAC] don't have the professional experience or actual educational, clinical experiences and things like that. And so it's important for adults to have their professional expertise, who are also wanting to actually connect with youth and have an impact. So I think their role is very important, because they're the ones who can help facilitate and move things forward. So I think it's a collaborative effort. (Participant 4)

Organizational culture

Furthermore, youth acknowledged systemic factors that contributed to how empowering the environment could be. Youth stressed the importance of diversity, equity, inclusion, accessibility and belonging on the YAC. Youth felt that it was critical for YACs to uplift the voices of youth who have historically been excluded from conversations regarding MHA care. One youth shared, ‘Having diversity is really important in all settings now, but especially the youth council. I think having that diversity of socioeconomic status, race, gender, sexuality …age. I think being able to have those perspectives is really beneficial’ (Participant 6).

Youth also shared that organizations preparing to work with youth should have staff with the capacity to engage youth with historically marginalized identities. The focus on diversity, equity, inclusion, accessibility and belonging felt important to youth as they noted the shifts over time in approaching and uplifting equity work. One youth shared, ‘I definitely think that there is a generational shift with the resistance that our generation holds against inequitable and unequal practice’ (Participant 7). Youth advisors were invested in creating an equitable YAC and expected that FNP would support their efforts. Youth recognized that especially in MHA care, where equity-deserving communities have less access to care that is culturally sensitive and appropriate, it is critical to centre youth most marginalized by the system.

Embracing youth leadership

Youth advisors reflected on the importance of structuring the YAC in a way that was accessible and establishing collaborative practices to increase group cohesion. This theme of embracing youth leadership included subthemes of a *comfortable environment*, *collaborative practices*, *informed by youth experience* and *virtual tools for participation* . This theme reflects that youth advisors wanted to be able to lead the way to create an environment that would be open and honest.

Comfortable environment

Youth stressed the importance of a comfortable environment for youth to be able to share authentic feedback. For example, one youth shared that having Youth Engagement Partners involved in the recruitment and interviews for the YAC showed that youth were valued at multiple facets of the initiative and helped them to feel more comfortable in the interviews.

Youth also wanted the meetings to feel informal. One youth shared, ‘I think, just, chatting more with the youth and making sure that it's not so formal, it doesn't have to feel like a meeting, like more of a conversation’ (Participant 5). Another youth acknowledged the difference between professionalism and authenticity, sharing that in adult workspaces it can be hard for youth to feel like they can be themselves. Instead, they wanted the YAC meetings to be spaces where youth could present themselves authentically and freely share what came to mind.

Youth advisors recommended prioritizing youth comfort in the space, through promoting honesty and respect from adults and each other. Youth attempted to cultivate this environment by highlighting the importance of positivity. One youth shared, ‘I always try and pick out the positive things. Which I think is a good trait, because it prevents stress and stuff from building up’ (Participant 1). Youth advisors also shared the importance of creating a culture of open mindedness and open communication on the YAC.

Collaborative practices

Youth also reported important tactics for collaborating. Many youth had previous experience on group projects where they recognized the workload felt uneven, which contributed to their worries about how this group would work together. Youth shared concerns about group cohesion over the virtual environment but recommended strategies to help bridge the virtual divide and felt confident they could still establish positive relationships. Youth advisors recommended implementing tools such as creating a group charter and norms to help navigate any challenges that may arise. The YAC group norms included *actively listen to others*, *provide trigger warnings if possible* and *share the air—give everyone an opportunity to speak among others*. Setting up these agreements encouraged the collaborative environment by making expectations clear.

Informed by youth experience

Youth noted their individual strengths, such as aspects of their identity and personality, as well as the lived and professional experience they brought into the work, were an asset for the YAC. Some youth highlighted that their lived experience in MHA services helped them to understand the unique needs of youth traversing MHA care. Another youth identified their professional skills as a benefit stating, 'I've done a lot of research before at university, and I've been doing it at my current job. Figuring out creative and intriguing routes to go and look for what our project scope should be' (Participant 3). Other youth identified being a team player, creativity and dedication to working hard as key strengths in working to promote positive change at FNP and the MHA system more broadly. Youth members hoped to utilize their individual and group strengths to achieve their goals.

Virtual tools for participation

Finally, youth noted virtual tools for participation they felt were critical for engagement. For example, youth shared that using the online scheduling tool, Doodle, helped them to choose a standing time that worked for everyone for meetings. Youth also shared their appreciation of calendar invites and recap emails from the organization liaison to help them stay organized. Youth expected to be able to utilize virtual tools, such the Zoom chat, whiteboard functions and polls, and other online tools such as Google drive to achieve their individual goals to collaborate and remain engaged. They identified these tools as important to be able to move their work along for maximum impact.

Promoting youth-driven change

Youth were motivated to join the YAC, and were most excited about, the opportunity to make a positive impact on the youth MHA system. This theme of promoting youth-driven change included subthemes of *youth impact*, *accountability* and *outcomes*. Youth described the importance of feeling comfortable and confident in the organization to share their ideas with the goal of achieving positive change in the MHA system. This theme highlights the importance of organizational support to improve the MHA system through prioritizing youth feedback and ideas.

Youth impact

Overall, youth shared the importance of youth impact through the YAC. One youth shared, 'the objective of the YAC is specifically having a space in FNP to allow youth to have a contribution to how the organization moves forward to provide an outlet where youth are able to provide their input as to how an organization which focuses on families and youth will proceed' (Participant 4). Youth reported the reason for their involvement was to provide youth feedback to the organization to best meet the needs of youth clients. They hoped to have a positive impact within FNP and to be able to share their ideas and the outcomes of the YAC throughout the sector to encourage a systemic shift towards meaningful inclusion and engagement of youth.

Accountability

Youth advisors shared their goals to help other youth and guide FNP to be more youth-friendly. Youth recognized that youth-friendly services could reduce stigma for youth seeking care. One youth shared, 'youth engagement means getting youth involved in their own care, and just getting youth more aware and more educated, breaking stigma and also just giving youth the space to be able to express their struggles' (Participant 7). Many youths recognized that their task to complete a youth-led project to increase youth engagement at FNP was a unique opportunity to have a meaningful positive impact. The youth felt dedicated to successfully completing the project. Some youth also discussed that being meaningfully embedded within FNP allowed them to identify areas for organizational improvement. Their expectations included that their partnership with FNP should be accountable to youth across the GTA and result in both the youth and organization working towards positive change.

Outcomes

Youth shared they felt the YAC would be successful if youth were able to complete their chosen youth-driven project. Youth also shared that they felt that youth involvement within youth MHA organizations more broadly helps to improve services through using firsthand experience to guide programme improvements. Youth hoped that their participation would lead to increased youth clients at FNP, increased youth ratings of FNP as youth-friendly and more positive outcomes for youth seeking treatment such as improved mental wellness or access to culturally competent providers. In discussing their ideas for outcomes of the YAC, youth showed that they wanted tangible change.

DISCUSSION

This study explored the motivations, expectations, and goals of eight youths as they entered the work of a YAC within an MHA systems navigation organization. Youth were motivated by their lived experience in the MHA system to attempt to make it easier for other youth to access appropriate and timely care. Driven by this passion, youth had high expectations for their level of involvement, and a sense of how their strengths could contribute to positive change. Understanding youth motivations behind joining the YAC helps to clarify the intent of youth to create positive change for other youth in the MHA system. This finding is in line with previous work demonstrating youth are motivated by improving society for future generations.[43]

These youth expected FNP to move beyond surface-level opportunities for impact, and to provide legitimate opportunities for youth voices to be heard and acted on. This is consistent with research in the field that emphasizes the importance of moving away from tokenization in youth engagement efforts.[18,22,25,44] Opportunities for youth to be empowered by organizations to make positive change are critical as previous research supports that youth must be empowered as partners in the work and be given platforms to draw on their lived experience to provide authentic feedback.[9,15] Youth have the right to be consulted on matters that impact them,[14] and previous studies have demonstrated their input and feedback can, in turn, improve systems.[10,27]

It is important that organizations create these opportunities for youth to drive positive change, but they must also pay careful attention to the youth's experience within the programme. To maximize the impact of youth engagement, organizations must be aware of the reasons youth are drawn to the work and help to support the kind of involvement they want to have. Results from this study support that youth are interested in taking part in leadership roles and utilizing their strengths to create collaborative and supportive advisory council environments. Youth advisors expected organizational support, respect from adults and for adult facilitators to be trained in working with equity-deserving communities. Current research in youth engagement in healthcare has also supported the need for antiracist and equity-focused programming.[44,45] Youth's expectations to be taken seriously and allowed to have meaningful impact adds to the current research, demonstrating authentic inclusion may also encourage youth to remain engaged.

The results of this study showcase the importance of structuring YACs with a strengths-based view of youth and creating opportunities for youth to thrive. FNP used PYD to structure the YAC to underscore the importance of creating a mutually beneficial partnership. Previous research has demonstrated the value of youth–adult partnerships as a means to recognize the strengths of both youth and adults as critical in improving policy and practice.[9,46,47] In this project, youth recommended that one way they would feel valued by adults as partners on the team would be for the organization liaison to report on the ways that the YAC was having an impact at FNP in each meeting to help youth to understand the impact they were having as a group and help keep the organization accountable to the YAC. Strategies such as these should be codeveloped in youth engagement efforts to promote healthy youth–adult partnerships. This study highlights that youth recognized their own strengths, experience and leadership capacity and expected that they would be provided space to utilize these skills. Youth are ready to be engaged as partners in this work, and organizations should move to see them in this way.

LIMITATIONS

Results from this study represent the views of eight YAC members at an MHA navigation organization in Toronto. It is possible that the focus of FNP on MHA navigation, rather than direct service delivery, impacted the way youth considered the scope of the project. It is also of note that measures were taken by the organization to approach the work democratically and to give youth power in the planning process. It is possible that these youth were primed to apply for this position because of this approach, and this could have skewed their motivations and expectations. However, insights from these eight youths can help to inform how other MHA organizations approach the planning and implementation of YACs to empower other youths to take on these leadership roles.

Furthermore, this study took place in the context of the COVID-19 pandemic, meaning that YAC activities took place virtually. Thus, their comments regarding the environment often referred to virtual environments, and further exploration is needed regarding how these preferences may apply to in-person settings.

Finally, while some of these youth had prior experience in youth engagement work, most of these youth were new to the experience. Future research should examine the perspectives of youth who have more experience with YACs to capture their reflections and recommendations for the practice.

CONCLUSION

This study explored the perceptions of youth entering their roles as youth advisors on a YAC for an MHA navigation service in Toronto, ON. Study findings contribute to a growing body of literature on youth engagement in MHA services by uncovering youth's motivations to join the council and their expectations coming into the work. The insights demonstrate youth are motivated to make positive changes for their peers and gain personal and professional skills. Youth expect their ideas and insights to be seriously considered and acted upon to improve the mental health system overall. A greater understanding of youth's motivations and expectations can help to inform organizational planning, implementation and evaluation processes for youth engagement through an advisory council structure.

AUTHOR CONTRIBUTIONS

Adrienne Young conducted project administration, data collection, data analysis, and wrote the original draft of the manuscript. Roula Markoulakis provided supervision, provided methodology support, conducted data analysis, and reviewed and edited manuscript drafts. Roula Markoulakis, Sugy Kodeeswaran and Anthony Levitt contributed to conceptualization and funding acquisition. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request due to privacy/ethical restrictions.

DETAILS

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Parent's preferences for unscheduled paediatric healthcare: A discrete choice experiment

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ABSTRACT (ENGLISH)

Background

Unscheduled healthcare is a key component of healthcare delivery and makes up a significant proportion of healthcare access, with children being particularly high users of unscheduled healthcare. Understanding the relative importance of factors that influence this behaviour and decision-making is fundamental to ensuring the system is best designed to meet the needs of users and foster appropriate cost-effective usage of health system resources.

Objective

The aim of the study was to identify the parent's preferences for unscheduled healthcare for a common mild childhood illness.

Design

A discrete choice experiment (DCE) was developed to identify the preferences of parents accessing unscheduled healthcare for their children.

Setting and Participants

Data were collected from parents in Ireland ($N = 458$) to elicit preferences across five attributes: timeliness, appointment type, healthcare professional attended, telephone guidance before attending and cost.

Results

Using a random parameters logit model, all attributes were statistically significant, cost ($\beta = -5.064$, 95% confidence interval, CI [−5.60, −4.53]), same-day ($\beta = 1.386$, 95% CI [1.19, 1.58]) or next-day access ($\beta = 0.857$, 95% CI [0.73, 0.98]), coupled with care by their own general practitioner ($\beta = 0.748$, 95% CI [0.61, 0.89]), identified as the strongest preferences of parents accessing unscheduled healthcare for their children.

Discussion

The results have implications for policy development and implementation initiatives that seek to improve unscheduled health services as understanding how parents use these services can maximise their effectiveness.

Patient or Public Contribution

The development of the DCE included a qualitative research component to ensure that the content accurately reflected parents experiences when seeking healthcare. Before data collection, a pilot test was carried out with the target population to gather their views on the survey.

FULL TEXT

INTRODUCTION

Unscheduled healthcare, which constitutes unplanned, nonroutine utilisation of health services, is a key component of healthcare delivery and makes up a significant proportion of healthcare access.[1] Unscheduled healthcare is delivered mostly through general practitioners (GPs), out-of-hour GP services and emergency departments (EDs), as well as other services such as urgent care centres and minor injury units. There is an increasing demand for unscheduled services such as GP services[2] and EDs.[3] A survey of respondents in 34 countries found that 18%–40% of people surveyed had used an ED in the past year with lower ED use associated with greater accessibility of primary care.[4] Indeed, the unavailability of appointments with the GP within a reasonable timeframe (e.g., within 24 h) has been found to cause parents to seek healthcare in the ED[5] with the more flexible service offered by out-of-hours (OOH) care also leading patients to these services.[6] Increased attendance at EDs and OOH services has implications for health service policy and planning that aims to provide adequate primary care services in their community and critically, impacts patient experience through overcrowding, longer waiting times and the increased costs of hospital care. However, understanding patients' needs and preferences when they first initiate contact with a health service is vital to foster more efficient and cost-effective use of health services.

Patient preferences and other drivers of healthcare access must be accounted for to inform efficient, unscheduled care models that are responsive to patient needs and ensure patients use services in an intended manner.[7] Discrete choice experiments (DCEs) are commonly used to identify patient preferences due to their ability to elicit rich data on patient decision-making and preferences when accessing healthcare services.[8] In DCEs, participants make a number of preference choices, which allows for quantifying tradeoffs between features of a particular health service,[8] and this information can subsequently be used to inform healthcare policy and delivery. DCEs have been used to identify preferences for models of primary care with a multitude of preferences identified as influencing patient decision-making when selecting primary care services[7] as well as OOH GP care.[9] However, unscheduled care is delivered across a number of components of the health system, and previous research has shown patients take all possible service options into consideration when making engaging in health-seeking behaviour.[10] With regard to the development of paediatric healthcare, first contact care is a key priority for child health services,[11] and reducing demand for EDs, particularly in relation to visits that are deemed nonurgent, by directing patients to alternative services such as primary or urgent care services is critical.[10]

Children are particularly high users of unscheduled healthcare,[1] and how parents navigate unscheduled healthcare depends on a multitude of complex, interrelated factors. In addition to this, children are an important group to examine in isolation as parents behave differently when seeking healthcare for their children and would be less likely to adopt a ‘wait and see’ approach, which is reflected in lower urgency presentations that may be treated in emergency and urgent services.[12,13] Moreover, the inability to access primary care in a timely manner diverts parents to seek care in higher acuity services such as EDs.[14] Perceived urgency also influences patients to seek expedited care in EDs,[13] particularly pertinent to parents, a population that consistently reports a need to minimise risk and seek reassurance.[15] Children's conditions may deteriorate swiftly, generating additional anxiety when making decisions on behalf of their children, especially in the case of younger children, yet unable to communicate.[16] A systematic review also identified GP–parent relationship, proximity to an ED, and perceived waiting times as influencing a parent's healthcare seeking reassurance.[17]

Patients will navigate a health system to best serve their needs and preferences at any given time and as a result, the features of the services available at any given time will influence where care is sought. The aim of the study was to identify the parent's preferences for unscheduled healthcare for a mild, self-limiting illness. Thus, this study uses a DCE methodology that integrates attributes common across all services that offer unscheduled care to get a broader understanding of parent preferences when seeking unscheduled healthcare for their children.

METHODSData collection

The survey was administered online through Qualtrics™ in February 2021 and data from a random sample of 458 respondents was collected through Qualtrics™ research panels. The objective of the sampling was to achieve a representative sample of parents in Ireland. Before completing the survey, all participants were asked to confirm they were over 18 years of age and parents of children living in Ireland. The DCE survey captured demographic information such as the parent's age, gender, medical card status, medical insurance and employment status. Data from eight participants were removed ahead of the analysis due to incorrect data (e.g., age of child greater than 18 years or the number of healthcare visits reporting as an unlikely amount [i.e., 2677]). The final analysis was conducted with the remaining 450 respondents.

Study design

DCEs are underpinned by random utility theory[18] providing the respondent with several hypothetical choice alternatives, which are characterised by a number of attributes that differ in their levels across alternatives. Participants must make tradeoffs between attributes when deciding which alternative to choose, therefore, identifying the most important attributes in the respondent's decision-making.[8]

Attribute selection

The attribute development process is critical to ensuring the DCE is unbiased, relevant and useful for policy making.[19] A systematic review and qualitative research were conducted to generate the attributes that would populate the DCE. The systematic review synthesised studies (*n* = 56) examining factors that influence parental decision-making when seeking unscheduled paediatric healthcare.[17] For the qualitative component, semistructured interviews (*n* = 19) and one focus group (*n* = 4) were carried out with parents living in Ireland to understand parental health-seeking behaviour for their children.[15]

When reviewing possible attributes generated through these methods, the research team adhered to guidelines as set out by[19]: first, that attributes should pertain to the commodity, that is, unscheduled care providers and not personal traits of the respondent, second, attributes should not be overly dominant and third, attributes should be important to the respondent. Following this process, five attributes were selected, as outlined in Table 1 below.

Table 1 DCE attributes and levels.

Attribute	Level
How long to wait for an appointment	Same day
	Next day
	Two days' timea
Appointment System	Appointment between 9:00 AM and 5:00 PM
	Appointment for any time including evening/weekend

	No given appointment but may have to wait for an unknown amount of time to be seena
Advice before attending	No advicea
	Telephone advice from a healthcare professional about what to do
Who you will see	The practice nursea
	Any doctor or nurse
	Your own GP
Cost	€0a
	€15
	€30
	€45

Abbreviations: DCE, discrete choice experiment; GP, general practitioner. a
Reference category.
Attribute levels represent characteristics of services that offer unscheduled care. Dummy coding was used to code the levels in the categorical attributes. The levels of the cost attribute, which was included as a continuous variable, were set with reference to the cost of accessing primary and ED care in Ireland. As of 2017, 33% of the Irish population qualified for free access to general practice and public hospital care[20] as holders of a General Medical Services (GMS) card. A further 10% qualified for free access to GP care as holders of a GP visit card. Entitlement to a GMS card is means tested or based on having a specified chronic illness, while entitlement to a GP visit card is also means tested with a higher income threshold. All children aged under six are also entitled to a GP visit card. Therefore, the lower bound for cost was set at no charge (€0). Those without a GMS or GP visit card pay an average of €51 per visit to their GP[21] or an OOH service, €100 for an ED visit at a public hospital, and €75 to attend a local injury unit (LIU). As a substantial number of parents are unused to paying for medical care, the maximum cost was set at €45, with the remaining two cost options set at €15 increments.

Experimental design

Once the attributes and levels were selected, a Bayesian efficient design, based on minimising the Bayesian D-error criterion, was used to develop the choice sets and the alternatives using Ngene^{TM} software. In total, 24 choice sets were created, and a blocked design split the choice sets into 2 blocks of 12 to minimise the burden on respondents. An example of a choice set used in the study is presented in Figure 1. Face validity was assessed before an initial pilot (*n* = 80) in January 2021, after which the design was updated to adjust the wording of the levels of one attribute (appointment type) and to update priors to generate the experimental design for the main sample.

	Service A	Service B
How long to wait for appointment	In two days' time	Same day
Appointment system	Given appointment between 9am-5pm	Walk in with no appointment (unknown wait)
Advice before attending	Telephone advice from healthcare professional about what to do	No advice
Who you will see	The practice nurse	Any doctor or nurse
Cost	€15	€30

○ Service A

○ Service B

Enlarge this image.

The vignette presented the following scenario for all choice sets:

The next section will ask you to choose your preferred health service in a set of hypothetical scenarios. For each scenario, please imagine that your youngest (or only) child has not been well (not been themselves) for a period of time. You have managed the illness to the best of your ability; however, you have now decided that you need further support from a health professional in a health service [each attribute is then described as per Figure 1]. When responding to these scenarios, we would like you to think of a time before the COVID-19 pandemic and to not consider how the pandemic may impact your choice

Each choice card contained two alternatives and the respondent chose their preferred option, service A or service B. Parents were presented with a forced choice, that is, there was no opt-out option. A forced choice was included as the vignette was set up so that parents had already decided that, in their opinion, their child needed medical care. Given parents will have different thresholds for seeking care, we opted for the forced choice so as not to add this additional factor to the DCE.

The accessibility of local healthcare services (according to the participant), taking into account distance, transport and appointment availability, was also assessed on a scale of 1 (very easy) to 5 (very difficult). Questions were also asked about the health status and service utilisation of the respondent's youngest child, and all parents were asked to answer the choices presented with this child in mind. The youngest child was selected as younger children have higher rates of healthcare utilisation,[1,22] and it was assumed that asking parents to respond on each child would lengthen the survey and add unnecessary complexity.

Data analysis

The analysis was completed using Stata® 16. A conditional logit model with robust standard errors was first estimated to determine the general direction and significance of attributes and covariates on the choice of service. To further examine unobserved heterogeneity amongst respondents, random parameters mixed logit model was estimated firstly in preference space. Random parameter models estimated in the willingness-to-pay (WTP) space were also undertaken to estimate the WTP for the noncost attributes.[23]

A conditional logit model with robust standard errors was first estimated to determine the general direction and significance of attributes and covariates on the choice of service. This model assumes the respondents' utility (U) is determined as follows: [Image Omitted. See PDF] where *i* refers to the respondent, and *j* each alternative presented as part of the choice set. β is estimated from a vector of attributes (X) describing the alternative (*j*), *Z* is a vector of individual characteristics that do not vary over alternatives but do vary over individuals and εij is the stochastic disturbance representing unobserved characteristics of respondents. The utility gained from a chosen option must be higher than that of the alternative. In this study, each respondent was presented with 2 alternatives (*j*), service A and service B, and there were 12 choice sets for each respondent to answer. Respondent characteristics are alternatively invariant and only matter if they alter preferences. Therefore, interactions between attributes and family status, characteristics of the youngest child, mother's employment and educational status, and accessibility of health services, were assessed individually to identify variations in preferences.

To further examine unobserved heterogeneity amongst respondents, random parameters mixed logit model was estimated first in preference space. Each parent responding to the survey was presented with a number of scenarios (*s*) and was required to choose between two alternatives (*j*): [Image Omitted. See PDF]

Xijs is a vector of attributes of the healthcare service (see Table 1), βi′ is a vector of individual-level coefficients, and εijs captures the unobserved factors that influence choice. The noncost attributes are assumed to be normally distributed while the cost attribute is negative log normal. The simulation is based on 500 Halton draws.

Random parameter models estimated in WTP space were also undertaken to estimate the WTP for the noncost attributes. The marginal rate of substitution using WTP was also assessed in WTP space to estimate WTP[23]: [Image Omitted. See PDF]where *MU*xk is the marginal utility of attribute xk and *MUc* is that of cost. The ratio of the noncost to cost coefficient is computed giving a direct WTP estimate. The noncost attributes were normally distributed and the cost coefficient incorporates differences in scale across respondents and is assumed to be random and log-normally distributed with a negative distribution.

The Stata® user-written packages *mixlogit* and *mixlogitwtp* were used to estimate the preference models and WTP mixed logit models respectively.[24,25]

RESULTSParticipants

Table 2 presents the demographic characteristics of the respondents. Of the total sample (450), 65% were female and the mean age was 39.6 years (SD = 8 years). The mean number of children for respondents was 2 (SD = 1) and the mean age of the youngest child was 7 (SD = 4.5 years). Irish was the predominant ethnicity (71%), 68% were married and most had a minimum of third-level education (58%). A higher proportion of parents were employed, with 51% working full-time and 12% of respondents describing themselves as healthcare professional. A medical card was held by 39% of respondents, somewhat higher than the national average of 33%, with a further 12% holding a GP visit card. Half of the respondents had private health insurance, slightly higher than the national figure of 46.2%.[26] When asked about the health status of their youngest child, 19% stated their child had an ongoing condition or disability, while 23% stated their child had a previous condition that required ongoing healthcare. The average number of healthcare attendances for the youngest child in the past year was 2.6 (SD = 7.2). When asked about the accessibility of their GP, OOHs GP and the ED on behalf of their youngest child, 9% assessed GP access as either difficult or somewhat difficult, compared with 22% for OOHs GP and 23% for ED. These results can be seen in Table 2.

Table 2 Descriptive statistics of the sample.

Variables (columns are % and *n*, unless otherwise stated)	Final sample (*N* = 448)	
Female	65%	294
Age of respondent (mean/SD)	39.6	8.1
Number of children (mean/SD)	2.2	1.2
Age of youngest child (mean/SD)	7.0	4.5
Ethnicity		
Irish	70%	317
Other White	17%	76
Other	13%	57
Family status		
Married	68%	305
Co-habiting	14%	64
Divorced/separated/single/unknown	18%	81
Highest level of education		
Secondary	20%	89

Postsecondary	22%	98
Third level	58%	264
Employment status		
Working full-time	51%	231
Working part-time	21%	93
Stay-at-home parent	22%	98
Unemployed	6%	28
Healthcare professional	12%	56
Medical card/GP visit card/Insurance		
Medical card	39%	175
GP visit card	12%	52
Health insurance	50%	227
Youngest child		
Youngest child's health		
Very healthy, no problems	69%	309
Healthy, but a few minor problems	28%	126
Sometimes quite ill/almost always unwell	3%	15
Youngest child has conditions/disabilities		
Ongoing conditions or disabilities	19%	86
Previous conditions or disabilities, not ongoing currently	23%	105
Number of times accessed healthcare in past 12 months (mean/SD)	2.6	7.2
Access to health service perceived to be somewhat difficult/difficult		
GP	9%	39

OOH GP	22%	89
Emergency Department	23%	96

Abbreviations: GP, general practitioner; OOH, out of hours; SD, standard deviation

All attributes were significant in the conditional logit model and in the expected direction (see Table 3). The strongest factor was same-day access (β = 0.935, 95% confidence interval, CI [0.796, 1.07]) which was followed by next-day access (β = 0.609, 95% CI [0.516, 0.702]), being seen by your own GP (β = 0.502, 95% CI [0.392, 0.613]), an evening or weekend appointment (β = 0.305, 95% CI [0.221, 0.389]), a 9:00 AM to 5:00 PM appointment (β = 0.264, 95% CI [0.186, 0.341]), telephone advice (β = 0.237, 95% CI [0.177, 0.297]), being seen by any nurse or doctor (β = 0.152, 95% CI [0.072, 0.233]) and cost (β = −0.015, 95% CI [−0.018, −0.012]). Characteristics of respondents interacted with each attribute to determine the variation in preferences, and two interactions were statistically significant. Those stating that they perceived access to a GP to be *somewhat difficult* or *difficult* were less likely to prefer attending their own GP (β = −0.334, 95% CI [−0.545, −0.123]) and preference for a same day appointment was greater for those with more than one child (β = −0.283, 95% CI [−0.579, 0.013]). The positive and significant Alternative Specific Constant suggests that parents were considering other factors when making their decision.[27]

Table 3 Results from conditional logit model.

	Odds ratio	Robust standard error	CI 95%	β	Robust standard error	CI 95%
Timeliness (base: 2 days' time)						
Same day	2.548***	0.180	2.22, 2.93	0.935***	0.071	0.796, 1.07
Next day	1.839***	0.087	1.68, 2.02	0.609***	0.047	0.516, 0.702
Appointment system (base: walk-in)						
Appointment 9:00 AM to 5 PM	1.301***	0.052	1.20, 1.41	0.264***	0.039	0.186, 0.341
Appoint available evenings and weekend	1.357***	0.058	1.25, 1.48	0.305***	0.043	0.221, 0.389
Who patient will see (*base: Practice nurse*)						
Any nurse or doctor	1.165***	0.048	1.04, 1.26	0.152***	0.041	0.072, 0.233
Own GP	1.653***	0.093	1.48, 1.85	0.502***	0.056	0.392, 0.613

Telephone advice available (base: No advice)	1.267***	0.039	1.19, 1.35	0.237***	0.031	0.177, 0.297
Cost (€0, €15, €30, €45)	0.985***	0.002	0.982, 0.988	−0.015***	0.001	−0.018, −0.012
Alternative Specific Constant	1.170***	0.042	1.09, 1.25	0.157***	0.035	0.087, 0.226
N	10,800					
Log likelihood	−3537					
AIC	7092					
BIC	7157					

Note: Standard errors are in parentheses. Abbreviations: AIC, Akaike information criterion; BIC, Bayesian information criteria; CI, confidence interval; GP, general practitioner. ***

p <.001.

Random parameters logit model results

A random parameters logit model was estimated in preference space and all attributes and that were statistically significant in the conditional logit model remained significant in the preference model (Table 4), including the interactions (see Supporting Information: Table 1). The strongest factor was cost ($\beta = -5.064$, 95% CI [−5.60, −4.53]) followed by same-day access ($\beta = 1.386$, 95% CI [1.19, 1.58]) next-day access ($\beta = 0.857$, 95% CI [0.73, 0.98]), being seen by your own GP ($\beta = 0.748$, 95% CI [0.61, 0.89]), an evening or weekend appointment ($\beta = 0.390$, 95% CI [0.28, 0.50]), a 9:00 AM to 5:00 PM appointment ($\beta = 0.363$, 95% CI [0.25, 0.47]) and telephone advice ($\beta = 0.312$, 95% CI [0.22, 0.40]) and being seen by any nurse or doctor ($\beta = 0.299$, 95% CI [0.19, 0.41]). The standard deviation for all attributes, other than a preference for an appointment the next day and a consultation with any nurse or doctor, were statistically significant, indicating substantial heterogeneity in preferences. WTP in preference space was highest for an appointment on the same day (€27.36) followed by an appointment the next day (€16.93), compared with an appointment in 2 days' time. The next highest was an appointment with their own GP (€14.77), followed by the option of an evening or weekend appointment (€7.70) and an appointment between 9:00 AM and 5:00 PM (€7.16). Finally, respondents were willing to pay €6.16 for telephone advice and €5.90 to be seen by any nurse or GP in the practice. The cost coefficient was significant and in the expected direction suggesting parents preferred to pay less overall, and the statistical significance of the standard deviation suggests variability in this response.

Table 4 Results from random parameters logit models in both preference space and willingness to pay space.

Note: Standard errors are in parentheses. Abbreviations: AIC, Akaike information criterion; BIC, Bayesian information criteria; CI, confidence interval; GP, general practitioner. ***

p <.001

**

p <.01

*

p <.05.

When estimated in the WTP space, the model fit was not as good as in the preference space. All attributes remained statistically significant, however, the interactions were not statistically significant in this model (see Supporting

Information: Table 1). WTP was highest for a same-day appointment (€66.99), followed by a next-day appointment (€39.03) compared with an appointment in 2 days' time. Parents were willing to pay €28.81 to see their own GP versus the practice nurse but had a lower WTP to see any doctor or nurse (€8.78). Respondents were willing to pay for an appointment system versus walk-in with an unknown wait time (€14.96 for 9:00 AM to 5:00 PM weekdays; €14.98 for a time including evenings and weekends), and €12.04 for telephone advice. As in preference space, the coefficient on cost was significant and in the expected direction.

DISCUSSION

This study utilised a DCE survey to assess parent's preferences when seeking first-contact unscheduled healthcare for their children. While all attributes were significant in the model, the results suggest that same-day or next-day access, as well as being seen by their own GP (i.e., a GP they were familiar with), were the strongest preferences of parents accessing unscheduled healthcare for their child. Other attributes included an appointment during evenings and weekends, appointments during standard working hours, the option to be seen by any GP or practice nurse and telephone advice. The present findings enhance the current literature in this area by focusing exclusively on children and by considering all unscheduled health services as one entity rather than distinctive services to identify the common factors that influence parents' decision-making.

Timeliness was the most important factor identified in the analysis as parents preferred to be seen on the same or the next day which reflects previous findings in the literature.[28] Many parents access healthcare to seek reassurance that their child's illness is not serious or will not become more urgent. Therefore, once they have decided to seek healthcare, this study shows that timely access is the single most important attribute, with parents' preference strongest for same-day or next-day access. While certain clinical factors may lead a parent to select an ED or LIU over a GP, there are many presentations of an ill child that are suitable for care across all settings. Young children make up a large proportion of ED attendances that may have been treatable at primary care.[12] Redirecting such presentations through primary care, leaving hospital resources available for those that need specialist diagnostics and care, has been a policy goal for many health systems internationally. However, increasing access to primary care is not guaranteed to reduce ED attendance in this population,[22] and therefore, understanding the drivers of decision-making and behaviour is critical. Parents will continue to utilise emergency and OOH services if they are more likely to offer same-day care to balance their child's needs with other important responsibilities[13] such as work commitments, particularly those with inflexible work arrangements,[6] caring for other children and childcare requirements.

With the next strongest preference for attending their own GP, many parents would prefer same-day access to their own GP to care at an ED or LIU, findings that are consistent with DCEs that focused on a particular type of healthcare.[28] Younger children make up a large proportion of ED visits amongst paediatric patients[22] and therefore, providing greater support to parents of younger children should be an important focus for policy and planning. Strengthening parents’ ability to cope with unexpected illness may reduce the utilisation of unscheduled services.[13] For instance, first aid training and education for new parents could foster greater confidence in their capacity to recognise and handle common childhood illness (reference removed for peer review). Moreover, access to telephone support before an appointment was a preferred option for parents in the DCE and is offered by the majority of GP practices in Ireland.[29] The use of remote consultations allowed for essential health services to continue during the COVID-19 pandemic and evidence is continuing to emerge regarding the benefits and pitfalls of this approach.[30] It is possible that this could provide a convenient,[6] timely and cost-effective approach to provide support and reassurance to parents of young children.

Limitations

A number of limitations of the study were identified. The DCE was designed to ensure it could be completed by parents without being cognitively challenging and could be completed within an acceptable timeframe. While the attribute development process identified the attributes and levels most relevant to parents' decision-making on accessing unscheduled healthcare (references removed for peer review), other attributes, such as characteristics of the consultation and location of the health service, are also relevant and do not feature in this study. Moreover, it is important to note that the study is related to a mild illness which is common in childhood, however, the findings may not be relevant to presentations to unscheduled health services. Finally, data collection occurred during the COVID-19 pandemic. While the vignette asked parents not to answer in the context of the pandemic, responses may have been impacted by the prevailing context and its impact on health-seeking behaviour.[22]

CONCLUSIONS

Parents often navigate the health system as a single entity with many entry points. Understanding the relative importance of factors that influence this behaviour and decision-making is fundamental to ensuring the system is best designed to meet the needs of users and foster the appropriate cost-effective usage of health system resources. Timely same-day access was a critical factor for parents when choosing unscheduled healthcare for their children, with care by their own GP as the second most important attribute. There is a need to recognise the factors that drive health-seeking behaviour when engaging in policy development and implementation to improve service provision.

AUTHOR CONTRIBUTIONS

Emma Nicholson: Conceptualization; investigation; methodology; formal analysis; project administration; writing—original draft. **Thérèse McDonnell:** Conceptualization; methodology; formal analysis; writing—original draft. **Ciara Conlon:** Investigation; methodology; project administration; writing—original draft. **Aoife De Brún:** Conceptualization; funding acquisition; methodology; writing—review and editing. **Edel Doherty:** Methodology; formal analysis; writing—review and editing. **Eilish McAuliffe:** Conceptualization; funding acquisition; methodology; writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available in Zenodo at https://zenodo.org/record/6572717#.Y9kbd3bP24Q reference number [6572717].

ETHICS STATEMENT

Ethical approval for the study was obtained from University College Dublin Human Subjects Ethical Review Committee (Ref: LS-18-107-McAuliffe). Each participant provided informed consent on their own behalf before taking part in the study.

DETAILS

Subject:	Parents &parenting; Emergency medical care; Health care policy; Health care; Childhood; Hospitals; Health care access; Health status; Policy making; Preferences; Health services; Statistical analysis; Qualitative research; Health initiatives; Pediatrics; Data collection; Hospitalization; Children; Patients; Parents; Cost analysis; Confidence intervals; Decision making; Medical research; Primary care; Family physicians; Logit models; Parameters; Medical personnel; Attributes; Health care delivery; Systematic review; Discrete choice; Help seeking behavior
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Exploring the views and experiences of people recovering from a stroke about a new text message intervention to promote physical activity after rehabilitation—Keeping Active with Texting After Stroke: A qualitative study

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ABSTRACT (ENGLISH)

Background

Participating in exercise following a stroke is essential for recovery. When community-based rehabilitation services end, some people struggle to remain active. We codesigned Keeping Active with Texting After Stroke (KATS), a text message intervention to support home-based, self-directed plans to continue exercising. KATS delivers a series of automated text messages over a 12-week period from the point of discharge from National Health Service-funded therapy. The aim of this study was to explore the views and experiences of the first cohort of participants to complete the KATS intervention about the meaning, engagement, workability and worth of the intervention.

Methods

We undertook a qualitative study, theoretically informed by Normalisation Process Theory. We conducted semi-structured telephone interviews with people with stroke from two Health Boards in Scotland. Data collection took place over two phases, with each participant being interviewed twice: first, halfway through intervention delivery (Week 6) and then again at the end of the intervention (Week 12). All interviews were audio-recorded, transcribed and analysed thematically.

Results

A total of 24 interviews were conducted with 12 participants. Our findings were organised around four overarching analytical themes: (1) making sense of KATS: timing and complementarity in the rehabilitation journey; (2) engaging with KATS: connection and identification with others; (3) making KATS work: flexibility and tailorable guidance; (4)

appraising the worth of KATS: encouragement and friendliness. Participants differentiated KATS from current rehabilitation practice, finding it relevant, fitting and worthwhile. Variations were reported in engagement with behaviour change techniques, but participants were able to tailor KATS use, making it work for them in different ways.

Conclusions

Perceived benefits went beyond promoting physical activity, including feeling supported and connected. Future research will test the effectiveness of KATS in promoting physical activity and explore any associations with relevant social and emotional secondary outcomes.

Patient or Public Contribution

A research funding proposal was developed in collaboration with five people with stroke and three spouses. After securing funding, six people with stroke were invited to join the project's Collaborative Working Group, alongside health professionals and stroke rehabilitation experts, to codevelop the intervention and support the feasibility study.

FULL TEXT

INTRODUCTION

In the United Kingdom and worldwide, stroke is among the top leading causes of death and disability combined, with the number of people living with stroke globally having almost doubled over the last 30 years.[1] Participating in exercise and physical activity following stroke contributes to substantial health benefits. The direct physical benefits of exercise can support recovery through the improvement of walking ability, balance and fitness.[2] In addition to the physical benefits of exercise, regular physical activity can also improve health-related quality of life, reduce poststroke fatigue, enhance social participation and help to restore independence.[3]

However, evidence suggests that physical activity levels after stroke are low and further decline over time,[4] with stroke survivors often experiencing physical deconditioning and leading sedentary lifestyles.[3] This may be due to a wide range of factors both directly and indirectly related to stroke (e.g., prestroke physical inactivity and sedentary lifestyles, direct neurological effects of stroke which can reduce the muscle mass available for activation, presence of comorbid conditions) resulting in few people with stroke meeting recommended levels of physical activity. Therefore, finding effective ways to support people to become and remain active after stroke is critical.

Many people with stroke in the United Kingdom receive physiotherapy and occupational therapy at home following discharge from intensive in-patient-based rehabilitation.[5] When this community rehabilitation ends, some people feel there is a gap in support provided and still struggle to remain active.[6] The structured exercise programmes, guided by therapists, must be replaced by self-directed plans to continue exercising and increase physical activity,[7] which can be challenging for many.[8,9]

Text message-based interventions have the potential to support and improve home-based, self-directed plans to continue exercising when community rehabilitation ends, or when community rehabilitation services are not available (e.g., in countries or communities where access to basic rehabilitation services may be lacking).

Research to date has shown promising effects on increasing physical activity in general populations,[10] however, interventions for people with stroke have yet to be fully tested. Pilot studies have reported the potential use of text message interventions for people with stroke, but their use has been limited and for diverse purposes: The STROKEWALK study delivered instructional text messages to promote regular walking and functional leg exercises over 3 months[11]; the iVERVE intervention used text messages as part of a self-management programme to support goal attainment for recovery after stroke and in secondary prevention after stroke[12]; and a text message reminder based intervention, which was part of a family-centred intervention, sought to support participation in daily activities.[13,14] These studies demonstrated that people with stroke can use text messaging as an intervention, although none specifically focused on using behaviour change strategies to support continuity with rehabilitation whilst facilitating the transition to active living after rehabilitation.

To provide continuity beyond formal rehabilitation and to help people with stroke to be physically active at the end of rehabilitation, we codesigned a novel text message intervention, the ‘Keeping Active with Texting After Stroke’ (KATS) intervention. The intervention and its development is described in detail elsewhere,[15] but briefly, we used a multistage iterative process to codevelop a theoretically informed text message intervention in collaboration with people with stroke, health professionals and experts in the field of stroke rehabilitation who were invited to join the study's Collaborative Working Group.[16] Key contributions from people with stroke and the Collaborative Working Group throughout the codevelopment process included: assessment of mobile phone use following stroke; identification of current needs and gaps; design of intervention goals; design of message contents and message delivery patterns; acceptability assessment; revision and refinement of messages. The intervention was designed to dovetail with community rehabilitation services after a stroke, to provide support and continuity at a time when many people with a stroke feel vulnerable. It was intended to enhance motivation, combat feelings of abandonment postrehabilitation and support the uptake and maintenance of physical activity and recovery-specific exercises. The text messages were designed to provide support for goal setting, planning and self-monitoring of physical/recovery activities and exercises. The intervention was theoretically informed by the Health Action Process Approach[17] and used a range of established behaviour change techniques[18] to increase motivation and provide support for people with stroke to be physically active.

An ongoing feasibility study was designed to test and refine the KATS intervention ready for evaluation in a future randomised controlled trial. We undertook a qualitative study to explore the views and experiences of the first cohort of participants to complete the KATS intervention as part of their participation in the intervention's feasibility study. This qualitative study was informed by Normalisation Process Theory (NPT)[19]—a sociological theory which explains the processes involved in implementing and/or making a new intervention work in practice to allow for the intervention to become ‘normalised’ or embedded in individuals/groups everyday practices. Four core constructs describe generative mechanisms that facilitate normalisation: coherence (work to make sense of an intervention), cognitive participation (work to engage with an intervention), collective action (work to enable an intervention to happen) and reflexive monitoring (work to appraise an intervention).

The aim of this study was to explore the views and experiences of the first cohort of people with stroke to complete the KATS intervention about the meaning, engagement, workability and worth of the intervention.

METHODS

We undertook a qualitative study, theoretically informed by NPT, using semi-structured telephone interviews with people with stroke from two Health Boards in Scotland. Ethical approval was granted by the North of Scotland Research Ethics Service (21/NS/0028).

The KATS intervention[15] comprised 95 text messages delivered to participants over a period of 12 weeks. Participants received at least one message every day. The first week was used to foster interest and engagement. Messages then followed a sequence to address and illustrate the process of behaviour change to increase physical activity. Messages used conversational, informal language to encourage engagement. Participants were advised that, while they were welcome to respond to any of the text messages, the KATS messaging system did not allow for the research team to reply to any of their responses. Some messages included pseudonymised quotes and examples from people with stroke who had participated in the intervention development process, and from participants in our previous studies.[20,21] These messages modelled behaviours and provided encouragement. Some messages were personalised to include participants' names. Text messages were delivered by an automated computer system which was programmed to send the messages to participants' mobile phones in a predetermined sequence. The software tool for delivery was developed by the Health Informatics Centre at the University of Dundee (C. J.). Participants were provided with a calendar (to facilitate recording of daily activities and reflection on progress) and a handbook (to reinforce key components of the intervention, and to provide information and signposting to online resources offering exercises for people who have had a stroke). At the end of the 12-week intervention participants received a £20 gift voucher.

Data collection took place over two phases between July and November 2021, using semi-structured telephone interviews, with each participant being interviewed twice: First, at 6 weeks postrecruitment (halfway through intervention delivery) and again at the end of the KATS intervention at Week 12. This was to enable the exploration of experiences of the intervention ‘in use’ alongside perceptions at the end of the intervention cycle. The choice of conducting telephone interviews, rather than using virtual platforms, was chosen to minimise the potential impact of digital literacy, or stroke-related problems which can affect the ability to use digital technologies, as barriers to participation. Interviews were conducted by a female nonclinical university-based researcher (L. I.) with extensive experience in intervention studies, including intervention development and feasibility testing studies using participatory and qualitative methods.

All participants from the first cohort to complete the KATS intervention as part of their participation in the intervention's feasibility study were invited and took part in this qualitative study. Recruitment for the feasibility study was undertaken in collaboration with staff from stroke rehabilitation services in two Health Boards in Scotland, who identified patients receiving rehabilitation and invited them to take part in the study. Interested patients signed an expression of interest form, which gave the research team permission to contact them when community rehabilitation was nearing completion. The research team did not have any prior relationship with the study participants. Potential participants were given general information about the research team and detailed information about the study and their potential participation at the point of being contacted by the research team. Informed consent was obtained using audio-recorded telephone conversations, as face-to-face contact was not permitted due to COVID-19 pandemic restrictions. A copy of the consent form signed and dated by the researcher was sent to the participant by email or post. Suitable times were arranged with all participants to collect data on participant characteristics before the start of the intervention. Participants were characterised by age, sex, time since stroke, whether they lived alone or not, sociodemographic category[22] (Scottish Index of Multiple Deprivation [SIMD]) and Modified Rankin Scale[23] to provide an assessment of disability/dependence. Times for telephone interviews were agreed at 6 and 12 weeks after the start of the intervention. All telephone interviews were audio-recorded and transcribed. Interview topic guides were informed by NPT[19] in combination with topics/prompts suggested by the larger feasibility study's Collaborative Working Group.[16]

Interview data were managed using NVivo software and analysed using thematic analysis[24] theoretically informed by NPT.[19] Data were initially open coded by the researcher who conducted the interviews (L. I.). To address any potential researcher bias or assumptions that might have impacted the analysis, the initial coding was critically reviewed by two other researchers (A. F. and J. M.). An agreed descriptive coding framework was developed, which was then revised and refined by the research team as coding proceeded and new data were collected and added to the data set. Descriptively coded data were then mapped against NPT constructs to inform the development of analytical themes (A. F.) which were critically reviewed (L. I. and J. M.) and further discussed and refined in group data analysis sessions until the findings were established. These sessions included regular data analysis meetings between the three researchers primarily undertaking data analysis tasks (L. I., A. F. and J. M.) as well as feedback sessions with the wider research team and the study's Collaborative Working Group, both of which included people with stroke.

RESULTS

A total of 24 interviews were conducted with 12 participants (Table 1). Each participant took part in two interviews, the first one halfway through intervention delivery (Week 6) and then again at the end of the KATS intervention (Week 12). Nine participants were male and three were female. Their ages ranged from 31 to 74 years (median 61 years). Three participants lived alone. There was representation across all sociodemographic categories of the SIMD.[22] The time since stroke ranged from 5 to 184 weeks (median: 57 weeks). Participants self-assessed their degree of disability/dependence using the Modified Rankin Scale,[23] with scores ranging between 1 and 4 (maximum 5) and the majority of participants scoring 3 on the scale.

Table 1 Summary of participants' sociodemographic characteristics.

Characteristics	*N* = 12
	n

Sex	
Male	9
Female	3
Age	
<60 years	5
60–65 years	2
>65 years	5
Living arrangements	
Lives with partner/family	9
Lives alone	3
Scottish Index of Multiple Deprivation	
1–2 (Most disadvantaged)	4
3–4	6
5 (Least disadvantaged)	2
Time since stroke	
<1 year	5
1–2 years	5
>2 years	2
Modified Rankin Score (self-assessed)	
1 (No significant disability)	2
2	1
3	8
4	1

5 (Severe disability)	0

Below we describe our main findings, organised around four overarching analytical themes, which were informed by the four core constructs of NPT (Table 2).

Table 2 Structure and organisation of themes.

Abbreviations: KATS, Keeping Active with Texting After Stroke; NPT, Normalisation Process Theory. **Making sense of KATS: Timing and complementarity in the rehabilitation journey**

Participants perceived the KATS intervention as both relevant and fitting based on their rehabilitation journeys.

The perceived relevance of the KATS intervention was particularly driven by the timing of the intervention, which followed on from the point of discharge from National Health Service (NHS) funded therapy, a difficult time in the rehabilitation journey that some associated with a feeling of abandonment:

When [rehab centre] was finishing you have the slight feeling of being abandoned, you know. I know that wasn't the intention at all, but having the KATS study following on from that helped to make me feel I was still being kept in the loop and considered. So, I think the timing was probably pretty good, actually. (GW1007, male, 70 years—Week 12 interview)

I think it just follows on nicely because it started almost immediately when the physio stopped coming to the house. I don't think I would have seen the point in getting messages from you lads when the physios were still coming here. (TW1003, male, 69 years—Week 6 interview)

Some participants noted that an earlier starting point for the intervention might have suited them better:

I would say that the study would have been more useful if I had done it early—maybe as soon as I got out of hospital… Yes, I would say at the beginning of the supported discharge, so, I think this alongside supported discharge. (GW1001, male, 31 years—Week 6 interview)

The perceived fit of the KATS intervention was particularly driven by the consistency and complementarity of the intervention with the recommendations they had received from their therapists at the point of discharge from rehabilitation. In this context, KATS was seen as an element of continuity from services and additional support to enact recommendations and meet the expectations of rehabilitation:

[the proposed activities] were very much along a similar sort of pattern. (TW1004, male, 61 years—Week 6 interview)

[with the information and content of your messages] You're also crediting the girls [NHS physiotherapists] who came every day for those 6 weeks [of NHS funded therapy] because they were saying the things that you're saying in these texts, they were saying those things to me. There is no point in doing 6 weeks of these girls [NHS physiotherapists] coming and then just ignoring what they said. What you were saying in the texts was exactly what they were saying. (GW1008, male, 67 years—Week 6 interview)

Engaging with KATS: Connection and identification with others

The relevance and fit of the KATS intervention were further emphasised by the impact of COVID-19 pandemic restrictions, which brought about an increased sense of isolation among participants:

You see, your messages—I know it sounds crazy, but your messages are like, when I'm alone and sitting on my own, it's giving me purpose and a reason to try, if you know what I mean. I could sit here and watch TV and do nothing. (TW1010, male, 57 years—Week 6 interview)

I was a bit stir crazy just sitting in and what have you, but the messages would help me to get going and what have you. (…) When I look back now, and knew that your texts were coming through, yes, it was like somebody was here, no knocking on my door, no face-to-face, but I always knew somebody would be there and I'm not the only one in the world with the problems. (GW1002, female, 60 years—Week 12 interview).

In this context, it became apparent from some participants' experiences that the nature and content of the KATS messages mattered as much to them as receiving text messages did:

Well, that's how I feel, that there's somebody out there that cares, you know—I know it's text messages, but it's like when your text message comes through, I'm like, somebody cares, somebody is thinking of me… So, yes, the messages spur you on and give you challenges. (GW1002, female, 60 years—Week 6 interview)

Sometimes it was just the actual message that was helpful, because if you're not having the best day in the world or you're sitting in the house and it's pouring of rain, you can't do anything, you don't speak to anybody or whatever. Suddenly, you get this ping on the message it takes your mind away from the problems. (TW1010, male, 57 years—Week 12 interview)

Most participants expressed that they had identified with quotes and examples from other people with strokes provided in the KATS messages, and highlighted that they took comfort and felt reassured by the quotes:

Yes, well it was interesting to see that you weren't the only one that had a stroke, you heard other people's views and what their problems were and what they were doing to overcome their problems, so, it was good. (GW1008, male, 67 years—Week 12 interview)

You would pass the message that somebody said, this [activity] worked for them when it's raining or whatever, they try walking up the stairs. I remember that one because I did that because it was pouring with rain. I had been on my bike, but there are only so many times you can sit on the bike. Then I think the ping message came and I look at it and it says—I don't say the name, David again, he tried walking up the stairs on a rainy day, so, I did it, 3 or 4 times I walked up and down the stairs. Don't get me wrong, I'm a little bit out of breath each time but it's fun. (TW1010, male, 57 years—Week 12 interview)

Although details about the sources and pseudonymised nature of the quotes and examples used in the messages were documented in the intervention materials and explained to all participants at the beginning of the intervention, there were indications that some participants interpreted the quotes and examples as though they were coming from other people taking part in the KATS intervention at the same time as them:

Most of the messages were coming across, it was like people with their own engine, like I'm going to go and exercise, I'm going to do this, I'm going to do that. (…) I found that most of the people who were texting seemed to have their own engine, as I call it, their own drive and they were going to make sure that they were going to do this and they were going to do that, which is what I was doing. (…) If you're one of these people who are going to wait for someone to say, come on, you should be doing this or, come on, you should be doing that. I know a stroke can make you depressed, it can do that, but the people who were texting you, all seemed to have, or the majority of them seemed to have this attitude. (GW1008, male, 67 years—Week 6 interview)

Similarly, although participants were informed at the beginning of the intervention that the KATS messaging system did not allow the research team to reply to any of their responses, most participants still chose to actively reply to text messages, with all but one of the participants sending text message responses at some point during the intervention.

Overall, our analysis suggested that participants generally understood the KATS intervention, were able to broadly describe it, and had a shared sense of its purpose:

I think at the start I was a bit apprehensive; it was like a step into the unknown really, I had no idea what it was going to entail. Certainly, going through the process, I found as we went on that things got better and I was more understanding of what it was going to entail (…) It's not a tailored programme for specific people, it's just basically, for individuals to find their own way as they go through the process because everyone will have their own goals and things they want to achieve individually. (TW1013, male, 56 years—Week 12 interview)

However, it became apparent from participants' descriptions and references to the nature of the intervention that the more nuanced, complex components of the KATS intervention were not relevant for all participants. For example, whilst the KATS text messages were theoretically informed and explicitly designed to go beyond acting as simple reminders, aiming to provide a structure that facilitated behaviour change, some participants still described the value and helpfulness of the intervention primarily as a reminder or trigger to physical activity:

The most useful thing is just to remind you, because sometimes you forget to do things, if there is nobody there to remind you, if your wife is not at home or you can forget, and you're watching TV or listening to records, you need a jolly along to say, it's about time you did some exercise, get up and move around for half an hour or whatever. So, the most useful aspect is a reminder. (TW1004, male, 61 years—Week 6 interview)

Making KATS work: Flexibility and tailorable guidance

Despite participants seeing the point of the intervention and considering it relevant and fitting in the context of their rehabilitation journey, it was unclear to what extent participants took advantage of the full range of behaviour change techniques offered by the intervention as ways to encourage increases in their activity levels. As expected for a remotely delivered self-help intervention like KATS, there was variation in the amount of engagement with the range of behaviour change techniques offered by the intervention. This is illustrated by these two participants describing significantly divergent forms of engagement with the same intervention component, the calendar:

I've been using the calendar quite regularly the last few weeks, both for putting up things that are coming up, so, that you know what is going to be happening and also recording exercises that I've done, and I've found that quite rewarding. (GW1007, male, 70 years—Week 6 interview).

I'm afraid I don't even know where it [the calendar] is. It came in a brown envelope; it's still lying unopened. (TW1003, male, 69 years—Week 6 interview)

Participants found the messages to be understandable, helpful, interesting and relevant to guide their journey to recovery following discharge from therapy. Most participants made the intervention work by engaging with intervention components as suggested by the KATS messages and/or following more general suggestions or signposting included in the KATS messages. Some participants were able to link and tailor the guidance provided to meaningful tasks or get family members involved:

I just try to involve it [the hand affected by stroke] in everyday things, like taking hold of things, opening a door, putting on the shower and that sort of thing, and trying to consciously use the left hand [the hand affected by stroke] more for just doing things. That's one of the reasons I was keen to do the study, I wanted to try and keep these things going once the physio stopped. (GW1007, male, 70 years—Week 6 interview)

The motivational aspects embedded in the KATS messages connected well with most participants' mindset at this stage of rehabilitation/recovery, which was characterised by their determination to undertake everyday tasks and activities despite the perceived challenges and difficulty of staying active. Here, too, identification with others in a similar situation seemed to provide motivation and be a key driver of participants' commitment to continue to engage with the intervention. Participants highlighted how reading the quotes featured in the KATS messages and gaining insight into the experiences of other people with stroke had been motivating, with quotes and examples providing participants with role models for the behaviours they were seeking to engage with and embed into their lives:

It showed what they [other people with stroke] had done, and it helped me, I could do things that I thought I couldn't. (TW1009, female, 74 years—Week 6 interview)

Appraising the worth of KATS: Encouragement and friendliness

Participants valued being offered the opportunity to reflect on the physical activity they were doing at the time of receiving the text messages and consider the physical activity they could or should be doing:

I have read every message, I do sit and ponder on it and think about it and it does help me quite a lot and makes me think quite a lot of what is happening and what I should be doing and what have you. (GW1002, female, 60 years—Week 6 interview).

Other aspects of the messages, such as the terminology and tone used (e.g., relying on informal language and incorporating humour and trivia) were valued by participants. They appreciated the nonauthoritative, nonprescriptive nature of the KATS messages:

They [the messages] were quite friendly and not too formal, and I think that hits the right tone. You don't want to tell people to do things. You have to jog them along fairly gently. (TW1004, male, 61 years—Week 6 interview)

I think if you start moving down the formality route it's like you're bringing out the big stick or the wagging finger. You're giving instructions to people when you get formal as opposed to encouragement. (TW1003, male, 69 years—Week 12 interview)

Overall, regardless of the participants' level of engagement with the more detailed intervention components and activities, the KATS intervention was seen as worthwhile:

It's been like a good friend to me. (GW1002, female, 60 years—Week 12 interview)

I've found it very, very worthwhile. I've actually surprised myself how far I've come since starting the study (…) It's built up my confidence to actually attempt other things because I feel confident in that. (TW1013, male, 56 years—Week 12 interview).

Participants judged the KATS intervention to be advantageous for all stroke survivors following discharge from community-based rehabilitation services. Perceived benefits extended beyond the element of support to promote physical activity, for example the affective/emotional effect of not feeling alone; the motivational aspect of monitoring progress; and softening the sharp ending of rehabilitation/therapy services at the point of discharge.

DISCUSSION

This qualitative study explored the views and experiences of the first cohort of participants to complete the KATS intervention about the meaning, engagement, workability and worth of the intervention. We found that participants were able to differentiate the new KATS intervention from current rehabilitation practice and perceived the benefits it could bring about for people with stroke. There was variation in the amount of engagement with the range of behaviour change techniques offered by the intervention, however, participants were able to tailor their experience of the intervention and make it work for them in different ways. Overall, participants saw the KATS intervention as worthwhile.

One key perceived benefit of the KATS intervention was its potential to address an unmet need experienced at the point of discharge from NHS-funded therapy, which some participants associated with feelings of abandonment.[25,26] This important finding has already informed some intervention refinements. To ensure that the initial sense of abandonment is not echoed at the end of the KATS intervention, two additional weeks will be added at the end of the original 12-week intervention cycle. During these two additional weeks, the frequency of message delivery will gradually decrease, and the focus will shift to preparing participants for the end of the intervention and maintaining engagement in activities.

The KATS intervention was perceived as both relevant and fitting in the context of participants' rehabilitation journeys. These perceptions were emphasised by the experiences during COVID-19 restrictions, which brought about an increased sense of isolation that the KATS intervention helped address. This finding also helped demonstrate another important finding, that is, that some participants' understandings and perceived importance of the intervention were primarily tied to the very idea of receiving a text message (feeling seen, counted and supported) and were less about the content and components of the KATS intervention, which did not seem to matter as much to them as not feeling forgotten. Future research will further examine this finding with a view to establish whether it was disproportionally salient in our data due to the increased sense of isolation brought about by COVID-19 restrictions.

Participants sense of feeling seen and supported is a valuable finding and a potentially important outcome for the KATS intervention to consider in a future trial. However, our analysis also showed that the more complex behavioural aims/components of the intervention were not relevant to all participants. Therefore, future research should investigate whether addressing participants' need for support following discharge might overshadow the full projected benefits of the intervention, that is, whether some participants' satisfaction with ‘just receiving’ text messages may also mean that they were not sufficiently receptive or motivated to invest thought and energy into changing their physical activity behaviour. If so, further intervention refinement may be warranted, and any future trials to evaluate the effectiveness of the intervention should reflect this in the set of primary and secondary outcomes to be measured.

These findings could help refine the intervention to support readiness for change in physical activity after stroke more comprehensively, although the KATS intervention was not designed to require a specific form or level of engagement from participants. The development of the intervention consciously adopted a nonprescriptive approach focusing on providing guidance, ideas and choices (rather than giving rigid instructions or directive messages) to allow for different forms and levels of engagement and tailoring of the intervention to individual circumstances, needs and preferences. This is an aspect that differentiates the KATS intervention from existing interventions in this area.[11–14] The range of ways to engage with the intervention were apparent in participants' experiences, from those more thoroughly committed to enact the full range of proposed intervention activities through to those making the intervention work for them by just engaging with general suggestions/signposting provided or linking their physical activity to meaningful everyday tasks. A nonprescriptive approach that acknowledges different forms of engagement and tailoring is in line with a person-centred rehabilitation model[27] and was an aspect of the intervention highly valued by participants, alongside other aspects of the messages' tone such as informality, humour and trivia.

One key aspect that shaped participants' positive experiences with the KATS intervention was the inclusion of quotes and examples from other people with stroke in the text messages. This was particularly meaningful to participants, providing them comfort and reassurance, with many noting they had identified with the quotes and examples included in the text messages. There were indications in our data that some participants seemed to interpret the quotes and examples as though they were coming from other people taking part in the KATS intervention at the same time as them. Therefore, it is important for future evaluation to better understand how people perceive these messages and whether further intervention refinement might be needed. This observation raises ethical implications about how successful the KATS intervention communication strategies were in providing transparent explanations about the source and nature of the quotes. Clear explanation using communication strategies relevant to this population, of whom many have cognitive and communication impairments, is, therefore, another important aspect of the KATS intervention that should continue to be ensured by this and other interventions with this population.

Similarly, despite clear and explicit communication to all participants that text messages were prewritten (rather than in real time), and that the KATS messaging system did not allow for the research team to reply to any of their responses, most participants still chose to actively engage with the text messages by replying to them. The ‘humanisation’ of text message-based interventions has been described in other studies[28] and can be explained by increasingly generalised perceptions of mobile phones as highly personal and emotionally significant objects.[29,30] Future research could explore any potential overlaps with peer support interventions for people with stroke[31–33] and consider whether any of their mechanisms and outcomes (e.g., increasing knowledge and motivation, promote vicarious learning and problem-solving, feelings of hope and validation, decreased sense of isolation) can help improve how text messaging interventions can better address the support needs of people with stroke.

Whilst the ‘humanisation’ of the intervention can be considered an example of positive engagement, it is important to ensure that future research/implementation strategies for these types of intervention continue to explicitly address the ethical implications involved in being transparent about the origin of the messages, particularly when delivered to populations for whom digital literacy might be a persistent barrier to equity.[34]

Our study has some limitations. The sampling strategy for this qualitative study had to rely on the feasibility study sampling and recruitment strategy, which meant that our sample was not as diverse and information rich as it would have been if we had been able to employ a purposeful sampling strategy. The feasibility study sample had limited variation on certain domains (e.g., only three participants were women; only three participants lived alone; and the Modified Rankin Score for nine participants was three). Future research should seek to recruit from a wider range of geographical areas and clinical settings to allow for a more robust and comprehensive qualitative sampling strategy, and a more in-depth exploration of any issues of relevance to those specific domains for which our sample was limited.

CONCLUSIONS

Participants were able to differentiate the new KATS intervention from current rehabilitation practice, perceived it as relevant and fitting in the context of participants' rehabilitation journeys, and assessed it as worthwhile. There was variation in the amount of engagement with the range of behaviour change techniques offered by the intervention, but participants were able to tailor their experience of the intervention and make it work for them in different ways. Perceived benefits went beyond the element of promoting physical activity to include the emotional effect of not feeling alone, the motivational aspect of monitoring progress, and softening the sharp ending of rehabilitation/therapy services at the point of discharge. Future research will test the effectiveness of the KATS intervention in promoting physical activity and stroke recovery, including any associations with relevant social and emotional secondary outcomes, as well as explore more fully how social and behavioural mechanisms of action are experienced and enacted by participants.

AUTHOR CONTRIBUTIONS

Albert Farre: Conceptualisation; formal analysis; methodology; supervision; writing—original draft; writing—review and editing. **Jacqui H. Morris:** Conceptualisation; formal analysis; funding acquisition; methodology; supervision; writing—review and editing. **Linda Irvine:** Conceptualisation; formal analysis; funding acquisition; investigation; methodology; writing—review and editing. **Stephan U. Dombrowski:** Conceptualisation; funding acquisition; methodology; supervision; writing—review and editing. **Jenna P. Breckenridge:** Conceptualisation; funding acquisition; methodology; supervision; writing—review and editing. **Gozde Ozakinci:** Conceptualisation; funding acquisition; methodology; supervision; writing—review and editing. **Thérèse Lebedis:** Conceptualisation; supervision; writing—review and editing. **Claire Jones**: Conceptualisation; funding acquisition; software; supervision; writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data are available on reasonable request. Access to data can be arranged by contacting the study's Chief Investigator, Dr Jacqui H Morris (j.y.morris@dundee.ac.uk) to discuss data sharing, data requirements and conflicts of interest, in line with UK and other regulations, including ethics approvals.

DETAILS

Subject:	Exercise; Intervention; Physical fitness; Physical activity; Collaboration; Stroke; Home based; Research funding; Rehabilitation; Health boards; Feasibility studies; Qualitative research; Working groups; Complementarity; Health services; Feasibility; Behavior change; Participation; Messages; Workability; Community-based programs; Funding; Text messaging; Health promotion; Spouses; Short message service; Clinical outcomes; Bats; Flexibility; Community-based treatment; Medical personnel; Fitting; Interviews; Data collection; Design; Timing; Kindness
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Involving patients and caregivers to develop items for a new patient-reported experience measure for older adults attending the emergency department. Findings from a nominal group technique study

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ProQuest document link

ABSTRACT (ENGLISH)

Context

Patient experience is an important component of high-quality care and is linked to improved clinical outcomes across a range of different conditions. Patient-reported experience measures (PREMs) are psychometrically validated instruments designed to identify where strengths and vulnerabilities in care exist. Currently, there is no validated instrument available to measure patient experience among people aged over 65 years attending the emergency department (ED).

Objective

This paper aims to describe the process of generating, refining and prioritising candidate items for inclusion in a new PREM measuring older adults' experiences in ED (PREM-ED 65).

Design

One hundred and thirty-six draft items were generated via a systematic review, interviews with patients and focus groups with ED staff exploring older adults' experiences in the ED. A 1-day multiple stakeholder workshop was then convened to refine and prioritise these items. The workshop entailed a modified nominal groups technique exercise comprised of three discrete parts—(i) item familiarisation and comprehension assessment, (ii) initial voting and (iii) final adjudication.

Setting and Participants

Twenty-nine participants attended the stakeholder workshop, conducted in a nonhealthcare setting (Buckfast Abbey). The average age of participants was 65.6 years. Self-reported prior experiences of emergency care among the participants included attending the ED as a patient (*n*=16, 55.2%); accompanying person (*n*=11, 37.9%) and/or as a healthcare provider (*n*=7, 24.1%).

Results

Participants were allocated time to familiarise themselves with the draft items, suggest any improvements to the item structure or content, and suggest new items. Two additional items were proposed by participants, yielding a total of 138 items for prioritisation. Initial prioritisation deemed most items 'critically important' (priority 7–9 out of 9, *n*=104, 75.4%). Of these, 70 items demonstrated suitable inter-rater agreement (mean average deviation from the median <1.04) and were recommended for automatic inclusion. Participants then undertook final adjudication to include or exclude the remaining items, using forced choice voting. A further 29 items were included. Thirty-nine items did not meet the criteria for inclusion.

Conclusions

This study has generated a list of 99 prioritised candidate items for inclusion in the draft PREM-ED 65 instrument. These items highlight areas of patient experience that are particularly important to older adults accessing emergency care. This may be of direct interest to those looking to improve the patient experience for older adults in the ED. For the final stage of development, psychometric validation amongst a real-world population of ED patients is now planned.

Patient and Public Contribution

Initial item generation was informed using qualitative research, including interviews with patients in the ED. The opinions of patients and members of the public were integral to achieving outcomes from the prioritisation meeting. The lay chair of the Royal College of Emergency Medicine participated in the meeting and reviewed the results of this study.

FULL TEXT

INTRODUCTION

Patient experience is an important component of high-quality, patient-centred care and is associated with improved outcomes for a range of acute conditions including pneumonia, acute coronary syndrome and asthma.[1–3] Older adults currently account for about a quarter of emergency department (ED) attendances and this proportion is likely to increase further given the ageing global population.[4,5] Older adults may have a range of additional care requirements and psychosocial needs when accessing emergency care, compared to younger adults.[6,7] Capturing older adults' experiences of care may identify where vulnerabilities and subsequent opportunities for improvement in the provision of emergency care exist.

Patient-reported experience measures (PREMs) are validated, self-reported questionnaires that are directly reported by patients and aim to provide standardised evaluation of individual experiences of care. PREMs differ from patient-reported outcome measures (PROMs), which measure patients' views of their health status, and satisfaction surveys, which measure to what extent care meets patients' subjective expectations.[8,9] Hodson and Roberts[10] suggest that patient satisfaction measures often exhibit a ceiling effect, whereby responses are predominantly positive. Hence, satisfaction surveys may be less likely to identify negative determinants of experience compared to PREMs. This is important, as negative determinants of experience may represent particularly useful areas for performing quality improvement. As such, the use of PREMs to capture patient experiences of emergency care is suggested within the International Federation of Emergency Medicine framework for quality and safety in Emergency Medicine.[11] However, a systematic review of existing PREMs in emergency care determined that there was significant variation in the quality of existing instruments, including uncertain validity, reliability and responsiveness.[12] These findings are reflected in a further systematic review of 88 PREMs which reported inconsistent adherence to established criteria for the selection of health instruments.[13,14] Recently, PREMs have been developed to capture older people's experience of hospital and community care, although no instrument specific to the ED yet exists.[15,16] The PREM for patients attending the ED, aged over 65 (PREM-ED 65) aims to address the current gap, by developing and validating a PREM for use in older adults accessing emergency care. The first stage of PREM-ED 65 development aimed to generate a comprehensive understanding of determinants of older adults' experiences of receiving ED care. Initially, a systematic review of qualitative studies was conducted leading to the formulation of a conceptual framework for patient experience in the ED.[17] This framework highlighted the importance of meeting patients' communication, emotional, care, physical/environmental and waiting needs. Confirmation of conceptual validity and expansion of the framework was then achieved by undertaking semi-structured interviews with older adults during an emergency care episode, and focus groups with staff responsible for the provision of emergency care to older adults across three EDs.[18,19]

This study aims to describe the process of generating and prioritising a list of suggested items for PREM-ED 65 by involving multiple stakeholders including patient and public representatives, healthcare professionals and advocates for older adults.

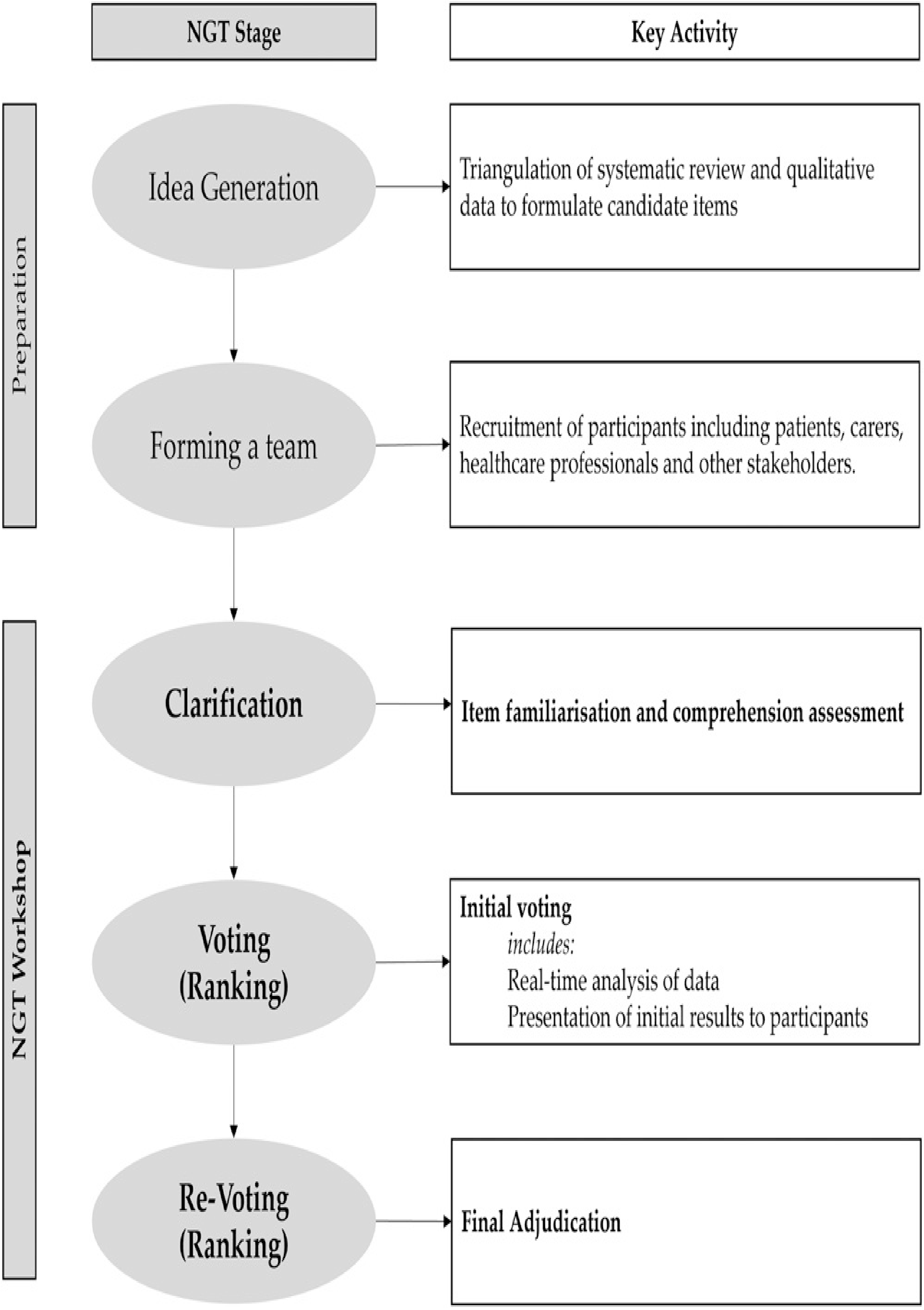
MATERIALS AND METHODSItem generation

An initial list of candidate items was developed by two researchers (B. G. and J. M. L.) following methodological triangulation of findings from prior studies conducted by the research team. These consisted of a qualitative metasynthesis of 22 studies of patient experience in the ED[17]; interviews conducted with 24 patients aged over 65 attending the ED[18]; and interprofessional focus groups with 37 ED staff.[19] Methodological triangulation describes the use of multiple data sources to study a phenomenon, and is useful to confirm findings, enrich data and increase overall validity.[20] Therefore, similar findings that occurred across more than one of the studies were identified as particularly relevant as a focus for future measurement of older adults' experiences of ED care. Item generation focused on these recurrent areas. To enrich understanding, excerpts of relevant findings were highlighted, extracted and grouped together. Each group of excerpts was then summarised by the two researchers and translated into a single suggested item for inclusion in PREM-ED 65. To ensure the conceptual underpinnings of the study were respected, the research team discussed the meaning of each item and categorised each item according to one of the five analytical themes: communication, emotional, waiting, care needs, physical and environmental needs, or team attitudes and behaviours.

Following identification, the wording of each of the draft items was subjected to a readability assessment, accomplished by calculating a Flesch Reading Ease (FRE) score. The FRE provides a simple formula for assessing semantic difficulty and is commonly used to interpret the readability of health information.[21] The score signifies how easy a statement is to read on a scale of 0 (*most difficult* [postgraduate reading level]) to 100 (*least difficult* [9-year-old reading level]). Typically, a score of 70 is assumed to be accessible to the average adult.[22] In practical terms, this represents the reading age of an average 12-year-old. Therefore, candidate items with a score of less than 70 at the initial assessment were modified by simplifying the vocabulary, syllable count and structure of the statement. Readability was considered satisfactory when a postadjustment score of greater than about 70 was attained.

Prioritisation of items

A 1-day workshop was held with multiple stakeholders (*n* = 29) to prioritise the list of candidate items. The day was structured using an adaptation of the nominal groups technique (NGT). The NGT provides a recognised method of gaining group consensus using a combination of discussion and voting. A particular advantage of NGT over other consensus methods is that it can provide a prompt result.[23,24] The workshop programme consisted of (i) item familiarisation and comprehension assessment, (ii) initial voting and (iii) final adjudication (Figure 1).



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A range of approaches was used to recruit a convenience sample of patients, carers, health professionals and relevant third-party stakeholders. This included e-mail advertisements to members of patient groups affiliated to local hospitals, clinical research departments and the ambulance service. Information posters were also displayed in three participating EDs. In addition, the lead researcher (B. G.) promoted the workshop to members of the public at a research engagement event during September 2019, directly approaching stakeholders including relevant charities advocating for older adults (Age UK; Healthwatch) and the lay committee of the Royal College of Emergency Medicine. Upon receipt of an initial expression of interest, potential participants were emailed a formal electronic invitation consisting of a participant information sheet, written consent form and registration form. Participants were issued with joining instructions on receipt of their registration form.

The workshop was held in the conference facilities of a nonhealthcare setting (Buckfast Abbey), in December 2019. No incentive was offered but refreshments including lunch were provided, and participants' travel expenses were reimbursed.

The workshop programme was designed to minimise both participant burden and the potential for respondent fatigue during prioritisation exercises. It was recognised that some participants would be living with frailty or disability and provisions for ease of access were ensured during planning. The pace of sessions was monitored by five facilitators distributed throughout the room, and extended breaks were provided.

The study received prospective ethical approval from the University of Plymouth Faculty of Health Research Integrity &Ethics Committee (1920/1173).

Item familiarisation and comprehension assessment

For the first workshop exercise, participants were asked to provide a comprehensibility assessment of items. For each item, participants were asked to determine whether the item was (i) ‘easy to read’ (Yes/No) and (ii) ‘easy to understand’ (Yes/No). Participants were invited to suggest new items if any gaps were identified.

Initial voting

The second workshop exercise was initial prioritisation. During this voting exercise, participants were presented with each item and asked to individually vote on the perceived importance for inclusion in PREM-ED 65. This was accomplished using a nine-point interval scale; priorities 1–3 were labelled ‘less important’, priorities 4–6 as ‘Important, but not critical’ and 7–9 were ‘Critically Important’.

The median priority and measure of inter-rater agreement (absolute deviation from the median [ADM]) was calculated for each item.[23,25] The mean ADM (MADM) across all items was then calculated, and individual items with an ADM greater than 50% of the mean value were deemed as having insufficient inter-rater agreement. This was used to determine whether the item was eligible for inclusion, exclusion or final adjudication in a second round of voting (Table 1). Data collection and analysis for initial voting was accomplished in real-time by members of the research team (F.B. and B.G.) using a preformulated instrument developed in Microsoft Excel.

Table 1 Criteria for initial prioritisation.

Priority to include item in PREM-ED 65$^{\text{(median score/item)}}$	Inter-rater agreement$^{\text{(MADM)}}$	Outcome
7–9 (Critical)	Sufficient	Include item
	Insufficient	Final adjudication
3–6 (Important, but not critical)	Any	
1–3 (Not important)	Insufficient	
	Sufficient	Exclude item

Note: Insufficient Inter-rater agreement threshold = MADM >50%. Abbreviations: MADM, mean absolute deviation from the median; PREM, patient-reported experience measure. **Final adjudication**

The third workshop exercise was the final adjudication. This consisted of dichotomous voting for items which did not meet inclusion or exclusion criteria during the first round. During this exercise, participants were presented with the item and requested to vote to either 'include' or 'exclude' the item. To facilitate inclusion of only those items for which there was clear positive consensus, a majority threshold of at least 75% was prospectively agreed to determine the criteria for inclusion. This threshold is comparable with other studies.[26,27]

Participant evaluation

Participants were invited to complete an optional 10-item anonymised paper-based survey at the end of the workshop. This aimed to evaluate overall satisfaction with the NGT process, the ability to meaningfully participate and invite suggestions for future improvements.

RESULTSInitial item generation

One hundred and thirty-six suggested items were derived following triangulation of findings from the metasynthesis, interviews with patients and focus groups with ED staff. Compared to the original conceptual framework, candidate items most frequently aligned to the themes of communication needs (33 items), care needs (33 items) and emotional needs (27 items). A smaller number of items concerned waiting needs (18 items), physical and environmental needs (15 items) and team attitudes and values (10 items).

Each of the initial 136 suggested items was tested against the FRE score. The median FRE score for the 136 items preadjustment was 67.3 (range: 11–100), equating to a reading age of about 15 years. Items with a score of less than 70 (*n* = 68) were individually adjusted with the intention of increasing readability. Adjusted items were then reviewed by the researchers to ensure meaning and construct validity was maintained. Following the adjustment of items, the median FRE score of the participants increased to 80.3 (range: 66–86). The initial list of candidate items is available in Electronic Supporting Information Material S1.

Workshop participants

Twenty-nine participants attended the consensus workshop (Table 2). The median age of professional participants was 55 years (range: 32–58 years) and lay participants was 73 years (range: 63–82 years). Eighteen participants (62.1%) were female. The majority were from a managerial or professional background (72.4%, *n* = 21). Participants were surveyed on any previous engagement with emergency care. Twenty-seven participants (93%) had experience of emergency care either as a patient (*n* = 16, 55.2%) and/or as an accompanying person (*n* = 11, 37.9%). A further seven (24.1%) participants reported experiences as a health professional, and eight (27.6%) in another professional role, for example, as a third-sector representative from a patient advocacy organisation. Other experiences (*n* = 14, 48.2%) included voluntary positions in the ED, with affiliated charities and research 'patient and public involvement' group members. Additionally, 11 (37.9%) participants reported currently receiving care for at least one long-term health condition. Participant characteristics are summarised in Table 2.

Table 2 Participant characteristics.

Characteristic	*n* (%)
Gender	
Male	11 (37.9)
Female	18 (62.1)
Age (years)	
<35	1 (3.4)

36–55	4 (13.8)
56–65	4 (13.8)
66–75	15 (51.7)
76–85	3 (10.3)
Not disclosed	2 (6.9)
Median age	71 years
Professionals	55 years
Lay participants	73 years
Occupation	
Not specified	4 (13.8)
Unskilled or semi-skilled	0 (0)
Skilled or technical	1 (3.4)
Professional or managerial	21 (72.4)
Voluntary/honorary role	3 (10.3)
Personal experience of emergency carea	
Yes	29 (100.0)
As patient	16 (55.2)
As accompanying person	11 (37.9)
As health professional	7 (24.1)
As third sector worker	8 (27.6)
Other	14 (48.3)
Personal experience of long-term condition	
Yes	11 (37.9)

No	14 (48.3)
Not disclosed	4 (13.8)

a
Sum of responses does not equal 100% as participants were asked to report all experiences of emergency care.

Item familiarisation and comprehension assessment

To reduce the burden on participants, the 136 items were divided between four groups (34 items/group). Each group was facilitated by either a member of the study team or a volunteer who was a final-year medical student. All facilitators received prior training in the study protocol and NGT method. Group members were encouraged to assess allocated items for comprehension using a 'think aloud' technique, led by a group facilitator.[28] All items were retained and were assessed as being easy to comprehend. Two additional items were added and agreed between participants, both following a large group discussion relating to the perceived importance of recognising disabilities in the ED (Quotations 1 and 2).

My disability did not get in the way of my care.

Staff recognised my hidden disability.

Quotations 1 and 2: Additional items suggested by participants.

As a result, a final list of 138 items was generated.

Initial voting

The final list of 138 items underwent initial prioritisation. Each workshop participant rated the priority of each of the items using the predetermined nine-point scale.

The median priority assigned to items was 8 out of 9 (range: 1–9, interquartile range = 6). Most items were considered 'critically important' (priority 7–9, *n* = 104, 75.9%). Only four items (3.1%) were considered 'less important' (priority 1–3). The remaining items were 'important but not critical' (priority 4–6, *n* = 29, 21.1%).

Items meeting the threshold for the satisfactory inter-rater agreement were eligible for automatic inclusion or exclusion in the first round. This was calculated as <50% of the overall mean average deviation from the median (MADM, <1.04).

Real-time data analysis of first-round prioritisation data yielded 70 (50.7%) items meeting criteria for automatic inclusion in PREM-ED 65 (priority 7–9 and MADM <1.04). By way of example, the highest ranking 10 items are presented in Table 3. All remaining items (*n* = 68, 49.2%) required further voting; this included the four items identified as less important, as inter-rater agreement was insufficient to justify automatic exclusion.

Table 3 Top 10 ranking items included via initial prioritisation (presented in rank order based on median priority and then inter-rater agreement (MADM).

Item	Median priority	MADM
Staff who were learning were always supervised.	9	0.11
The pain relief medicine worked well.	9	0.19
I could trust the A&E staff.	9	0.3
Pain relief medicine was brought to me quickly.	9	0.3
Staff were thorough and paid attention to the finer details.	9	0.33

Someone asked me about my views on being revived should my heart stop.	9	0.44
The A&E team were respectful and polite.	9	0.46
My disability did not get in the way of my care.	9	0.46
I felt like staff had reached the right diagnosis.	9	0.48
Staff undertook checks to make sure my skin was not at risk of damage.	9	0.48

Abbreviations: A&E, accident &emergency (ED); MADM, mean average deviation from the median.

Item final adjudication

The 68 remaining items were subjected to final adjudication. Of these, 39 (57.3%) items received insufficient favourable votes, resulting in their suggested exclusion from the PREM-ED 65. The lowest ranked 10 items are presented in Table 4. Notably, all four of the items originally prioritised as 'less important' were excluded during this round (average proportion of 'favourable' votes for these items, 32.4%).

Table 4 Bottom 10 ranking items, excluded via final adjudication.

Abbreviations: A&E, accident &emergency (ED); MADM, mean average deviation from the median.

Final prioritised list of candidate items for inclusion in PREM-ED 65

An additional 29 items were prioritised for inclusion because of final adjudication. Hence, a total of 99 out of 138 items remained eligible for inclusion in the instrument, representing 71.7% of the original items.

The finalised full prioritised list of included and excluded items are presented in Electronic Supporting Information Material S2.

Participant evaluation

A total of 27 out of the original 29 participants (93.1%) returned completed evaluation surveys. Overall satisfaction with the NGT workshop was high among all groups, extending to the quality of the information provided during the day (100% 'Good'/'Very Good'), perceived relevance of the day to prioritising experience in the ED (100% 'Agree'/'Strongly Agree'), and ability to engage/'have an adequate say' during the day (100% 'Agree'/'Strongly Agree').

DISCUSSION

This paper describes the process of generating and prioritising a list of candidate items for the PREM-ED 65. There is currently no accepted gold standard for generating or prioritising items for inclusion in either PROMs or PREMs, despite this being an essential step to ensuring face validity, content validity and representativeness of items to the target population. Approaches include reviews of existing similar instruments, generation of expert consensus, interviews, use of focus groups and patient/public involvement strategies such as the utilisation of special interest groups.[29–32] Previous studies have confirmed the successful use of NGT both among populations of older people and multiple stakeholders.[33–37]

PREM-ED 65 represents the first instrument to attempt to measure older peoples' experiences of ED care. We defined our intended PREM user group based on numeric age, as this provides the single most convenient and accessible inclusion criteria to facilitate routine usage of the PREM amongst older adults in ED settings. An age exceeding 65 years is commonly used to identify older people in the UK setting.[38] A multiple methods approach has been employed for the generation and prioritisation of items. This aims to produce an item set that captures all potentially relevant determinants of experience for the intended population. Methodological triangulation of the literature, and primary qualitative data from both patient interviews and professional caregivers, succeeded in generating a comprehensive list of suggested items that is well aligned to the original 'needs-based' conceptual framework of ED patient experience. Presentation of the items to multiple stakeholders confirmed comprehensibility and indicated that the original list was likely to be representative of older peoples' experiences in the ED. The emergence of two additional items, through group discussions, ensures that PREM-ED 65 will measure recognition of disabilities amongst older adults accessing emergency care. This may be important, particularly as the prevalence of disability increases with age. For example, self-reported disability among the UK population in 2022 was 9% in childhood, rising to 59% in adults aged over 80 years.[39] Specific to emergency care, Tanderup et al.[40] included the presence of disability as a discrete geriatric condition when evaluating characteristics of older adults attending an ED in Denmark. In this study, the presence of one or more geriatric conditions was associated with poorer health outcomes following ED attendance. Furthermore, improving transitions from ED care to community settings may prevent functional decline and increased disability that occurs in older adults following ED attendance.[41,42]

Our experience is that conducting NGT amongst a population of older adults is an achievable and rewarding means to effectively prioritise items for inclusion within a PREM. Using this approach it was possible to assess and prioritise all items within a single day. To this end, NGT may be more efficient than other consensus-building methods, most notably the Delphi method, where ongoing participant engagement is required during multiple asynchronous rounds of voting, often spanning months in duration. This requires high levels of participant engagement throughout the process, to avoid attrition.[43] Furthermore, NGT may yield the highest levels of accomplishment and satisfaction compared to either the Delphi method or unstructured groups.[44] This is reflected in the high satisfaction reported amongst participants in this study, as reported through postevent feedback.

For the NGT, the first round prioritisation revealed that most candidate items were deemed of ‘critical’ importance. Therefore, the method was effective in identifying very high-priority items for inclusion in the instrument—that is, those assigned 7–9 out of 9 and meeting the predetermined criteria for inter-rater agreement. The highest-ranking items related to themes including supervision of trainees, effectiveness of pain management, trustworthiness and communication skills of caregivers. Specific to older adults, participants agreed that assessment of tissue viability (‘staff undertook checks to make sure my skin wasn't at risk of damage’) was of critical importance. The latter is reflected in recent literature, highlighting that prolonged ED length-of-stay is independently associated with the development of hospital-acquired pressure sores. In the current international context, where ED crowding and prolonged length-of-stay is the norm, adequate tissue viability assessment and pressure sore prevention during the ED stay is essential.[45] Additionally, the importance of many of the other themes are prominently recognised in the literature. For example, stakeholders within this study were almost unanimous in emphasising the importance of clinical supervision for trainees in ensuring an optimal experience. Indeed, supervision of trainees in the ED has been recognised as essential to both ensuring patient safety, and facilitating clinicians' professional development.[46] In relation to pain management, older people may be more susceptible to receiving inadequate pain relief in the ED, compared to younger patients.[47]

Although the first round of voting was very effective in highlighting items for inclusion, it was not possible to exclude any item using this initial round, and it was, therefore, necessary to proceed to a round of dichotomous voting. Through the application of forced choice, it was possible to identify 38 items for exclusion. Examples of themes related to the lowest ranking items related to social communication (e.g., ‘I could chat or speak with other patients’), perceptions of the ED environment and patient empowerment.

The exclusion of unnecessary, unhelpful or otherwise redundant candidate items represents an important stage in the development of user-friendly health surveys. It is generally recognised that overly lengthy or cumbersome health surveys negatively affect participant engagement, potentially contributing to nonresponse bias, incomplete responses and satisficing to ‘reduce the cognitive burden of choosing’.[48,49] Each of these factors may adversely affect the validity of results, potentially compromising instrument credibility.[50] Furthermore, shortened questionnaires have been shown to effectively measure experiences of care.[51] The NGT has provided an initial means of reducing items for PREM-ED 65.

To validate the psychometric properties of PREM-ED 65, a quantitative study will be conducted with a population of ED patients. This study will aim to confirm how each item performs in a real-world setting by assessing participant engagement, floor/ceiling effects and differential validity of the items. Any items with low engagement or problematic validity will be removed to reduce the length of the questionnaire. The remaining items will undergo exploratory factor analysis to confirm structural validity. Additionally, the study will assess the internal consistency of measurement scales and test–retest reliability. The goal is to make PREM-ED 65 suitable for assessing the experiences of a wide range of older adults in the ED.

Limitations

The generation of candidate items from the primary literature and qualitative data is based on subjective interpretation. Participant engagement in the workshop activities was adequate throughout, and the aims achieved. We utilised multiple recruitment channels to include opinions from various stakeholders. We were mindful of promoting inclusivity among older adults in attendance by carefully selecting the venue and workshop programme. However, we acknowledge the limitations of convenience sampling. Notably, all participants in our study were White British and mostly from higher socioeconomic backgrounds (professional/managerial occupations). This apparent lack of diversity is reflective of the demography of the study locality, but nonetheless may affect the generalisability of results to ethnic minority groups, as well as individuals with limited literacy, and those from lower socioeconomic backgrounds. As an inclusive patient-public workshop, we did not measure participants' level of frailty or use this as an inclusion criterion for the study; however, we recognised the possibility that severely frail people may be underrepresented in our sample. We aimed to mitigate this potential bias by including participants who were carers or professional advocates for people living with severe frailty, such as the manager of a dementia care centre, an older peoples' falls service lead, nursing and allied health professionals. As it remains important for PREM-ED 65 to capture the experiences of the diverse population of older adults attending the ED, recruitment of a representative cross-section of older adults attending the ED will be prioritised during psychometric validation.

In our study, initial voting did not eliminate items. We suggest that actively encouraging nuanced discussion between participants, during the clarification stage of the NGT, may help enable differentiation of items earlier in the process. The lower priority assigned to some aspects of patient experience during final adjudication is incongruent with the importance assigned within the literature or by interview or focus group participants. Notably, workshop participants deprioritised items related to social interactions, shared decision making and physical comfort within the ED waiting room. This may be related to the sampling issues already discussed, but also potentially the phenomenon of rosy retrospection, which describes the cognitive tendency to both anticipate events and view the past more positively than was encountered.[52] As such, it is possible that some aspects of experience—such as the comfort of waiting room chairs, or the friendliness of staff—assume a much greater importance whilst ‘living’ an ED experience, as opposed to abstracting an experience during a workshop conducted in a nonhealthcare setting.

General concerns related to group-based idea generation include individual dominance, ‘groupthink’, where a desire for group harmony impedes the generation of new ideas, or ‘peer pressure’, where fear of criticism may have a similar effect. The nominal group technique effectively aims to limit these phenomena, by incorporating a combination of independent ideas generation, group discussion and individual voting. Specifically, nominal groups discourage a ‘single train of thought’ as might occur in unstructured group discussions.[53] Crucially, all participants in this study reported that they felt able to have an adequate say during the course of the workshop.

CONCLUSIONS

This paper describes a straightforward process for generating and prioritising candidate items as part of the development of an outcome measure instrument. The techniques described may be applicable to the development of other PREMs, PROMs and health surveys. The nominal group technique is both an effective and efficient method for identifying and prioritising critically important items for an instrument. However, forced choice adjudication may be necessary as a means of confirming items that are potentially redundant or unnecessary.

Findings from this study highlight areas of patient experience that are likely to be particularly important to older adults when attending the ED. In particular, the themes contained within the highest priority candidate items may be of direct interest to clinicians and policymakers concerned with improving the experiences of older adults accessing emergency care. In general, ongoing research is required to confirm the most reliable means to generate and prioritise items for inclusion in patient-reported measures. This is necessary to ensure optimum face validity, content validity and reliability of all future instruments. As for PREM-ED 65, the final stage of development will consist of psychometric testing amongst a population of older adults attending the ED.

AUTHOR CONTRIBUTIONS

Blair Graham conceived and led the design of the study. Jos Latour and Jason E. Smith assisted with the design of the study. Blair Graham and Ffion Barham undertook data collection during the workshop. Blair Graham led the analysis and interpretation of data, and the development of the article. All authors contributed to the interpretation of the data and finalised the article.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

This study received institutional approval from the University of Plymouth (19/20 1173). Written informed consent was obtained from all study participants.

DETAILS

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Co-development of a school-based and primary care-based multicomponent intervention to improve HPV vaccine coverage amongst French adolescents (the PrevHPV Study)

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ABSTRACT (ENGLISH)

Introduction

Despite various efforts to improve human papillomavirus (HPV) vaccine coverage in France, it has always been lower than in most other high-income countries. The health authorities launched in 2018 the national PrevHPV research programme to (1) co-develop with stakeholders and (2) evaluate the impact of a multicomponent complex intervention aimed at improving HPV vaccine coverage amongst French adolescents.

Objective

To describe the development process of the PrevHPV intervention using the GUIDance for rEporting of intervention Development framework as a guide.

Methods

To develop the intervention, we used findings from (1) published evidence on effective strategies to improve vaccination uptake and on theoretical frameworks of health behaviour change; (2) primary data on target populations' knowledge, beliefs, attitudes, preferences, behaviours and practices as well as the facilitators and barriers to HPV vaccination collected as part of the PrevHPV Programme and (3) the advice of working groups involving stakeholders in a participatory approach. We paid attention to developing an intervention that would maximise reach, adoption, implementation and maintenance in real-world contexts.

Results

We co-developed three components: (1) adolescents' and parents' education and motivation using eHealth tools (web conferences, videos, and a serious video game) and participatory learning at school; (2) general practitioners' e-learning training on HPV using motivational interviewing techniques and provision of a decision aid tool and (3) easier access to vaccination through vaccination days organised on participating middle schools' premises to propose free of charge initiation of the HPV vaccination.

Conclusion

We co-developed a multicomponent intervention that addresses a range of barriers and enablers of HPV vaccination. The next step is to build on the results of its evaluation to refine it before scaling it up if proven efficient. If so, it will add to the small number of multicomponent interventions aimed at improving HPV vaccination worldwide.

Patient or Public Contribution

The public (adolescents, their parents, school staff and health professionals) participated in the needs assessment using a mixed methods approach. The public was also involved in the components' development process to generate ideas about potential activities/tools, critically revise the successive versions of the tools and provide advice about the intervention practicalities, feasibility and maintenance.

FULL TEXT

INTRODUCTION

Human papillomavirus (HPV) infection is the most common viral infection of the reproductive tract and a major public health issue.[1,2] Depending on HPV genotypes, persistent HPV infections can cause anogenital warts (HPV 6/11), precancerous lesions of the cervix, vagina, vulva, anus, penis and head and neck, which may sometimes progress to cancers.[3] The two most common ‘high-risk’ genotypes (HPV 16/18) cause about 70% of all cervical cancers, the most common HPV-related cancers.[2] It is the fourth most frequent cancer in women worldwide, accounting for 604,127 new cases and 341,831 deaths in 2020 (respectively, 3379 and 1452 in France).[4,5]

Vaccination is the most effective primary prevention strategy against HPV infection.[2,5] Bivalent, quadrivalent, and nonavalent vaccines have been marketed. All vaccines target HPV 16/18, while the quadrivalent vaccine also targets HPV 6/11 and the nonavalent one adds five oncogenic types.[2] HPV vaccination programmes have shown substantial impacts on HPV infections, anogenital warts and high-grade precancerous cervical lesions.[6–9] They have also recently been associated with a reduced risk of invasive cervical cancer.[10,11] HPV vaccines have an ‘excellent safety profile’ according to the World Health Organisation.[2]

Since 2006, most high-income countries have introduced HPV vaccination in their vaccination schedules for adolescents, either for girls only or for girls and boys, depending on the country.[12,13] In France, HPV vaccination was introduced for girls in 2007 and the nonavalent vaccine is now recommended to all adolescents aged 11–14 years. Despite various efforts by health authorities to improve HPV vaccine uptake,[14,15] complete HPV vaccine coverage has always been lower than in most other high-income and European countries,[12,13] estimated at 23.7% amongst 16-year girls in 2018[16] (see details on the French context in Section 2.1).

In this context, the French Institute for Public Health Research (IReSP) and the theme-based multiorganisation institutes for cancer and for public health (ITMO Cancer and ITMO Public Health) launched in 2018 a national research programme to improve HPV vaccine coverage amongst French adolescents (The PrevHPV Programme—https://iresp.net/presentation-du-projet-prevhpv/). This programme is conducted by a consortium of eight French research teams with expertise in epidemiology, public health, primary care, health psychology, infectious diseases, health economics and biostatistics (The PrevHPV Consortium—see list in Supporting Information Materials: Appendix A) and funded as part of the National Cancer Plan 2014–2019. The aim of the PrevHPV Programme was to (1) co-develop with stakeholders and (2) evaluate the impact of a multicomponent complex intervention[17] that targets several population groups and organisational levels.

The objective of the present article is to describe the development of the PrevHPV intervention. The protocol for the evaluation of its effectiveness, efficiency and implementation (NCT 04945655) has been described in detail elsewhere.[18]

METHODS

We describe the development of the PrevHPV intervention using the GUIDance for rEporting of intervention Development (GUIDED) framework as a guide[19] (see completed GUIDED checklist in Supporting Information Materials: Appendix B). In accordance with this framework, we first describe the context in which the intervention was developed.

Context of the PrevHPV intervention

In France, HPV vaccination was initially recommended for girls aged 14 years,[20] then for girls aged 11–14 years[21]; in 2021, it was included in the vaccine schedule for all adolescents, girls and boys, aged 11–14 years.[22] The currently recommended vaccine is the latest nonavalent one with two injections 6 months apart. A catch-up with three injections is possible up to age 19 and for men having sex with men up to age 26.

HPV vaccination in France depends on persons' initiative, requires parental authorization for those under 18 years, and is prescribed and administered by physicians or midwives; in practice, general practitioners (GPs) are the main prescribers and providers of HPV vaccination, for both doses.[23] Since April 2022, under specific medical prescriptions, it can also be administered to individuals aged 16 or older by nurses or pharmacists trained in vaccination. There is currently no nationwide school-based vaccination programme in France. Care pathways to access vaccination often include several steps: for the majority of cases, adolescents and their parents must first get the vaccine prescription during an appointment with a physician, then go to a community pharmacy to obtain the vaccine, and finally, make another appointment with their physician for its administration. Occasionally, individuals will also get vaccinated at vaccination centres, but their geographical accessibility can be difficult. The HPV vaccine is costly (116 euros for 1 dose in 2022). It is only partially (65%) covered by the National Social Health Insurance but the financial barrier to access remains low as 95% of the population with complementary health insurance are fully reimbursed.

France has been one of the European countries with the highest percentage of the general population with low confidence in vaccine safety for a long time, and the recent 2020 data confirmed this fact.[24] Regarding the HPV vaccine, 32% of French mothers of adolescent girls agree that the HPV vaccine may lead to long-term health problems and 20% that it is unsafe.[25] This may partly result from controversies that occurred in France about HPV vaccine efficacy and safety (especially its suggested association with autoimmune diseases). Despite the accumulation of evidence that the HPV vaccine does not have severe adverse effects,[26–28] the French medical community has been debating the benefits and risks of the HPV vaccine, including possible concurrence with the Pap screening programme. Healthcare providers have an essential role in influencing parental decisions towards HPV vaccination.[25] Even if most of the French GPs (60%–70%) frequently recommend the HPV vaccine, some do not systematically mention the HPV vaccine with adolescents and their patients, especially GPs who are prone to vaccine hesitancy. About 25% of the GPs have doubts about HPV vaccine safety and/or efficacy and these doubts strongly influence their recommendation practices.[29–31] And even when GPs are convinced of the importance of HPV vaccination, they may face difficulties during interactions with patients: 80% of GPs acknowledge having difficulties in informing about HPV vaccination and convincing hesitant patients to get vaccinated.[29–31]

Purpose of the PrevHPV intervention development process

The overall aim of the PrevHPV intervention was to improve HPV vaccine coverage amongst French adolescents. The aim of the PrevHPV intervention development process was to develop an evidence-based and theory-based multicomponent intervention that addresses all identified barriers to HPV vaccination in France and had the potential to be implemented in routine and spread to the whole country.

Based on the scientific literature (see Section 2.5), three components were identified: adolescents' and parents' education and motivation (component 1); GPs' training (component 2) and easier access to vaccination (component 3).

Target populations

Target populations of the PrevHPV intervention included:

- 1.
  adolescents attending middle schools, typically aged 11–14 years, who are the main target population for HPV vaccination in France[22];
- 2.
  parents of adolescents attending middle school, who decide whether to vaccinate their child and
- 3.
  GPs, who prescribe most HPV vaccines in France,[23,32] and have a fundamental role in patients' decision-making process towards vaccination.[25,33]

Contribution of published intervention development approach

The UK Medical Research Council (MRC) framework for developing and evaluating complex interventions guided our overall approach to the development of the PrevHPV intervention. It recommends incorporating evidence and theories into the intervention development process.[17]

How evidence from different sources informed the intervention development process

To develop the PrevHPV intervention, we based our decisions on findings from published evidence, primary data collected as part of the PrevHPV Programme, and the advice of working groups involving stakeholders (see details in Section 2.9).

Published evidence

Facilitators and barriers to the uptake of HPV vaccination: The following facilitators of HPV vaccination have been identified in systematic literature reviews: recent or regular visits with a physician, physician recommendation, parental acceptance, peer encouragement and health insurance coverage. The identified barriers included the cost of the vaccine, parental concerns (child not sexually active, safety of the vaccine, belief that the vaccine will encourage sexual activity, preference to wait till their child is older) and lack of information/knowledge.[33–35]

A meta-analysis showed that physician recommendation had the greatest influence on parents' uptake of HPV vaccine for their child, followed by HPV vaccine safety concerns.[36]

Interventions to improve general vaccination rates amongst adolescents: We used the catalogue published by the European Centre for Disease Prevention and Control, which offers a collection of interventions that address vaccine hesitancy in general[37] and other published evidence (e.g., a review of the literature on adolescent vaccination[38]).

The evidence suggests that the use of a combination of different interventions (i.e., multicomponent/multilevel interventions, each component/level addressing an identified barrier) appears to be more effective than single-component interventions.[39] Of note, educational strategies based on motivational interviews implemented in maternity wards have been found effective in reducing vaccine hesitancy amongst parents of newborns; it may be a promising way to motivate hesitant individuals to accept vaccination.[40]

Interventions to improve HPV vaccination coverage: Less evidence is available for interventions aiming to increase HPV vaccine uptake. Interventions targeted (separately or in combination) adolescents, parents, health professionals and the environment.

Interventions targeting both parent's and adolescents' psychosocial factors (knowledge, beliefs, outcome expectations, intention to vaccinate) have shown promising results. Amongst interventions targeting health professionals, those which combined reminder and education were found to be more effective. Overall, substantial impacts were observed with multicomponent/multilevel interventions combining interventions at the parental/adolescent and provider levels.[41–46]

Strategies at the environmental level may take place in hospitals, postpartum units, schools and universities/community colleges.[43] In particular, evidence shows that most European countries with high HPV vaccine coverage such as Belgium Flanders, the United Kingdom and Scandinavian countries have implemented school-based vaccination programmes with no mandatory medical prescription.[13]

Potential of eHealth technologies to increase vaccination rates: An overview of systematic reviews led to a recommendation of using and evaluating eHealth technologies (i.e., information and communication technologies in support of health and health-related areas) to encourage immunizations and increase vaccination adherence.[47] eHealth tools (e.g., videos, websites, serious video games) are promising to improve HPV vaccine uptake.[48,49]

Primary data collected as part of the PrevHPV Programme

Before and during the development of the PrevHPV intervention, we carried out the PrevHPV diagnostic phase aimed at identifying knowledge, beliefs, attitudes, behaviours and practices, preferences, as well as the facilitators and barriers to HPV vaccination amongst four different population groups in France: adolescents, their parents, school staff (e.g., teachers, school nurses) and health professionals (GPs and health students). We also aimed at assessing the acceptability of school involvement in promoting the HPV vaccine and carrying out HPV vaccinations in schools.

We used a mixed methods approach and carried out quantitative cross-sectional online surveys, qualitative studies using focus groups and semistructured individual interviews, and discrete choice experiment (DCE).[50] Data were collected from January 2020 to May 2021. See Supporting Information Materials: Appendix C, for details on the number of participants in each survey/population group.

Results from this diagnostic phase informed the intervention development process, for example, those from the DCE study which used quantitative cross-sectional online surveys to estimate preferences and pretest communication contents amongst adolescents. It showed that a statement presenting a low vaccine coverage positively (‘Already one-third of pupils of your school have registered to get vaccinated’) was more effective than referring to insufficient coverage (‘Not enough pupils…’) to motivate vaccine acceptance (odds ratio [OR], 95% confidence interval: 1.48 [1.23, 1.78]). This was also the case of statements related to social conformism: ‘Most pupils of your school have registered to get vaccinated (80%)’ (OR: 1.98 [1.64, 2.38]) and ‘In some countries like England and Portugal, >80% of teens are vaccinated’ (OR: 1.94 [1.61, 2.35]). Prevention of cancer led to higher acceptance amongst girls compared to the prevention of genital warts, while the notion of sexual transmission had no substantial impact on either gender.[51]

How theory informed the intervention development processTheoretical frameworks

We developed the PrevHPV intervention using the Integrated Behavior Change (IBC) Model[52] as the theoretical background. Drawing from several previous theories (e.g., the Theory of Planned Behavior,[53] the Self-Determination Theory[54]), the IBC Model posits autonomous motivation (i.e., a person acts because he/she is convinced that a particular behaviour is good for his/her health) as a distal determinant of behaviour. The effects of autonomous motivation on behaviour are mediated by attitudes, subjective norms and perceived behavioural control which themselves determine intention. It thus ascribes much importance to people's need for autonomy, which, in the case of vaccination, can be supported by a healthy environment (e.g., during interactions with physicians). In addition, the IBC model stresses the role of action planning as a way to reduce the gap between intention and behaviour.

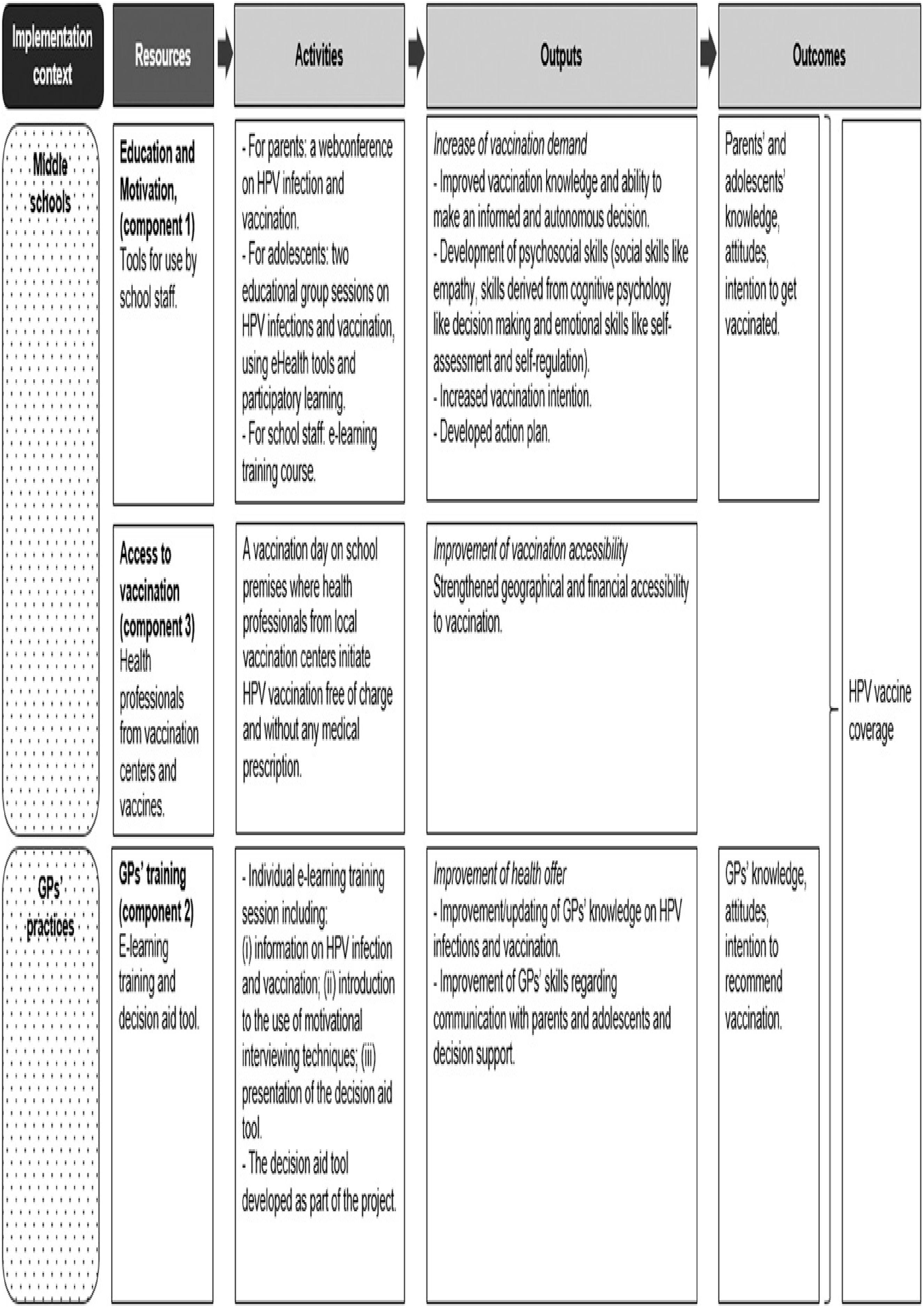
PrevHPV intervention theory

We developed a general logic model for the PrevHPV intervention (Figure 1) based on evidence from the literature (see Section 2.5) and the theoretical model presented above. The PrevHPV intervention comprises three components targeting the three key stakeholders involved in the HPV vaccination (adolescents, parents and health professionals):

- 1.
  Adolescents' and parents' education and motivation (component 1): it aims at increasing the vaccination demand through the development of adolescents' and parents' individual psychosocial skills, knowledge and their ability to make an informed and autonomous decision. The psychosocial skills can be divided into three categories: social skills (e.g., empathy, communication, advocacy); psychological skills from cognitive psychology (e.g., decision making) and emotional skills (e.g., self-assessment and self-regulation);

- 2.
  GPs' training (component 2): it aims at improving health offer, especially health professionals' recommendation for vaccination. On the one hand, it improves health professionals' knowledge of HPV and its prevention; on the other hand, it improves their skills in terms of communication with parents and adolescents using motivational interviewing techniques and decision support and

- 3.
  Easier access to vaccination (component 3): it aims at strengthening geographic and financial accessibility to vaccination by bringing the care environment into the school environment.



Implementation context	Resources	Activities	Outputs	Outcomes	
Middle schools	**Education and Motivation, (component 1)** Tools for use by school staff.	- For parents: a webconference on HPV infection and vaccination. - For adolescents: two educational group sessions on HPV infections and vaccination, using eHealth tools and participatory learning. - For school staff: e-learning training course.	*Increase of vaccination demand* - Improved vaccination knowledge and ability to make an informed and autonomous decision. - Development of psychosocial skills (social skills like empathy, skills derived from cognitive psychology like decision making and emotional skills like self-assessment and self-regulation). - Increased vaccination intention. - Developed action plan.	Parents' and adolescents' knowledge, attitudes, intention to get vaccinated.	HPV vaccine coverage
	Access to vaccination (component 3) Health professionals from vaccination centers and vaccines.	A vaccination day on school premises where health professionals from local vaccination centers initiate HPV vaccination free of charge and without any medical prescription.	*Improvement of vaccination accessibility* Strengthened geographical and financial accessibility to vaccination.		
GPs' practices	**GPs' training (component 2)** E-learning training and decision aid tool.	- Individual e-learning training session including: (i) information on HPV infection and vaccination; (ii) introduction to the use of motivational interviewing techniques; (iii) presentation of the decision aid tool. - The decision aid tool developed as part of the project.	*Improvement of health offer* - Improvement/updating of GPs' knowledge on HPV infections and vaccination. - Improvement of GPs' skills regarding communication with parents and adolescents and decision support.	GPs' knowledge, attitudes, intention to recommend vaccination.	

Enlarge this image.

Guiding principles during the intervention development process

Our main focus was to develop an effective intervention that would maximise reach (i.e., participation of the target population), adoption (i.e., participation of practices/schools), implementation and maintenance within French middle schools and GPs' practises, in accordance with the RE-AIM framework.[55]

For component 1 (adolescents' education and motivation), to minimize the cost of the intervention and maximize chances of maintenance, we developed activities and tools that can be implemented by regular school staff (e.g., school nurses, teachers). This includes an e-learning training course to help these professionals develop their knowledge and skills to conduct educational group sessions on HPV infections and vaccination. Besides, to develop the content of the tools, we followed the recommendations for health education amongst young people and included various educational methods: the provision of information, active participation and development of psychosocial skills.[56] In particular, we aimed at developing playful activities/tools to motivate the active and interactive participation of the adolescents to involve them in their learning.

Regarding component 2 (GPs' training), we took care to minimize the time required for GPs and maximize the accessibility of the training (online format) and ease of use of the decision aid tool.

For component 3 (easier access to vaccination), we aimed to develop documents (e.g., information sheets and consent forms for parents, templates of posters to inform pupils on school premises) that can be used in routine practice easily. We also facilitated the first contact between schools and vaccination centres and then let them discuss to organise the vaccination days.

How stakeholders contributed to the intervention development processSteering committee

A steering committee is in charge of supervising the progress of all aspects of the PrevHPV Programme, including the development of the multicomponent intervention, and meets once a year. It comprises the scientific leaders of the eight teams of the PrevHPV Consortium, as well as representatives of the following regional/national institutions: Inserm (French National Institute for Health and Medical Research), IReSP, ITMO Cancer AVIESAN, ITMO Public Health AVIESAN, INCa (French National Cancer Institute), Santé publique France (French Public Health Agency), Ministry of Health, Ministry of National Education and the Ile-de-France Regional Health Agency.

Working groups involving stakeholders

For each component of the intervention, we set up a working group comprising members of the consortium and several professional stakeholders (e.g., school nurses, staff from vaccination centres, GPs—see details in Table 1). Each group aimed at defining the organisation of the component (e.g., activities, duration, content, the role of each actor) and developing the tools for a participatory approach in a co-construction process.[57] They met virtually approximatively every month throughout the development process (January 2020 to June 2021). Stakeholders generated ideas about potential activities/tools together with members of the consortium, critically revised the successive versions of the tools and provided advice about the intervention practicalities, feasibility and maintenance.

Table 1 Stakeholders' involvement in the PrevHPV intervention development process.

Professional stakeholders participating in the working group	Other stakeholders involved in the intervention development process
Component 1: Adolescents' and parents' education and motivation	

Expert in education and health promotion (*n* = 1) Expert in public health, responsible for medical students' training (*n* = 1) Expert in education sciences (*n* = 2) School nurse technical advisor at the school district level (*n* = 1) Expert in serious video games' development (*n* = 2)	*Serious video game*: adolescents and parents of adolescents (*n* = 17) provided feedback on the serious video game's visual aspects, suitability and readability of the quizzes (questions, answers) through online questionnaires (March–April 2020). *Videos*: one medical student created the videos as part of a contest organised by the research teams (April–October 2020). *School staff handbook*: one teacher in life sciences and one school nurse technical advisor critically revised the handbook which describes activities to implement during sessions with adolescents (June 2021).
Component 2: General practitioners' (GP) training	
GP (*n* = 9)	*Decision aid tool—phase 1 (design)*: adolescents' knowledge, beliefs towards HPV and its vaccination, needs and expectations towards such a tool (e.g., content, visual aspects) were explored through online focus groups (*n* = 14 adolescents) (October–December 2020). *Decision aid tool—phase 2 (test of the alpha version)* Adolescents (*n* = 6) and parents of adolescents (*n* = 8) provided feedback on the decision aid tool through online focus groups and one individual interview (January–April 2021). *GPs* (*n* = 11) pilot tested the decision aid tool in real-life settings during 2-6 weeks and provided feedback to the research team through individual semistructured interviews (May–September 2021).
Component 3: Easier access to vaccination	
Medical staff from vaccination centres (*n* = 2) School nurse technical advisor at the school district level (*n* = 1) School psychologist (*n* = 1)	*Vaccination day poster*: adolescents (*n* = 5), one school nurse technical advisor at the school district level and one GP provided feedback on the poster (e.g., visual aspects, suitability) aimed at informing adolescents on the vaccination day in the school premises (June 2021).

Abbreviation: HPV, human papillomavirus.

During the development process of specific tools, other stakeholders (e.g., adolescents, parents of adolescents, health students) were involved to coproduce the tools and/or providing feedback on some features (e.g., length, suitability, readability, visual aspects) (see details in Table 1).

How the intervention changed in content and format from the start of the development process

Due to the iterative nature of the intervention development process, there were some changes in the intervention content and format throughout the development process.

Regarding the content, based on results from the PrevHPV diagnostic phase and discussions amongst working groups, we made special efforts to define the best way to communicate HPV and its vaccination amongst adolescents and their parents. For example, we presented HPV infection as a sexually transmitted infection, and have been careful to talk about cancer risks without inducing fear. Also, during the development of an eHealth tool targeting adolescents (a serious video game, see details below in Section 3.1) feedback from parents and adolescents also led to several changes to improve readability and suitability; minor changes included changing a word to an easier one or rewording some questions/answers that were hard to understand.

Regarding the format, a noticeable change was in the mode of delivery of the information action targeting parents of adolescents. We initially planned to organise face-to-face meetings on school premises. Due to the COVID-19 pandemic, we switched to online meetings.

RESULTS

The three components of the PrevHPV intervention are described below using the Template for Intervention Description and Replication checklist as a guide.[58] For more details, see the completed checklist in Supporting Information Materials: Appendix D.

Adolescents and parents' education and motivation (component 1)

This component is carried out in middle schools because schools occupy a great part of adolescents' life and offer a unique opportunity to reach most adolescents.

First, component 1 includes an online information group session (duration: 1 h 30 min) on HPV infection and vaccination for parents of adolescents attending middle schools. The web conference was delivered by two medical experts on HPV, using a standardised presentation. A discussion is opened for parents' questions and/or comments at half-time and at the end of the session. Parents can also access a replay of the web conference and additional information resources on HPV and its vaccination on an internet website developed as part of the project.

Second, adolescents from middle schools participate during school hours in two educational group sessions on HPV infections and vaccination, using a pedagogy based on active learning. These sessions (duration: 2 h each) are delivered by the school staff (e.g., nurses, teachers in life sciences) using an educational package comprising:

- 1.

  A handbook that describes activities to be implemented during each session. Each session consists of three activities based on eHealth tools (videos, serious video games), discussions/debates or role-playing to motivate the active and interactive participation of pupils. Between the two sessions, adolescents are invited to carry out a small investigation of knowledge and attitudes about HPV infection and vaccination amongst some of their relatives (see Supporting Information Materials: Appendix E, for more details);

- 2.

  Six short videos (12 min in total) and a fact sheet created by a medical student and

- 3.

  A serious video game accessible on an Internet website were developed as part of the project. This tool is a digital game applied to educate pupils on HPV infection and vaccination and is not primarily intended for entertainment purposes.[49]

Before the sessions, the school staff is encouraged to attend an e-learning training course developed as part of the project using the Wooclap platform. This includes presentations (e.g., on HPV infections, vaccinations, cervical cancer) and some quizzes (duration: 1 h).

GPs' training (component 2)

Component 2 consists of an individual e-learning training session for GPs i.e. accessible on computers and smartphones. Lasting 3 h, GPs are able to access the training whenever they want and then progress at their own pace.

The training includes 12 videos divided into three main parts:

- 1. Up-to-date information on HPV infections and vaccination (vaccine coverage, safety and efficacy);
- 2. An introduction to the use of motivational interviewing techniques in the field of vaccination (theory and practice through role-playing) and
- 3. A presentation of a decision aid tool developed as part of the intervention and explanations on how to use it during consultations. This tool, developed in accordance with the International Patient Decision Aid Standards,[59,60] aims at supporting hesitant parents/adolescents by making their decision about HPV vaccination explicit, providing information about options and associated benefits/harms, and helping clarify congruence between decisions and personal values.

Easier access to HPV vaccination (component 3)

Component 3 consists of one or several (depending on the number of parental consents returned) vaccination day(s) on the school premises during which health professionals (e.g., one physician and one nurse) from the local vaccination centre initiate HPV vaccination in accordance with safety and hygiene standards. Vaccination with the nonavalent HPV vaccine is offered free of charge without any prior medical prescription.

Before the vaccination day, school staff provide parents with information sheets and consent forms and then collect parents' written consents. They are also encouraged to display posters aimed at informing pupils about the vaccination day on school premises.

During the vaccination day, health professionals from the vaccination centre check the adolescents’ eligibility for vaccination (i.e., ≥11 years old, never vaccinated against HPV, with no contraindication to vaccination, and whose parents have given their written consent). They provide each vaccinated adolescent with several documents: a medical prescription for the second injection which will be performed by the adolescent's GP (or another health professional allowed to vaccinate against HPV) and a letter to inform her/him about the initiation of the HPV vaccination; a letter to his or her parents to confirm that he/she has been vaccinated and remind them of the vaccination schedule; and a letter to the pharmacist to inform her/him about the initiation of the vaccination.

DISCUSSION

In this paper, we described the development process of the PrevHPV school-based and primary care-based multicomponent intervention whose primary aim was to improve HPV vaccine coverage amongst French adolescents.

We described its development in a transparent and structured manner using the GUIDED checklist as recommended by the latest UK MRC framework for the development and evaluation of complex interventions.[61] This approach helps intervention developers/funders understand the context and methods that were used and make judgements about the quality and relevance of the intervention and whether to implement an intervention within their specific context. It also enables methodological lessons to be learned and incorporated into future intervention development studies.[19]

The PrevHPV intervention development process has several strengths. We used both published research evidence and results from the PrevHPV diagnostic phase on target populations' needs to develop a multicomponent intervention that addresses a range of barriers and enablers of HPV vaccination. It is in line with the behaviour change model ‘Capability, Opportunity and Motivation model of Behaviour’ which argues that three key components interact to generate behaviour: Capability (knowledge and skills), Opportunity (physical and social), and Motivation (reflective and automatic).[62,63] Besides, we used a participatory approach in a co-construction process involving adolescents, parents, GPs, staff from schools and vaccination centres in the activities/tools development.[57] We also involved regional and national stakeholders (e.g., policymakers, funders) throughout the development process. We have also systematically paid attention to the future implementation of the intervention in a real-world context. This approach is recommended to develop new interventions that have a better chance of being effective when evaluated and then of being adopted widely in the real world.[64] One limitation of the intervention development process is that it was conducted during the COVID-19 pandemic. As schools were closed from March to May 2020 in France, the collection of primary data (the PrevHPV diagnostic phase) had to be delayed. The pandemic context has also limited the availability of stakeholders and the opportunities to involve them in face-to-face interviews/meetings. This has finally required great adaptability from all professionals involved in the development process to maintain collaborative work through online meetings. In addition, the stakeholders involved in the development process were volunteered and thus probably particularly interested in the topic and supportive of the HPV vaccination. It would have been helpful to test the intervention tools amongst vaccine-hesitant people as well.

At the end of the intervention development process, we have a good understanding of the rationale of the PrevHPV intervention and the underpinning evidence and theory. We provided professionals (e.g., school staff, experts, GPs) with guidelines and tools that they can apply with some flexibility to take into account the constraints and the schools/GPs' practises environment.[65] However, uncertainties remain regarding its reach (regarding parents' participation in the web conference, adolescents' participation in the vaccination day at school, and GPs' participation in the e-learning training), dose and fidelity (regarding the two 2-h sessions for adolescents). Results from the evaluation of the effectiveness and implementation of the PrevHPV intervention[18] will help refine the intervention before, if efficient, scaling it up.

CONCLUSION

This paper uses the GUIDED checklist to describe the development process of the PrevHPV school-based and primary care-based multicomponent intervention aimed at improving HPV vaccine coverage amongst French adolescents. The next step is to build on the results of the evaluation of the PrevHPV intervention[18] to refine it before providing tools and recommendations for a nationwide scale-up.

AUTHOR CONTRIBUTIONS

Morgane Michel, Anne-Sophie Le Duc-Banaszuk, Karine Chevreul, Aurélie Gauchet, Bruno Giraudeau, Judith E. Mueller, Amandine Gagneux-Brunon and Nathalie Thilly conceived the protocol of the PrevHPV Programme. Amandine Gagneux-Brunon led the development of the adolescents and parents' education and motivation component with input from Aurélie Bocquier, Sébastien Bruel, Stéphanie Bonnay, Marion Branchereau, Sandra Chyderiotis, Aurélie Gauchet, Judith E. Mueller and Nathalie Thilly. Sébastien Bruel and Dragos-Paul Hagiu led the development of the decision aid tool and contributed to the development of the general practitioners' training component. Anne-Sophie Le Duc-Banaszuk and Marion Branchereau led the development of access to vaccination in the school component with input from Aurélie Bocquier, Stéphanie Bonnay, Aurélie Gauchet and Amandine Gagneux-Brunon. Stéphanie Bonnay facilitated the partnership between the teams of the consortium and with the steering committee. Aurélie Bocquier and Nathalie Thilly drafted the first version of the manuscript and all authors provided comments and feedback for improvement of the manuscript. All authors approved the final version of the manuscript.

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The PrevHPV Study group includes the authors of the present manuscript, for team 1: Nelly Agrinier, Estelle Fall; for team 2: Marie Ecollan, Serge Gilberg, Josselin Le Bel, Henri Partouche, Juliette Pinot, Louise Rossignol, Arthur Tron, Minghui Zuo; for the team 3: Julien Ailloud, Julie Bros, Olivier Epaulard, Catherine Juneau, Gaëlle Vareilles; for team 5: Elisabeth Botelho-Nevers, Emily Darlington, Géraldine Jambon, Florian Jeanleboeuf, Julie Kalecinski, Christine Lasset, Laetitia Marie Dit Asse, Mabrouk Nekaa; for team 7: Anne-Sophie Barret, Isabelle Bonmarin, Daniel Levy-Bruhl, Jocelyn Raude, Jonathan Sicsic; for team 8: Bruno Giraudeau; Clémence Castagnet (Inserm/PRC) and Mélanie Simony (IReSP).

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of the PrevHPV diagnostic phase are available from the French National Institute for Health and Medical Research (Inserm) but restrictions apply to the availability of these data, which are not publicly available. Data are, however, available from the authors upon reasonable request and with permission of the Inserm. The reuse of data is subject to compliance with the General Data Protection Regulation and French regulations.

ETHICS STATEMENT

The PrevHPV diagnostic phase was granted approval by the Evaluation Committee of Inserm, the Institutional Review Board (IRB00003888, IORG0003254, FWA00005831) on 10 December 2019. All study participants gave their informed nonopposition to participation, in line with French legal guidelines.

DETAILS

Subject:	Intervention; Vaccines; Adolescents; Drug stores; Primary care; Human papillomavirus; Schools; Stakeholders; Feasibility; Behavior change; Parenthood education; Health behavior; Public health; Family physicians; Children &youth; Teenagers; Computer &video games; Infections; Cancer; Maintenance; Facilitators; Health authorities; Distance learning; Internet; Insurance coverage; Working groups; Immunization; Medical personnel; Needs analysis; Middle schools; Tools; Girls; Uptake; School based; Viral infections; Motivational interviewing; Health insurance
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Family caregiver roles and challenges in assisting patients with cancer treatment decision-making: Analysis of data from a national survey

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ProQuest document link

ABSTRACT (ENGLISH)

Background

We aimed to describe the roles and challenges of family caregivers involved in patients' cancer treatment decision-making.

Methods

Family caregiver-reported data were analyzed from a national survey conducted in the United States by CancerCare® (2/2021–7/2021). Four select-all-that-apply caregiver roles were explored: (1) observer (patient as primary decision-maker); (2) primary decision-maker; (3) shared decision-maker with patient and (4) decision delegated to healthcare team. Roles were compared across five treatment decisions: where to get treatment, the treatment plan, second opinions, beginning treatment and stopping treatment. Ten challenges faced by caregivers (e.g., information, cost, treatment understanding) were then examined. χ^2 and regression analyses were used to assess associations between roles, decision areas, challenges and caregiver sociodemographics.

Results

Of 2703 caregiver respondents, 87.6% reported involvement in patient decisions about cancer treatment, including 1661 who responded to a subsection further detailing their roles and challenges with specific treatment decisions. Amongst these 1661 caregivers, 22.2% reported an observing role, 21.3% a primary decision-making role, 53.9% a shared decision-making role and 18.1% a role delegating decisions to the healthcare team. Most caregivers (60.4%) faced ≥1 challenge, the most frequent being not knowing how treatments would affect the patient's physical condition (24.8%) and quality of life (23.2%). In multivariable models, being Hispanic/Latino/a was the strongest predictor of facing at least one challenge ($b = -0.581$, $\text{Wald} = 10.69$, $p < .01$).

Conclusions

Most caregivers were involved in patients' cancer treatment decisions. The major challenge was not understanding how treatments would impact patients' physical health and quality of life. Challenges may be more commonly faced by Hispanic/Latino/a caregivers.

Patient or Public Contribution

The CancerCare® survey was developed in partnership with caregiving services and research experts to describe the role of cancer family caregivers in patient decision-making and assess their needs for support. All survey items were reviewed by a CancerCare advisory board that included five professional patient advocates and piloted by a CancerCare social worker and other staff who provide counselling to cancer caregivers.

FULL TEXT

INTRODUCTION

When patients receive a cancer diagnosis, a number of decisions about treatment have to be navigated. In most cases, patients consult with family members and close friends who know them well and are often greatly impacted by these decisions themselves.[1–3] These family and friend caregivers assume a variety of decision support roles in cancer treatment decision-making such as gathering information, providing emotional and psychosocial support, helping patients understand and process information, assisting with clarifying the patients' values and identifying decision points.[1,2,4,5]

While identifying the various kinds of decision support roles (e.g., information gatherer, values and illness understanding discussant, option clarifier) that caregivers assume is becoming clearer, less is known proportions of *how* caregivers are partnering with their patients to make different treatment decisions. For example, it is unknown whether caregivers are more likely to serve as observers providing an opinion or instead serve as equal partners with patients in the treatment decision-making process. Additionally, while qualitative reports have illuminated challenges faced by caregivers when assisting with decisions, such as having enough information or understanding costs,[1,6] little work has attempted to quantify proportions of individuals experiencing these challenges. Given the link between family involvement in decision-making and patient outcomes such as satisfaction and treatment adherence, [6,7] understanding this type of systems-level quantitative data is important to developing and testing broad strategies that enhance the support of families who partner with patients in their healthcare decisions.

Given this, we used data from a large national sample of cancer family caregivers in the United States to describe their involvement and role in patients' cancer treatment decision-making and the challenges faced by family caregivers when assisting with these decisions. Furthermore, we explored associations between the sociodemographic characteristics of caregivers and patient clinical characteristics and the extent to which they encountered challenges to identify subpopulations who may be in most need of support.

MATERIALS AND METHODS

This was an analysis of data from a large national online US survey of 2703 family and friend caregivers of patients with cancer recruited through national consumer research panels from February to July 2021. The aim of the survey was to gain an understanding of cancer caregivers' needs and experiences in shared decision-making.[8,9] The survey study was conducted by CancerCare®, a US nonprofit organization providing free, professional cancer support services. The survey was developed after focus groups with caregivers and social workers about the ways they support patients in treatment decision-making and in partnership with experts in cancer family caregiving (including J. N. D.-O. and E. M.-S.). All survey items were reviewed by a CancerCare advisory board that included five professional patient advocates and piloted by a CancerCare social worker and other staff who provide counseling to cancer caregivers. The final survey included 63 items and is available in the Supporting Information: Appendix.

Respondents were drawn from national market research panels in the United States vetted by PureSpecturm Inc. (a market research and insights platform), who self-identified as a close friend or family member of an individual with cancer, 18 years of age or older and reported assisting with ‘health-related decisions’. ‘Family caregiver’ was defined in the survey as an individual providing unpaid support in the past 12 months to a family member or friend who is close to them, who has cancer, and who did not have to live in the same home. The survey sample had approximately 25% coverage in each of the US Northeast, Midwest, Southeast, and Southwest/West regions. The study was deemed exempt by the University of Alabama at Birmingham Institutional Review Board after the survey data was deidentified and sent to the investigative team by Cancer*Care*.

MeasuresDemographic and clinical characteristics

Caregivers self-reported data about their sociodemographics including age, gender, race, Hispanic/Latino ethnicity, education, geographic location, their relationship to the patient and the length of time they had been providing care. Caregiver respondents also reported the clinical characteristics of the patient, including the patient's cancer type and stage.

Items to measure treatment decision-making, decision support roles and challenges

Determining caregiver respondents' involvement in cancer treatment decision-making was done by evaluating an item set in the Cancer*Care* survey that asked them to check all of the different decision areas they had ever been involved in since providing support to their care recipient with cancer. Five of those items were queried specifically about decisions related to treatment. Those items included: ‘Deciding where to get treatment’, ‘Deciding whether to begin treatment’, ‘Deciding on the treatment plan (e.g., surgery, radiation, chemotherapy, immunotherapy, targeted therapy)’, ‘Getting a second opinion on the treatment plan’ and ‘Deciding whether or not to stop cancer treatment completely’. Subsequent to these items, the Cancer*Care* online survey had a ‘Decision Deep Dive’ section asking respondents to respond to further questions, which autopopulated on the online form, about their particular role and challenges faced within particular decision areas they ‘remembered the most clearly’.

Within the Deep Dive section of the Cancer*Care* survey, the respondent's decision support role was presented as four different types to which the respondent selected all the roles that represented the part they played in that particular cancer treatment decision area. The first was as an observer: ‘The person with cancer made the decision. I was an observer and played a supportive role’. The second was as the primary decision-maker: ‘I made the decision. The person with cancer and other family and/or friends provided their input'. The third was as a shared decision-maker: 'The person with cancer and I made the decision together. We both agreed on the best choice'. The fourth was as a co-delegator of the decision to the healthcare team: 'The healthcare team made the decision. The person with cancer and I provided the input but the final decision was up to the healthcare team'.

Also, under the 'Decision Deep Dive' section, participants rated the extent to which they were faced with challenges concerning their involvement in a particular treatment decision area, using a set of 13 items representing possible difficulties. These items included: 'Not everyone on the care team agreed', 'Some team members didn't agree with the doctor's recommendations', 'I didn't have enough information to make this decision', 'I didn't understand how the treatment would work', 'I didn't understand the out of pocket costs of treatments', 'I didn't know caregiver responsibilities for each of the treatment options', 'I didn't know how treatments would affect the person with cancer's physical condition', 'I didn't know how treatments would affect the person with cancer's quality of life', 'I didn't understand the treatment schedules', 'I didn't understand the risks and benefits of treatments', and 'I didn't know the wishes of the person with cancer'. Response options were: 'Strongly agree', 'Somewhat agree', 'Neither agree or disagree', 'Somewhat disagree' and 'Strongly disagree'. Challenges in a caregiver's involvement were considered present for responses of 'Strongly' and 'Somewhat' agree.

Statistical approach

Descriptive statistics were used to characterize caregiver respondent-reported sociodemographic and patient clinical characteristics. We assessed involvement in treatment decision-making at both the level of the individual decision areas and in aggregate.

Using data from those respondents completing the 'Decision Deep Dive' section on one of the five cancer treatment decision-making areas, we used cross-tabulations and Pearson χ^2 tests to: (1) examine associations between reporting each of the caregiver roles in patient decision-making and the five treatment decision areas; (2) examine associations between the five treatment decision-making areas and reported challenges faced by caregivers in decision involvement and (3) assess associations between individual sociodemographic characteristics and experiencing one or more challenges when helping their care recipient with decisions.

Multinomial logistic regression was used to examine simultaneously the association between sociodemographic and patient clinical characteristics by reporting one or more challenges in helping patients with cancer treatment decisions. All analyses were conducted using IBM SPSS Statistics®, Version 25.

RESULTSDemographics and clinical characteristics

There were a total of 2703 caregivers who responded to the survey, of whom 2367 (87.6%) reported involvement in at least one type of cancer treatment decision (Table 1). Of the 2367, 1661 completed the 'Deep Dive' portion of the survey focused on one of the cancer treatment decision areas where questions about roles and challenges were posed. The total sample (*N* = 2703), those who participated in at least one type of cancer treatment decision (*N* = 2367), and those who participated in at least one type of cancer treatment and completed the 'Deep Dive' questions (*N* = 1661) had similar proportions across all characteristics.

Table 1 Caregiver sociodemographic characteristics.

Characteristic	Total, *N* = 2703, %	Participated in cancer treatment decision-making, *N* = 2367, %	Participated in cancer treatment decision-making and responded to 'Deep Dive' questions, *N* = 1661, %
Caregiver age			
18–34	812 (30.0)	697 (29.5)	476 (28.7)

35–54	1307 (48.4)	1186 (50.1)	839 (50.5)
55 and older	578 (21.4)	481 (20.3)	343 (20.7)
Caregiver gender			
Male	1224 (45.3)	1103 (46.6)	793 (47.7)
Female	1434 (53.1)	1236 (52.2)	851 (51.2)
Transwoman/man or gender nonconforming	44 (1.6)	9 (0.5)	9 (0.5)
Caregiver race			
White	2106 (77.9)	1859 (78.5)	1322 (79.6)
African American/Black	342 (12.7)	286 (12.1)	183 (11.0)
Asian	154 (5.7)	137 (5.8)	95 (5.7)
Alaskan Native, American Indian, Native Hawaiian or Pacific Islander	33 (1.2)	23 (1.0)	18 (1.1)
Hispanic/Latino			
Yes	439 (16.2)	380 (16.1)	262 (15.8)
No	2256 (83.5)	1982 (83.7)	1395 (84.0)
Caregiver education			
Postgraduate degree	763 (28.2)	692 (29.2)	498 (30.0)

Some postgraduate	169 (6.3)	150 (6.3)	109 (6.6)
College graduate (4 years)	896 (33.1)	793 (33.5)	565 (34.0)
Vocational/technical school (2 years)	158 (5.8)	127 (5.4)	79 (4.8)
Some college	420 (15.5)	362 (15.3)	250 (15.1)
High school graduate or less	293 (10.8)	239 (10.1)	158 (9.5)
Caregiver total household income			
<$75,000	997 (36.9)	831 (35.1)	548 (33.0)
≥$75,000	1672 (61.9)	1510 (63.8)	1093 (65.8)
Location			
Urban	2253 (83.4)	1973 (83.4)	1394 (83.9)
Rural or small town	351 (13.0)	313 (13.2)	213 (12.8)
Caregiver–patient relationship (the patient is the caregiver's…)			
Parent	892 (33.0)	808 (34.1)	582 (35.0)
Friend	676 (25.0)	564 (23.8)	405 (24.4)
Spouse/partner	314 (11.6)	285 (12.0)	200 (12.0)
Sibling	162 (6.0)	139 (5.9)	89 (5.4)

Child	48 (1.8)	36 (1.5)	24 (1.4)
Extended family (e.g., aunt/uncle, grandparent, cousin)	587 (21.7)	514 (21.7)	348 (21.0)
Length of time providing care			
Up to 1 year	860 (31.8)	744 (31.4)	530 (31.9)
1–3 years	1160 (42.9)	1031 (43.6)	736 (44.3)
3–5 years	339 (12.5)	304 (12.8)	204 (12.3)
5 or more years	344 (12.7)	288 (12.2)	191 (11.5)
Patient's cancer type			
Solid tumour cancersa	2280 (84.4)	2017 (85.2)	1418 (85.4)
Haematologic cancersb	408 (15.1)	339 (14.3)	234 (14.1)
Patient's cancer stage			
In remission	566 (20.9)	453 (19.1)	312 (18.8)
1–2	970 (35.9)	855 (36.1)	629 (37.9)
3–4	1167 (43.2)	1059 (44.7)	720 (43.4)

a

Solid tumour cancer types: Bladder, brain, breast, colon/rectal, gynaecologic, head and neck, kidney, lung, melanoma, pancreatic, prostrate, thyroid.

b

Haematologic cancer types: Leukaemia, lymphoma, multiple myeloma.

Amongst the Deep Dive group (*n* = 1661), about half were between the ages of 35 and 54 (50.5%) and female (51.2%). Caregivers were White (79.6%), African American (11.0%) and Asian (5.7%). Over 16% (*n* = 439) were Hispanic/Latino/a. Most caregivers were the patient's child (35.0%), friend (24.4%) and spouse/partner (12.0%). The majority of patients had solid tumour cancer (85.4%) and slightly higher proportions of patients had stage 3–4 cancers (43.4%) than those with stage 1–2 cancers (37.9%) and those who were in remission (20.9%).

Roles of caregivers in patient decision-making by decision area

Of the 1661 caregivers who were involved in cancer treatment decision-making and completed the 'Deep Dive' portion of the survey, over half acted in the role of sharing these decisions with the patient (53.9%) (Table 2) and over 1-in-5 acted in the role of an observer (22.2%) and primary decision-maker (21.3%). Overall, the most commonly reported decision area was where to get treatment (36.1%). Significant associations were observed between specific cancer treatment decision areas and reporting observer and primary decision-maker roles (column *p*'s <.001). The largest proportion of caregivers in an observer role were those involved in decisions about the treatment plan (29.5%). The largest proportion of caregivers acting as a primary decision-makers were those involved in decisions about where to get treatment (49.6%).

Table 2 Roles of caregivers in patient decision-making by decision area.

Decision area	Total *N* = 1661	Observer supporter, patient primary decision maker, 22.2% (*N* = 369)	Caregivers as primary decision-makers, 21.3% (*N* = 353)	Shared decision with the patient, 53.9% (*N* = 895)	The delegated decision to the healthcare team, 18.1% (*N* = 300)
Overall	Column % (*n*)	Column % (*n*)	Column % (*n*)	Column % (*n*)	Column % (*n*)
Deciding where to get treatment	36.1 (599)	24.4 (90)	49.6 (175)	36.1 (323)	33.3 (100)
Deciding on the treatment plan (e.g., surgery, radiation, chemotherapy, immunotherapy, targeted therapy)	27.0 (449)	29.5 (109)	21.0 (74)	28.7 (257)	31.7 (95)
Deciding to get a second opinion on the treatment plan	12.8 (213)	15.2 (56)	9.4 (33)	12.6 (113)	11.7 (35)
Deciding whether to begin treatment	17.6 (293)	19.8 (73)	14.7 (52)	17.7 (158)	18.7 (56)

Deciding whether or not to stop cancer treatment completely	6.4 (107)	11.1 (41)	5.4 (19)	4.9 (44)	4.7 (14)
Column *p* valuea	n/a	<.001	<.001	.06	.20

Note: The sample sizes for individual decision areas were based on survey respondents selecting a decision they remembered clearly whereupon additional ‘Deep Dive’ section questions were asked about their role. Response options for the caregiver role (on the columns) were a ‘check all that apply’.

a

Pearson χ^2.

Challenges faced by family caregivers involved in treatment decisions

Out of 1661 caregivers, 60.4% (*n* = 1003) experienced at least one challenge when they were involved in their patient's treatment decision-making. The most common challenges reported by caregivers were not knowing how treatment(s) would affect the person with cancer's physical condition (24.8%) and quality of life (23.2%) (Table 3). Associations between decision areas and specific challenges faced were found for all challenges (all column *p*'s <.001), with the highest proportion of challenges faced (for all challenges) observed for deciding on the treatment plan.

Table 3 Challenges faced by family caregivers involved in treatment decisions by treatment decision type[a].

Decision area	Total *N* = 1661	Not everyone on the care team agreed, 13.7% (*N* = 228)	Some team members didn't agree with the doctor's recommendation, 13.5% (*N* = 224)	I didn't have enough info to make this decision, 11.8%, (*N* = 196)	I didn't understand how the treatment would work, 14.8% (*N* = 246)	I didn't understand the out-of-pocket costs of treatments, 17.3% (*N* = 287)	I didn't know caregiver responsibilities for each of the treatment options, 15.9% (*N* = 264)	I didn't know how treatment(s) would affect the person with cancer's physical condition, 24.8% (*N* = 412)	I didn't know how treatments would affect the person with cancer's quality of life, 23.2% (*N* = 386)	I didn't understand the treatment schedules, 10.4% (*N* = 172)	I didn't understand the risks and benefits of treatment, 13.4% (*N* = 222)
	Column %	Column % (*n*)	Column % (*n*)	Column % (*n*)	Column % (*n*)	Column % (*n*)	Column % (*n*)	Column % (*n*)	Column % (*n*)	Column % (*n*)	Column % (*n*)
Deciding where to get treatment	36.1	2.6 (6)	3.1 (7)	4.1 (8)	4.1 (10)	3.4 (10)	2.7 (7)	2.9 (12)	2.8 (11)	4.7 (8)	3.6 (8)

Deciding on the treatment plan (e.g., surgery, radiation, chemotherapy, immunotherapy, targeted therapy)	27.0	34.2 (78)	33.5 (75)	35.2 (69)	38.6 (95)	39.7 (114)	38. 3 (101)	43.7 (180)	43.3 (167)	38.9 (67)	36.5 (81)
Deciding to get a second opinion on the treatment plan	12.8	25.9 (59)	23.7 (53)	23.4 (46)	24.8 (61)	20.2 (58)	17.8 (47)	19.7 (81)	18.7 (72)	20.3 (35)	21.2 (47)
Deciding whether to begin treatment	17.6	23.7 (54)	24.1 (54)	24.5 (48)	32.5 (80)	26.4 (76)	31.4 (83)	26.2 (108)	26.7 (103)	36.0 (62)	28.8 (64)
Deciding whether or not to stop cancer treatment completely[b]	6.4	13.6 (31)	15.6 (35)	12.8 (25)	–	10.1 (29)	9.8 (26)	7.5 (31)	8.6 (33)	–	9.9 (22)
Column *p* value[c]	–	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001

[a] % of respondents for challenges areas who ‘somewhat’ or ‘strongly’ agreed with the statement.

[b] Item stems altered to fit the context of stopping treatment (e.g., ‘Not everyone on the care team agreed about stopping treatment’, ‘I didn't understand the out-of-pocket costs of stopping treatment’).

[c] Pearson χ^2.

Challenges reported by caregivers by demographic and patient cancer characteristics showed unadjusted differences in experiencing one or more challenges for younger caregivers, Hispanic/Latino/a caregivers, and caregivers with less formal educational attainment (Table 4). In multivariable models, Hispanic/Latino/a ethnicity was the strongest predictor of facing at least one challenge ($b = -0.581$, Wald = 10.69, $p < .01$).

Table 4 Challenges reported by caregivers by demographic and patient cancer characteristics.

Note: Bold values are statistically significant at $p < 0.05$

a

Pearson χ^2.

DISCUSSION

Family caregivers assume a variety of roles when supporting patients faced with cancer treatment decisions. However, little has been reported to date that quantifies the roles family caregivers play and the challenges faced when assisting with these decisions. To address this gap, we analyzed data from a large national survey of cancer family caregivers and found that a very high proportion (87.6%) were involved in patients' cancer treatment decision-making. This finding in addition to others[2,5,10] challenges the dominant clinical and research paradigm that has been guided by the two-actor paradigm of shared decision-making that narrowly focuses on the clinician and the patient.[11–13]

Just over half of caregivers (53.9%) had a shared role in making cancer treatment decisions with patients. Hobbs et al.[4] published similar rates of sharing decisions about cancer treatment with family caregivers, as reported by over 5200 patients with lung and colorectal cancer. In their study, 49.4% reported sharing decisions with families. In our study, the treatment decision with the lowest rate of shared decision-making with families was about whether or not to stop cancer treatment completely. Further study is needed to understand why caregivers are less likely to be shared decision-makers for these decisions. Possible reasons for families being less involved include the belief that stopping treatment is 'giving up' or increases patient symptom burden, such as pain. Families may also worry about signalling a loss of optimism on behalf of a loved one, which is counter to being a 'good' family member or friend.[14] It might also be the case that some oncology clinicians and/or the patients themselves believe this treatment decision should be dictated solely by the patient's wishes.[15]

The results suggest that, while families are highly involved in patient treatment decision-making, how they are involved can differ across different decisions. A number of factors may explain these differences, such as (but not limited to) differences in perceived stakes of the decision including the severity of the patient's illness condition, patient preferences, family and cultural values, the perceived impact of the decisions on the caregiver's health, patient-caregiver discordance on decisions, unique challenges of the sociodemographic context (e.g., access to care, insurance) and the treatment decision-making conversation practices and communication skills of clinicians.[3,10,13] A study of the decision-making roles of 281 caregivers of patients with stage IV solid tumour cancers in Singapore by Ozdemir et al.[10] reported that caregivers were more likely to be involved in decision-making if those decisions had a higher impact on the caregiver's finances, schedule and health. This underscores how caregiver roles may vary based on the perceived impact of patient treatment decisions on family members and their financial circumstances and health.

Most caregivers (60.4%) faced one or more challenges when assisting with decisions, the most frequent being not knowing how treatments would affect the patient's physical condition (24.8%) and quality of life (23.2%). These challenges were especially notable for caregivers involved in decisions about the treatment plan. Recent research has found that large proportions of cancer caregivers lack or have misunderstandings of their care recipient's prognosis, survival and curability of the disease.[16] There are several reasons why caregivers may have difficulties knowing how treatments might affect patients' quality of life. One reason is that prognostic information may not be effectively communicated (or not communicated at all) by the clinical team. Another reason may be the discordance in information needs during visits such that patients want to know very little about the treatment's impact on their lives and thus caregivers are unable to gain this information.[14] Finally, some families may desire to maintain an optimistic and hopeful outlook in the face of their care recipient's poor prognosis such that the reality of the patient's current and future condition is distorted.[15]

Being Hispanic/Latino/a was the strongest predictor of facing at least one decision-making challenge. Decision-making challenges may stem from cultural factors that shape healthcare experiences for Hispanics/Latinos/as impacted by cancer. For example, Latinas with higher acculturation have been found to value participating in decision-making more than less acculturated Latinas.[17] Furthermore, Hispanic/Latino culture values collective decision-making with family members giving input on healthcare decisions.[18,19] Other studies have noted high involvement by Hispanic families in patient decision-making, with many attributing it to a cultural preference towards high family involvement and reliance on family to assist with English translation.[20,21] However, a survey of 387 Hispanic patients with advanced cancer by Yennurajalingam et al.[21] found that only 34% had a preference for sharing decisions with families. Hence, our findings should be considered within the larger range of preferences by Hispanic individuals reported in the literature.

Our findings suggest several implications for clinical care, specifically decision support, of patients with advanced cancer and their families as they face numerous treatment decisions over the arc of care. First, clinicians should adopt a mindset towards shared decision-making that moves beyond the patient–physician two-actor paradigm and includes families in the decision-making process. Second, clinicians may expect patients and families to differ on how the family member is involved in decisions, which could vary depending on the type of decision being made. Consequently, clinicians should discern the specific partnership on a case-by-case basis and tailor their decision support accordingly. Finally, caregivers can face a number of challenges when trying to support patient treatment decision-making, particularly understanding the patient's physical condition and quality of life. Studies have shown the benefits of prognostic disclosure discussions,[22,23] hence clinicians should seek to initiate and conduct conversations with patients and families about prognosis and the likely course of the cancer trajectory. A growing body of resources is available to facilitate training in these conversation skills.[24,25]

Study limitations

There are several limitations to this study. First, our survey may overestimate the proportion of caregivers involved in treatment decision-making as the survey asked for respondents who had in some way been involved in 'health-related decision-making'. Second, the CancerCare survey was cross-sectional, thus we are unable to evaluate changes in caregiver roles and challenges over time. Future work should include longitudinal follow-up to ascertain how caregiving decision-making roles may change over time as the patient's cancer trajectory progresses. Third, the use of market research panels likely caused a selection bias towards individuals with access to the internet. Further, the use of these panels also impedes the ability to calculate survey response rates. These issues lessen the generalizability of the findings. Fourth, the survey sample had demographic characteristics that differ from other large population assessments of family; for example, this sample had a higher proportion of adult child family caregivers and a lower proportion of spouse/partner caregivers compared to other nationally representative surveys.[26] Further, the survey did not collect other key background data to characterize the caregiving sample, such as the number of hours per week providing care. These considerations should also be considered when interpreting the applicability of the results. Finally, we ascertained the decision-making roles of family caregivers based on their self-report and not patients. There may be discordance in how patients viewed the caregiver's role, including patient preferences for how they would have liked caregivers to have been involved.[27,28]

CONCLUSIONS

Using data from a large national survey, we found that the majority of family caregivers were involved in patients' cancer treatment decisions. The biggest challenge in supporting patients in their treatment decision-making was having a lack of information about how treatments would impact the care recipient's physical health and quality of life. Challenges in supporting patients were especially pronounced amongst Hispanic/Latino/a caregivers. These results in consort with a growing body of work in this area should prompt the development and refinement of strategies for assessing and including families in cancer treatment decision-making.

AUTHOR CONTRIBUTIONS

James N. Dionne-Odom: Conceptualization, methodology, writing—original draft, writing—review and editing; **Erin E. Kent**: Conceptualization, methodology, writing—review and editing; **Gabrielle B. Rocque**: Writing—review and editing; **Andres Azuero**: Conceptualization, methodology, writing—review and editing; **Erin R. Harrell**: Conceptualization, writing—review and editing; **Shena Gazaway**: Conceptualization, writing—review and editing;

Rhiannon D. Reed: Writing—review and editing; **Reed W. Bratches**: Writing—review and editing; **Avery C. Bechthold** : Writing—review and editing; **Kyungmi Lee**: Writing—review and editing; **Frank Puga**: Writing—review and editing; **Ellen Miller-Sonet**: Funding acquisition, supervision, data curation, writing—review and editing; **Katherine A. Ornstein**: Conceptualization, methodology, writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from Ms. Ellen Miller-Sonet on behalf of CancerCare® upon reasonable request.

DETAILS

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Lived experiences of young adults facing a recent diagnosis of cancer: A phenomenological study

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ABSTRACT (ENGLISH)

Introduction

Young adulthood is a period of prosperity and freshness characterized by developmental achievement, which can be inhibited by various diseases such as cancer. Typically considered a terminal disease, if diagnosed in young adulthood, cancer may trigger a tremendous psychosomatic shock. The nature of facing a recent cancer diagnosis affects the whole coping process. Addressing young adults' experiences at the confirmation point of cancer diagnosis will facilitate supporting them through the early recognition of probable problems in the future. Therefore, the present study aimed to analyse the lived experiences of young adults facing a recent cancer diagnosis.

Methods

This qualitative study adopted an interpretive phenomenology design. In this study, 12 patients (with an age range of 20–40) were selected using the purposive sampling method. Data collection was done through in-depth, semistructured interviews. The data were analysed following the method proposed by Diekelmann et al.

Findings

Three main themes and nine subthemes were extracted from the data: (1) spiritual detachment and then acceptance through spirituality in the form of denial and then forced acceptance, sense of guilt and spiritual help-seeking, and anger towards God and then humbleness, (2) the shock of facing an extraordinary life shaped by disturbed role-play and unusual lifestyle, (3) anticipatory anxiety concerning the sense of rejection, negative perspective towards future, inability to afford the costs and worries about the future of the family members.

Conclusion

This was the first study providing significant insights into the experiences of young adults facing a recent cancer diagnosis. The diagnosis of cancer can shadow all aspects of young adults' lives. The findings of the present study empower healthcare professionals to provide newly diagnosed young adults with appropriate health services.

Patient Contributions

To identify and recruit the participants, we explained the objectives of the present study to the unit managers either by phone or in person. The participants were approached and interviewed by three authors. Participation was voluntary and the participants received no financial contribution for their time.

FULL TEXT

INTRODUCTION

Adulthood, the period that spans the end of adolescence to the time of death, is often divided into three stages: young adulthood (the age range of 20–40); middle age; and late adulthood. Young adulthood is supposed to be the core of strength and manifestation of beauty; it is full of joy, happiness, love and hope. Young adulthood is a time of brilliance, happiness, strength, hope, effort and excitement.[1] Although young adulthood is known to be a healthy time of life, various health-threatening diseases such as cancer may jeopardize achieving the developmental characteristics of this stage.[1,2]

Despite recent medical diagnosis and treatment advancements, cancer is still associated with pain, limitation, disability and death.[3] Cancer is the second-leading cause of death worldwide[4] and the third in Iran.[5,6] According to the World Health Organization (WHO), cancer caused 10 million deaths (one per six deaths) worldwide, with an average age of 72 in 2020.[4] Cancer is still considered a disease that people avoid even talking of, associating with concepts such as evil enemy, unpredictable, indestructible, death and suffering.[3] Cancer, commonly known as an incurable and terrible disease, is equivalent to death. Therefore, facing cancer diagnosis shocks young adults[7–9] and affects their physical, mental and emotional health and developmental tasks.[10]

Whatever the nature of this exposure would be, it affects the course of the disease afterward. Healthcare providers as witnesses of this phenomenon should be knowledgeable in providing the required care services. Exploring young adults' experiences at the stage of diagnosis confirmation will facilitate the provision of help through early recognition of potential problems. Studies in this area, especially in Iran, are limited. Reaction to cancer diagnosis seems context-based. Therefore, the present study aimed to explain the lived experiences of young adults facing recent cancer diagnosis, over the last 1–3 months. Using phenomenology-driven design in this study enables the researchers to understand the subjective meaning of facing a cancer diagnosis in young people. This perspective also provides a proper understanding of what impact this experience may have on young people's lives. Furthermore, qualitative data analyses will explain their perceptions of experiencing a recent cancer diagnosis.

METHODS

This qualitative study was conducted using an interpretive phenomenology from November 2021 to April 2022 and reported based on a set of consolidated criteria for reporting qualitative research (COREQ) checklist.[11] The research environment was the outpatient chemotherapy department and haematology ward of the largest hospital in one of the northwestern cities in Iran.

Participants

The purposive sampling method was used to select the participants. The inclusion criteria were (a) adults aged between 20 and 40, (b) a definite diagnosis of cancer over the last 1–3 months, (c) willingness to communicate and express real-life experiences and (d) absence of any known psychotic illness based on medical documents. The participants who were selected had diverse characteristics in gender, education, occupation and definitive diagnosis of different cancer types to achieve the maximum level of diversity and richness of information. The first and second authors contacted the potential participants. These two researchers scheduled face-to-face interviews. Fourteen patients were contacted gradually. Two were unwilling to share their experiences. Finally, 12 participants agreed to be interviewed.

Data collection

Three authors conducted semistructured, in-depth interviews under the supervision of the senior author. Two of the interviewers were PhD students in Nursing and intensive care/emergency nurses for 14 years, trained in doing qualitative research and conducting interviews. The other interviewer was a clinical nurse with 7 years of experience in the haematology ward. The nurse was trained by the other two interviewers on how to conduct interviews in qualitative research in several sessions before the study. Therefore, the interviewers were familiar with the unit managers and asked them to introduce the eligible patients. The supervisor of this study was a faculty member in Nursing with prior experience in conducting qualitative research. The interview questions were made based on the literature review[12–14] and the expert opinions of the researchers. At the beginning of the interviews, demographic questions were asked, and then continued with more specific questions related to the purpose of the research (Supporting Infomation: Box 1). All interviews were audio recorded with the consent of the participants. A total of 15 interviews were done with 12 participants to reach data saturation,[15] of which three were supplementary to acquire rich and in-depth data. The senior investigator assessed saturation which is presented in authors section. In general, all interviews were conducted in person in a quiet place without the presence of others. The mean, minimum and maximum duration of the interviews were 56, 45 and 80 min, respectively.

Data analysis

The goal of analysing phenomenological data is to 'transform lived experience into textual expression and thus gain essence'.[16] Based on Heideggerian beliefs Diekelmann et al.[17] devised a step-by-step process of analysing narrative text. The analysis is typically done by an interpretive team and involves seven steps: (a) reading all interviews to gain an overall understanding; (b) writing interpretive summaries and coding them; (c) analysing emerging themes with the team; (d) returning to the text to confirm the analysis; (e) comparing and contrasting texts to identify common meanings; (f) identifying patterns that link the themes; and (g) eliciting basic pattern and final draft by the interpretive team.

In this study, data analysis started by repeatedly listening to the recordings to extract the overall idea and then continued according to the abovementioned seven steps. Data management was done using MAXQDA10 software.

Trustworthiness

The following strategies were carried out to achieve rigour and trustworthiness.[16] Credibility was obtained through prolonged engagement with the participants and data, and the allocation of enough time to data collection. Dependability was ensured by examining the consistency between the quotes and the codes/subthemes that emerged from the research team and two external observers familiar with qualitative research. Confirmability was ensured by presenting quotes as precisely as extracted from the interviews. Transferability was enhanced by detailing the entire research process, the characteristics of the participants and the research context.

Ethical considerations

The ethics committee approved this study, and permission was obtained from the relevant authorities. The purpose of the study and relevant information were clarified. The researchers also highlighted the voluntary nature of participation, its confidentiality and the right to withdraw. Verbal and written consent was obtained before the interview. Permission to record the interview with an audio recorder was also obtained.

FINDINGS

The participants aged between 20 and 40 were predominantly female (Table 1). Three main themes and nine subthemes were extracted from the data reflecting the lived experiences of the young adults facing the recent diagnosis of cancer (Table 2).

Table 1 Demographic characteristics of the participants.

Participants	Sex	Age	Marital status	Education	Occupation	Children	Cancer type
1	Female	26	Single	Bachelors	Housewife	No	Breast malignancy
2	Female	35	Married	Bachelors	Housewife	Yes	Gum malignancy
3	Male	30	Single	Bachelors	Employee	No	Colorectal malignancy
4	Male	40	Married	None	Freelancer	Yes	Colorectal malignancy
5	Female	36	Married	Bachelors	Employee	Yes	Bone marrow
6	Male	38	Married	Associate degree	Manual worker	Yes	Colon
7	Female	37	Married	None	Housewife	Yes	Lymphoma
8	Female	39	Married	Diploma	Housewife	Yes	Breast malignancy

9	Female	40	Married	None	Housewife	Yes	Leukaemia
10	Female	40	Married	None	Housewife	No	Uterus
11	Female	39	Divorced	None	Housewife	No	Uterus
12	Female	38	Married	Primary school	Housewife	No	Breast malignancy

Table 2 Overview of the main themes and subthemes extracted from the data.

Main themes	Subthemes
Spiritual detachment and then acceptance through spirituality	Denial and then forced acceptance
	Sense of guilt and spiritual help-seeking
	Anger towards God and then humbleness
The shock of facing an extraordinary life	Disturbed role-play
	Unusual lifestyle
Anticipatory anxiety	Sense of rejection
	Negative perspective towards future
	Inability to afford the costs
	Worries about the future of family members

Spiritual detachment and then acceptance through spirituality

Facing a recent cancer diagnosis is the most traumatic event in young people that leads to experiencing contradictory feelings of spiritual detachment and then acceptance through spirituality in the form of denial and then forced acceptance, sense of guilt and spiritual help-seeking, and anger towards God then humbleness.

Denial and then forced acceptance

According to more than two-thirds of the participants facing a sudden cancer diagnosis, they experienced reciprocal feelings from forced acceptance to the denial of the disease. It was unbelievable to accept having such an incurable disease in young adulthood. Therefore, they insisted that there must have been a mistake or this could not have been true. They even hide the situation from friends and relatives.

When I first discovered that I had cancer, I cried so much and became so upset that I fell asleep. I kept saying that something must have happened; it could not be correct; we had no history of such a disease in our family; why me? (Participant 10)

Meanwhile, the participants stated that they had no choice but to accept the disease inevitably. Dealing with the disease would calm them, make it easier to bear the pain and discomfort, and increase their hope. Also, with knowledge of the recovery process of similar patients, the participants feel optimism.

Over time, after being visited by many physicians in different cities, and being tested several times, the disease was confirmed. I had no choice but to give up and accept it. (Participant 1)

Sense of guilt and spiritual help-seeking

Guilt was another paradoxical emotion that some participants experienced. According to them, being diagnosed with cancer is a punishment from God for committing sins, so they blamed themselves.

In the beginning, I was always crying, thinking about the bad things I did and why I got sick. This must be because of my sins. (Participant 5)

On the other hand, more than half of the participants stated that they tried to accept the disease and endure the exhausting process by asking God through praying, reciting the Quran and giving vows. They referred to their close relationship with God as a source of their peace. In case of experiencing the alleviation of symptoms, they were grateful to God.

At this time, you feel closer to God and put more trust in him. You talk to God faithfully as your trust in God has increased tremendously. (Participant 2)

Anger towards God and then humbleness

Anger towards God by complaining, fighting and being unkind to God is another paradoxical emotion of young adults since they believed that God, as the absolute source of power, could have prevented this terrible and overwhelming disease.

As soon as I found out, I cried, screamed, and kept saying, ‘God, why me? I always help others; I was always looking for good deeds; why did you let me get sick? Aren't you God? Don't you have the power? Why do you like to hurt me?’ (Participant 12)

Some 50% of participants stated that they experienced changes in their tendencies from materialism to spirituality. Since they consider themselves closer to death, they desire simple living, modesty and gentleness when interacting with others.

I was very arrogant, but now I am not anymore. Ever since getting the disease and feeling closer to death, I have learned to have a simpler lifestyle and treat others gently. (Participant 2)

The shock of facing an extraordinary life

More than half of the participants interpreted the recent diagnosis of cancer as the shock of facing an extraordinary life, which triggered their disturbed role-play and unusual lifestyle.

Disturbed role-play

As the age of the participants (20–40 years) implies, independence is an inseparable concept in all dimensions of their lives. After facing the disease and the diagnosis of cancer, the patients felt that this disease, which is both traumatic and dreadful in their minds, threatens their independence. The loss of independence was so difficult and exhausting that most participants stated they preferred death over dependency on others. Being a burden was one of their main concerns. That is why they made all their efforts to maintain their independence.

I am worried about being dependent on others and burdening them. I pray to God and ask not to make me dependent on anyone. I prefer death to be a burden on others. (Participant 4)

Almost all patients mentioned the significance of their independence in playing different roles in their personal and social lives. A lack of identity in playing a role is one of the crucial experiences after being diagnosed with cancer. Almost all patients further highlighted experiencing impairments in playing different roles such as the role of a mother and a wife. Even considering the recent diagnosis of the disease (over the last 1–3 months), this disease prevented them from going to work and caused concerns about staying home.

At the moment, I am going to the doctor. I do not go to work. The other day, my wife told me my son works with my car. Well, our life has turned into a mess, and I do not know what is going to happen. (Participant 4)

Unusual lifestyle

A sudden encounter with a cancer diagnosis in young adulthood means disturbances, nightmares, a sense of anxiety and extreme apprehension about the disease which leads to departing from the ordinary lifestyle. Accordingly, cancer is considered a dreadful disease that leads to a feeling of extreme change in the lives of young people. To almost all participants, fear and worry about the disease and the consequences of its treatment have disturbed their whole lives. It caused harsh conditions for the patients and their families. This means that they cannot live their usual lives. They thought of cancer as a life with severe complications. They stated that having learned about the diagnosis and treatment of their disease, they experienced some physical reactions such as heart palpitations, diarrhoea, vomiting, weight loss, hair loss, weakness and lethargy, low blood pressure, bone pain, weakened immune system and even a case of foetal death. These factors led to the deterioration of the patients' living conditions. These factors caused some participants to search for any method to relieve symptoms and use alternative treatments such as herbal teas and even go to fortune tellers, exorcists, and so on.

Since the diagnosis of the disease, our whole life has changed, and even the whole system of my body has been messed up. I had heart palpitations. I got digestive symptoms. I feel that from now on, my life will be full of complications and different from others. (Participant 8)

Anticipatory anxiety

Another theme evident in nearly all participants' statements was excessive worries about potential future events such as a sense of rejection, negative perspective towards the future, inability to afford the costs and worries about the future of the family members as the sub-themes.

Sense of rejection

More than half of the participants stated that they believe cancer is not a disease that can be cured quickly. They even considered it a terminal disease that may cause them to be worried about being rejected by their partners, families and friends.

They also expressed that facing a cancer diagnosis and upon inquiry about the complications of the disease and its treatment, they felt apprehensive about the judgement of others about the changes in their appearance. Moreover, the patients stated that after starting the treatment, the mental picture of their body was impaired following hair loss and severe weight loss. Subsequently, they felt embarrassed and avoided attending gatherings, and even during the coronavirus disease 2019 pandemic, they expressed satisfaction with the ban on holding gatherings. Some patients who underwent surgery expressed concern about the scar on the surgical site, and those who underwent mastectomy complained about limitations on wearing their favourite clothes.

I think about how my hair will fall out when I do chemotherapy and how I will look in public, and I feel like I'm going to be embarrassed; I think about these things all the time. (Participant 6)

The altered body image reinforced the sense of rejection which was specifically more common among married women who were worried about their husbands leaving them at any moment.

You know, sometimes I think that if it takes too long and I fall out of shape, my husband will go to someone else. Of course, he is not that kind of man, but I always think about this. I pray to God that this will not happen to me. (Participant 7)

Negative perspective towards the future

One of the patients' concerns after facing a cancer diagnosis is the feeling of disappointment due to the uncertain future of the disease. They stated that they had doubts about recovery because they feared the incurable nature of the disease and were worried about its treatment that would be prolonged mainly due to the lack of medicine. Furthermore, the participants expressed feelings of inability to adapt to the disease. In some cases, due to the public's opinion about the incurability of the disease, they felt the imminent death. They even thought of suicide due to being in an unknown situation, losing their spirit and feeling negative towards recovery.

Well, the name of this disease is scary, and people do not even dare to talk about it. All I think about is that the end of this disease is death, so I am not sure of being completely cured. (Participant 8)

Inability to afford the costs

Another main concern of all patients is treatment costs since it has been relatively accepted in society that the treatment of this disease is costly. Concerns about affording treatment were mostly reported. Besides, work-related difficulties arise from extended leaves, which may lead to an insurance cut-off. These factors caused the patients not to follow their treatment seriously.

I live in a village and sell several cows every time I come here for treatment. While I am away, my sister is responsible for the housework and the cows. I always asked God whether I can pay for my treatment. (Participant 11)

Worries about the future of the family

Some 50% of participants, especially the married ones, stated that upon encountering the sudden diagnosis of cancer, they experienced worrying about the future of their family and children, not seeing their children's weddings, missing their children and being away from them. On the other hand, most of the participants stated that this kind of distress aggravated their confusion. These were the main factors in pursuing treatment.

All I'm saying is, God, for the sake of my children's future, help me get well. At least give me a chance to raise my children because I do not know what will happen to them if I die. (Participant 8)

With this disease, my life has completely changed. All family members were shocked and confused. My family tries not to say anything, but I feel that they are worried. My disease has destroyed the whole family. (Participant 9)

DISCUSSION

This study provides significant insights into the aim of the study by explaining the lived experiences of young adults facing a recent cancer diagnosis. Since the study has been done 1–3 months after being diagnosed with cancer, this short time period can provide great insight into the immediate outcomes of being diagnosed with cancer. Three main themes were extracted: spiritual detachment then acceptance through spirituality, the shock of facing an extraordinary life and anticipatory anxiety.

Spiritual detachment and then acceptance through spirituality was the first main theme, which showed the contradictory feelings and behaviours of the participants. When young patients faced the sudden diagnosis of cancer, they experienced different mental and emotional reactions, including denial and then forced acceptance, a sense of guilt and spiritual help-seeking, and anger towards God and then humbleness on both sides of the spectrum. Various studies, in line with the findings, reported that upon facing a cancer diagnosis, people show different reactions such as denial, astonishment, sadness, blame, anxiety, fear, worry, despair, anger, guilt and loneliness along with some positive emotions.[18,19] In the current study, young people suffering from various types of cancer considered spiritual help-seeking as one of the pleasant experiences essential for adapting to the conditions caused by the disease. In a similar study, Mehrabi et al.[20] referred to the reliance on religion and spirituality as the primary source of psychological support. In another study on women with breast cancer, also religious beliefs and practices were stated as the keys that helped patients cope with the disease.[21] While another study mentioned engaging in mindfulness activities like art therapy programs and yoga as a coping strategy in young women with metastatic breast cancer.[22] On the other hand, Curtis et al.[18] reported both internal resources and external ones necessary to cope with cancer. In the present study, patients handle the situation just by taking advantage of religious beliefs. This may be for the differences in the participants' age, the average age of participants of that study was 53. The religious background of society can influence coping skills as well. Also, the time span of treatment and diagnosis are the other two influencing factors.

Participants were shocked by facing an extraordinary life manifested through disturbed role-play and experiencing an unusual lifestyle. In contrast, another study investigating young women with metastatic breast cancer reported that participants experienced higher shock and impaired quality of life compared to their first diagnosis.[22] Most participants experienced vital concerns about the loss of independence and subsequent disruption in role performance, which were not compatible with the development of independence in young adults. At a young age, there are specific developmental tasks such as physical, psychosocial, cognitive, moral and spiritual ones. At this stage of life, the musculoskeletal system is well-developed. Psychological and social development includes being independent of parents, having a realistic self-image and self-love, managing one's life, interacting with the family, dealing with the tensions of change and growth, establishing excellent and intimate relationships with others, getting married, taking emotional, social and economic responsibilities, and living a healthy life.[1] In line with the current study, in a qualitative phenomenological study on young adults with thyroid cancer, Smith et al.[19] reported, that young people experienced a loss of youthful immunity that contrasted with a sense of growth and change in life. Additionally, in other study studies, the diagnosis of breast cancer in women and the subsequent surgery led to experiencing identity disorders in the affected women so that they lost their womanhood.[18,21] For many patients, cancer diagnosis and treatment could be considered as a highly stressful experience that makes individuals vulnerable to negative long-term psychological consequences including emotional distress, depression, anxiety, sleep problem, fatigue and reduced quality of life.[23,24]

In this study, the young people also experienced an unusual life along with the confusion that dominated the lives of the patients and their families. Most participants stated that imagining life with complications led to experiencing nightmares, anxiety and extreme apprehension due to the shock of illness and loss of life. In line with the present study, a range of emotions, including experiences of shock and vulnerability, have been reported in young people with thyroid cancer.[19]

For most of the participants, cancer was equivalent to excessive worry about bad happenings in the future, indicating concern about the change in the mental image of the body resulting in fear of rejection, negative perspective towards future, fear of not being able to provide financial expenses and concern about the future of the family. The present study showed that young people were so worried about physical changes in their bodies, such as hair loss, weight loss, colour change and so on, that they avoided attending parties, meeting others and choosing their clothes. Other studies have similarly demonstrated that changes in body image, feeling ashamed of being in public and dealing with negative attitudes and stigma are the main challenges that women with breast cancer may experience.[20,21,25]

One of the bitter experiences of some participants, especially the married ones, was their concern about the future of their family and children, which was stated as one of the main factors in pursuing treatment. In the same way, in other studies, concerns about the future of children and family members, as well as the acceptance of the spouse, is reported to be the most important psychological and emotional reaction of women with cancer. This concern is also one of the main factors in starting the treatment[21,24]

The patients also had negative perspectives towards the future when thinking about the uncertain future of the disease and the fear of being incurable, being in an unknown situation and being hopeless about recovery that may activate the thoughts about suicide in some participants. In other studies, fear of death and uncertainty about the future has been reported as the main concerns for people with cancer.[13,21] On the other hand, in many studies, having an optimistic attitude, including the hope of recovery and returning to a healthy life, has been reported as a very motivating resource for adapting to cancer at different ages[21,26,27]

Cancer treatment has caused an enormous cost to families and societies.[20] As in the current study, most young people with cancer expressed financial problems as a primary concern for continuing treatment. Hamid et al.[21] similarly highlighted financial problems as one of the challenging issues for women with cancer in India. Hence, the patients may delay the onset of treatment due to financial problems. The present study differs from the abovementioned study in terms of involving both genders of young adulthood. However, in both countries, due to the high cost of cancer treatment and the health insurance problem, the concern about treatment costs is reported to be one of the main factors preventing patients from pursuing treatment. These findings are in contrast to the results of a study by Williams and Jeanetta,[25] who reported that women with cancer in the United States do not face financial problems due to their health insurance support. McNeil et al.[28] examined the financial impact of cancer, the use of income support and parental caregiving (6–24 months after diagnosis) in adolescents and young adults aged 15–25 in Australia. In line with our study, they reported that more than half of the participants had financial problems due to cancer. Although adolescents, parents and young adults reported that financial support was essential to them during and after cancer treatment, they encountered financial issues triggered by direct medical and indirect expenses.

LIMITATIONS

Our study is affected by some limitations. For instance, since this study is qualitative, the findings may not be directly generalized to other communities or contexts. Considering the fact that cancer is a critical disease that individuals feel unpleasant to talk about, lengthy and exhausting interviews were not unexpected. Moreover, male patients were less willing to express their experiences; thus, fewer males participated in the study.

CONCLUSION

By extracting the mentality and experiences of young people facing a recent cancer diagnosis, this study has added new findings to the existing body of knowledge regarding the difference in culture and beliefs of these patients. The findings showed that cancer diagnosis in young people significantly affects them because as the patients admitted, it had been the most traumatic experience in their lives. Emotional turmoil, including anger at God, denial of the disease and extreme embarrassment were among the common immediate reactions of the young patients. However, they accepted the reality and used different methods to deal with their illness over time.

Implications and suggestions

Relying on the findings of this study, healthcare providers can facilitate offering health services to young adults who have recently been diagnosed with cancer by concentrating on the early recognition of possible future problems. Moreover, exploring the individuals' perceptions of their disease in the early stages may reduce the impact of the diagnosis. According to the literature, it can promote coping and compatibility with diagnosis through interventions such as providing appropriate information, gaining membership in peer groups, having access to the stories of other cancer patients, improving communications with healthcare professionals[18,19] and reliance on religion and spirituality [20,21] as well as mindfulness and meditative activities.[22,29] Furthermore, the policymakers working in the healthcare system can benefit from the findings of the present study to formulate some health insurance plans for the purpose of covering the costs of young people with cancer.

Considering the fact that this research study was conducted on the acute phase of the disease, it is suggested to investigate and compare the views of these patients with those who have survived cancer from different personal and social perspectives. Testing these findings in the framework of quantitative research helps to increase the reliability and generalization of the results and their applicability. Given that, the experience of an unusual lifestyle was a vital concern for participants. However, there is less research on the quality of life of young adults facing a recent cancer diagnosis. Thus, it is worth conducting research on the quality of life of young adults facing a recent cancer diagnosis for planning to promote their quality of life.

AUTHOR CONTRIBUTIONS

Mehraban Shahmari and Leily Zare contributed to the conception and design, collection of data, analysis, and interpretation of data, drafting of the article and reviewing and editing the original draft. Alireza Nikbakht Nasrabadi contributed to the analysis and interpretation of data, review and editing of the final draft, final approval of the version for publishing and general supervision of the research group. Elaheh Rezaie contributed to the collection of data and drafting of the article. Seemin Dashti and Elhameh Nasiri contributed to drafting the article and reviewing and editing the original draft.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data supporting the findings could be made available by the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

This study was done in full accordance with the ethical principles of the Declaration of Helsinki. The proposal for this study was approved by the Ethics Committee of the Research Council of TUMS with the code: IR.TUMS.VCR.REC.1399.594. To participate in the study, informed written consent was obtained from the participants.

DETAILS

Subject:	Cancer; Newly diagnosed; Spirituality; Phenomenology; Terminal diseases; Medical diagnosis; Disease; Relatives; God; Coping; Young adults; Diagnosis; Data analysis; Qualitative research; Interviews; Data collection; Health services; Hematology; Role playing; Guilt; Uterus; Adults; Medical personnel; Acceptance; Help seeking behavior
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Meaningful engagement through critical reflexivity: Engaging people with lived experience in continuing mental health professional development

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ABSTRACT (ENGLISH)

Engaging people with lived experience of mental health system encounters in the design and actualization of continuing professional development initiatives for mental health professionals can have transformative systemic impacts. Yet, despite evidence that involving people with lived experience benefits mental health professional education, far less focus has been placed on how to engage people with lived experience in continuing professional development initiatives. Tensions persist regarding the role of lived experience perspectives in continuing professional development, as well as how to establish people with lived experience as partners, educators and leaders in a thoughtful way. We propose that meaningful and equitable partnerships with people with lived experience can be realized by engaging in critical reflexivity and by systematically challenging assumptions. This paper explores three topics: (1) the current state of engagement with people with lived experience in continuing professional development initiatives; (2) barriers to meaningful engagement and (3) recommendations for using critical reflexivity to support the involvement and leadership of people with lived experience in continuing professional development for mental health professionals.

Patient or Public Involvement

This viewpoint manuscript was co-designed and co-written by people with diverse lived and learned experiences. Each author's professional roles involve meaningfully and equitably partnering with and centring the perspectives of those with lived experience of mental health system encounters. In addition, approximately half of the authorship team identifies as having lived experience of accessing the psychiatric system and/or supporting family members who are navigating challenges related to mental health. These lived and learned experiences informed the conception and writing of this article.

FULL TEXT

INTRODUCTION

Engaging people with lived experience (PWLE) of mental health system encounters in the development and leadership of continuing professional development (CPD) initiatives for mental health professionals can have transformative systemic impacts.[1] This involvement can infuse CPD initiatives with real-world insights on health, health systems navigation and approaches that reflect compassionate, humanistic and recovery-oriented care.[2,3] Recovery-oriented care aligns with the Institute of Medicine's first core competency: to ‘identify, respect and care about patients' differences, values and expressed needs’.[4,5]

Despite evidence that engaging PWLE benefits mental health professional education, far less emphasis has been placed on how to meaningfully engage PWLE in CPD initiatives.[3] Tensions persist regarding the role of lived experience perspectives in CPD, as well as how to thoughtfully establish PWLE as partners, educators and leaders in CPD. We propose that meaningful and equitable partnerships with PWLE can be achieved through critical reflexivity and by systematically challenging assumptions.[6] Critical reflexivity promotes exploration of knowledge generation through meaningful engagement, including different types of knowers and encourages both learners and educators to question how power structures influence the way that knowledge is generated.[6] This paper explores three topics: (1) the current state of PWLE engagement in CPD initiatives; (2) barriers to meaningful engagement and (3) practical recommendations for supporting the involvement and leadership of PWLE in CPD for mental health professionals through critical reflexivity.

REFLEXIVITY AND POSITIONALITY

This paper was inspired by a workshop on the meaningful involvement of PWLE in CPD for mental health professionals, which was delivered by seven of this article's authors. As an interdisciplinary group that includes diverse learned and lived expertise, we continually challenge ourselves to engage in ongoing learning and advocacy, with the goal of moving toward more meaningful and ethical engagement of PWLE in our work. We encourage readers to do the same, regardless of where they are in this process. Given that our intersectional experiences have shaped how we conceptualize, approach and write on this topic, we include positionality statements for each author (see Table 1). We invite readers to consider the perspectives and positions we write from as well as the voices that have been left out.

Table 1 Authors' positionality statements.

Name	Positionality statement
Holly Harris	I acknowledge the intersectional privilege/oppression that I experience on account of my identity. I am a white, middle-class, cisgender female with master's-level education. I identify as someone who is neurodivergent and a consumer/survivor of the psychiatric system. I am employed by a tertiary mental healthcare facility as a research coordinator and have been working in community-engaged research and programming for the past 5 years. I leverage my lived experiences as a source of strength, resilience and expertise to highlight the voices of those who have been historically silenced. I acknowledge that my lived, academic and professional experiences influence the value I place on specific ideas and my interpretation of data.
Chantalle Clarkin	Aspects of my identity and social location confer power, access and privilege. I am a white, queer, cisgender female living with a stable mental illness. I studied nursing in a small CÉGEP programme and have 22 years of experience as a registered nurse, working in a variety of hospital, community and clinical research contexts. I was the first in my family to complete a university degree, and my educational journey includes a master's degree in nursing and a doctorate in education. I am employed full-time as a staff scientist in a large mental health organization, where I conduct community-engaged research that is co-designed with people with lived experience from start to finish. My personal and professional experiences, identities and social location shape how I come to understand myself and the world, and influence my research, scholarship and teaching practices. I believe that an authentic partnership with PWLE is key to disrupting power structures that maintain divisive and exclusionary hierarchies in health care, research and academia.
Jordana Rovet	I acknowledge that my lens for engaging with this paper has been shaped by my intersectional privileges, oppression, lived experiences and professional background. I am a white, cisgender female and a registered social worker with a master's degree. I have spent the last 10 years working alongside people with lived experience of mental health, substance use and addiction challenges, and I am acutely aware of the social and political context in which this work is embedded. I recognize the importance of actively reflecting on the tensions that I hold due to various aspects of my positionality and I am committed to engaging in a process of learning and unlearning.
Allison Crawford	I am a psychiatrist and scientist working in an academic health sciences centre. My social location is as an economically and socially advantaged, white, straight, cisgender female who is the first generation of my family to attend university. While I do not usually occupy the role of lived experience, I value the importance of critical reflexivity in my clinical and research work in mental health, particularly given the personal and familial engagement I have had with the medical and mental health system. I have benefited immensely from the interprofessional colleagues I work with, including people with lived and living experience. Throughout my work, I have often engaged with rich, diverse and equity-seeking communities. I strive to critically reflect upon what those partnerships mean and to interrogate the role of my power and positionality in those engagements.

Andrew Johnson	I am a writer, editor, publisher and educator who works in the mental health space. For the past 25 years, I have worked in a large academic health science centre in a large Canadian city. Through progressively gaining experience and responsibility, I have reflected, and continue to reflect, on my ongoing privilege as a white, straight, middle-aged man, and how that social location affects my commitments to deeply and authentically promoting inclusion, equity and diversity in all aspects of my professional life. To that end, the current phase of my career has given me an opportunity to lead the development of programmes that centre the voices of people with lived and living experiences of substance use, addiction and/or mental health challenges. To do so, I see my role as listening, sharing power and allowing others to step forward by me stepping back.
Anne Kirvan	I acknowledge that my perspectives and beliefs are shaped by my social location, as well as by my personal and professional experiences. I identify as a white cisgender female. I have a master's degree in social work, and I am employed as a clinical services consultant at a mental health and addiction hospital in a large Canadian city. I am also a PhD candidate in social work. I recognize the power and privilege associated with being an educator and researcher, and seek to use my positional power to collaboratively create spaces to meaningfully engage and partner with PWLE. I intend to continually learn from the perspectives and expertise that PWLE brings to this work, and to integrate that learning into my practice.
Sam Gruszecki	I identify as a white cisgender middle-aged male. I work as a coordinator for a recovery college at an organization that employs many of the people involved with this paper. I had collegial and community-based experience with most of them before starting this work. I am the child of an immigrant and lack postsecondary education. Some of my lived experience includes navigating anti-Semitism, neurodivergence, multiple diagnoses and services and poverty. I have been involved in recovery college work, funded through major hospitals, as a peer support specialist, lead peer and coordinator since 2014. My experiences in research are relatively limited and I continue to learn along the way.
Stephanie Wang	As I engage throughout the development of this paper, I strive to identify, critique and consider the positionality from which I contribute. I am a managing director of a community-based charity and also have other roles, including being part of a recovery college and CPD initiatives at a mental health hospital in a large Canadian city. I hope to acknowledge and reflexively contemplate the different forms of power, privileges and oppression that may be associated with the positions in which I am situated. This includes how I frequently partner with PWLE in educational, community and research contexts as someone who has my own experiences with mental health and identifies as a cisgender female from a multicultural background. My intent is to be open-minded, learn and promote equity in health systems.

Sophie Soklaridis	I am the daughter of Greek parents who immigrated to Canada. I grew up in Lourdes, Newfoundland and Scarborough, ON, Canada. I hold assumptions and perspectives that are shaped by how I see/experience the world and how the world sees/experiences me. I am employed as a senior scientist and currently work across several academic medical institutions in Canada and Ethiopia. I recognize that the academic institutions I work in in Canada are privileged sites of North American knowledge production that have historically marginalized paradigms outside of a traditional biomedical model. My intent is to use my positional power to amplify the voices of colleagues, service users and family members as valued partners in the research process.

Abbreviations: CPD, continuing professional development; PWLE, people with lived experience.

CURRENT STATE OF PWLE INVOLVEMENT IN CPD

There is growing momentum to engage PWLE in the development and delivery of CPD. Power-sharing is central to meaningfully and inclusively involving this population in CPD, whereby PWLE has the power to decide if, when and how they engage in these initiatives. However, most CPD initiatives for mental health professionals are still developed and delivered without the truly inclusive involvement of PWLE.[4] Often, structure and support for engaging these voices are lacking, meaning that when opportunities for co-production do arise, lived experience knowledge is marginalized.[7] Rather than being recognized as equal partners, PWLEs are commonly engaged on an ad hoc basis and for a narrow aim (e.g., one-off lectures), which does not move beyond the role of consultation.[7,8]

Inviting people to share their stories is the most common form of engaging PWLE in CPD for mental health professionals.[7] Storytelling can be a source of pride for PWLE and can shed light on important issues through sharing real-world examples.[2] However, stories are usually framed to complement a predetermined curriculum.[9] When course leaders ask PWLE to frame their stories to fit established curricula, it can give the appearance of demonstrating support for the knowledge of PWLE by virtue of inclusion.[9] However, establishing curriculum objectives without the meaningful involvement of PWLE is nothing more than superficial inclusion, which can reinforce power differentials between mental health professionals and the people they serve. To equitably partner with PWLE in CPD, we must question the current state of affairs and rethink how to involve PWLE in decision-making.[7,10]

BARRIERS TO INCLUSION OF PWLE IN CPD

There are social and structural barriers to the meaningful and inclusive involvement of PWLE in CPD. For example, most educational initiatives are designed to have one or two faculty co-leads who lead with privileged forms of expertise (i.e., professional and/or academic). Often, there are no mechanisms for leaders of CPD initiatives to work with PWLE to define the scope for participation, thus reinforcing power hierarchies and barriers to equitable partnerships. A larger social issue to consider is the volunteer, underemployed and underpaid arrangements that constitute most roles for PWLE in CPD.[11] Power dynamics are further perpetuated when those who are situated as leaders or administrators are afforded more stable employment opportunities as part of their professional roles, while PWLEs are constrained to precarious employment (e.g., contractual, part-time, unpaid, lacking legal protection).[8,12,13]

Another barrier to equitable partnerships is the notion of professional acceptability. For instance, a study on the experiences of PWLE engaged in CPD found that programme leaders were more likely to offer opportunities to PWLE whom they deemed articulate and who had higher levels of education or existing relationships with clinicians.[14] This suggests that PWLE who are considered ‘professionally acceptable’ are more likely to be involved in CPD. PWLEs are often not engaged or are dismissed because they are perceived as being less proficient in context-specific terminology and in understanding roles, procedures and policies.[13] The assumption that engagement requires cumbersome unidirectional capacity-building whereby PWLE must be ‘brought up to speed’ is inherently flawed. The literature places great emphasis on preparing PWLE to engage in CPD while deflecting attention away from the need to also better prepare those working with and learning from PWLE.[12,15] By focusing solely on building capacity among PWLE, initiatives fail to make space for mutual learning or to challenge dominant beliefs about legitimate forms of knowledge, both of which are critical to meaningful inclusion.[16]

RECOMMENDATIONS

While evidence supporting the inclusion of lived experience in education mounts across health disciplines, there remains a significant lack of scholarly guidance on how to establish and engage in these partnerships. Drawing on the limited body of scholarship and on our learned and lived expertise, we offer initial thoughts to consider when striving to forge equitable partnerships with PWLE in CPD initiatives.

The process is as important as the outcome

Prioritizing the process of engagement, and investing time and resources from the outset, allows expectations and support needs to be identified for everyone involved (i.e., educators, programme leaders, PWLE, learners). A key factor in establishing meaningful educational partnerships is the ongoing commitment to shift from tokenistic modes of participation to more meaningful forms of engagement.[17]

Critical self-reflection presents an opportunity to recognize diverse forms of knowledge

Working across different areas of expertise requires thinking differently about what counts as knowledge(s), including questions pertaining to the necessary and sufficient conditions for knowledge creation, scope of knowledge and limits of knowledge. The epistemological process of reflecting on values and beliefs—at the individual, programme and organizational levels—is essential to the success of working relationships. A critically reflexive perspective within CPD, and more broadly within healthcare programmes and service delivery, presents opportunities to bridge gaps between theory and practice.

Before engaging PWLE in CPD initiatives, it is useful to examine one's own values and beliefs in action. For example, reflect on your assumptions about engagement, preferences, experiences, expectations and boundaries.[18] One approach to developing a feasible strategy begins by delineating the why, who, how and what of lived experience engagement in CPD initiatives. Examples of critically reflexive questions and sample actions are provided in Table 2.

Table 2 Sample critically reflexive questions and actions.

Understand intentions and motivation for doing this work

Reflecting on the question ‘Why now?’ can help to surface organizations' motivation for change, as well as their readiness and commitment to engaging PWLE in CPD initiatives. Asking ‘Why now?’ also reflects an understanding that engagement does not occur in isolation, but rather is temporally situated and context-driven.

Reflect on what knowledges are sought and for what purpose

Thoughtful consideration is necessary when deciding who to recruit, how many people to recruit, what knowledges and perspectives are being sought for the role and whose voices are included and excluded in the process. Offering intentionality when creating equitable partnerships and power-sharing can avoid the tokenistic engagement of PWLE. Tokenism refers to the practice of seeming to involve PWLE in decision-making when in fact their involvement is perfunctory.

Commit to sharing power

The collaborative approaches discussed in this paper require power-sharing, as well as individual and organizational commitments to challenge existing power dynamics. This could include considering how decisions are made (e.g., hierarchical decision-making, shared decision-making, co-production). There are also numerous opportunities to increase choice, autonomy and self-determination for PWLE in CPD. We recommend that educators carefully consider leadership and supportive roles for PWLE in these programmes. Power is a central and crucial consideration, including the power-equalizing conditions in place and the openness of leadership to share and relinquish power.[20]

CONCLUSION

Meaningful inclusion of PWLE in CPD initiatives for mental health professionals can bridge gaps between theory, practice, academia and community involvement, and can also reduce stigma and social distance between those with lived and learned expertise. To date, little guidance has been provided on how to meaningfully engage PWLE of engagement with the mental health system in CPD initiatives for mental health professionals. Beyond process and policy change, we feel that meaningful engagement requires a shift in perspectives at all levels. By engaging PWLE in CPD for mental health professionals through critical reflexivity, CPD initiatives can become more relevant, impactful, authentic, vibrant and consistent with a larger vision of systemic equity.

AUTHOR CONTRIBUTIONS

Holly Harris: Conceptualization; project administration; writing—original draft; writing—review and editing. **Chantalle Clarkin**: Conceptualization; writing—original draft; writing—review and editing. **Jordana Rovet**: Conceptualization; writing—original draft; writing—review and editing. **Allison Crawford**: Conceptualization; writing—review and editing. **Andrew Johnson**: Conceptualization; writing—original draft; writing—review and editing. **Anne Kirvan**: Conceptualization; writing—original draft; writing—review and editing. **Sam Gruszecki**: Conceptualization; writing—original draft; writing—review and editing. **Stephanie Wang**: Conceptualization; writing—original draft; writing—review and editing. **Sophie Soklaridis**: Conceptualization; supervision; writing—original draft; writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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

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Healthy Parent Carers: Acceptability and practicability of online delivery and learning through

implementation by delivery partner organisations

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ProQuest document link

ABSTRACT (ENGLISH)

Background

Parent carers of disabled children are at increased risk of physical and mental health problems. The Healthy Parent Carers (HPC) programme is a manualised peer-led group-based programme that aims to promote parent carer health and wellbeing. Previously, the programme had been delivered in person, with recruitment and delivery managed in a research context. This study explored implementation by two delivery partner organisations in the United Kingdom. Facilitator Training and Delivery Manuals were modified for online delivery using Zoom due to COVID-19.

Methods

The study methodology utilised the Replicating Effective Programs framework. A series of stakeholder workshops informed the development of the Implementation Logic Model and an Implementation Package. After delivering the programme, delivery partner organisations and facilitators participated in a workshop to discuss experiences of implementing the programme. A wider group of stakeholders, including commissioners, Parent Carer Forums and charity organisations representatives and researchers subsequently met to consider the sustainability and potential barriers to delivering the programme outside the research context.

Results

This study explored implementation by two delivery partner organisations in the United Kingdom that were able to recruit facilitators, who we trained, and they recruited participants and delivered the programme to parent carers in different localities using Zoom. The co-created Implementation Logic Model and Implementation Package were subsequently refined to enable the further roll-out of the programme with other delivery partner organisations.

Conclusions

This study provides insight and understanding of how the HPC programme can be implemented sustainably outside of the research context. Further research will evaluate the effectiveness of the programme and refine the implementation processes.

Patient and Public Contribution

Parent carers, delivery partner organisation staff and service commissioners were consulted on the design, delivery and reporting of the research.

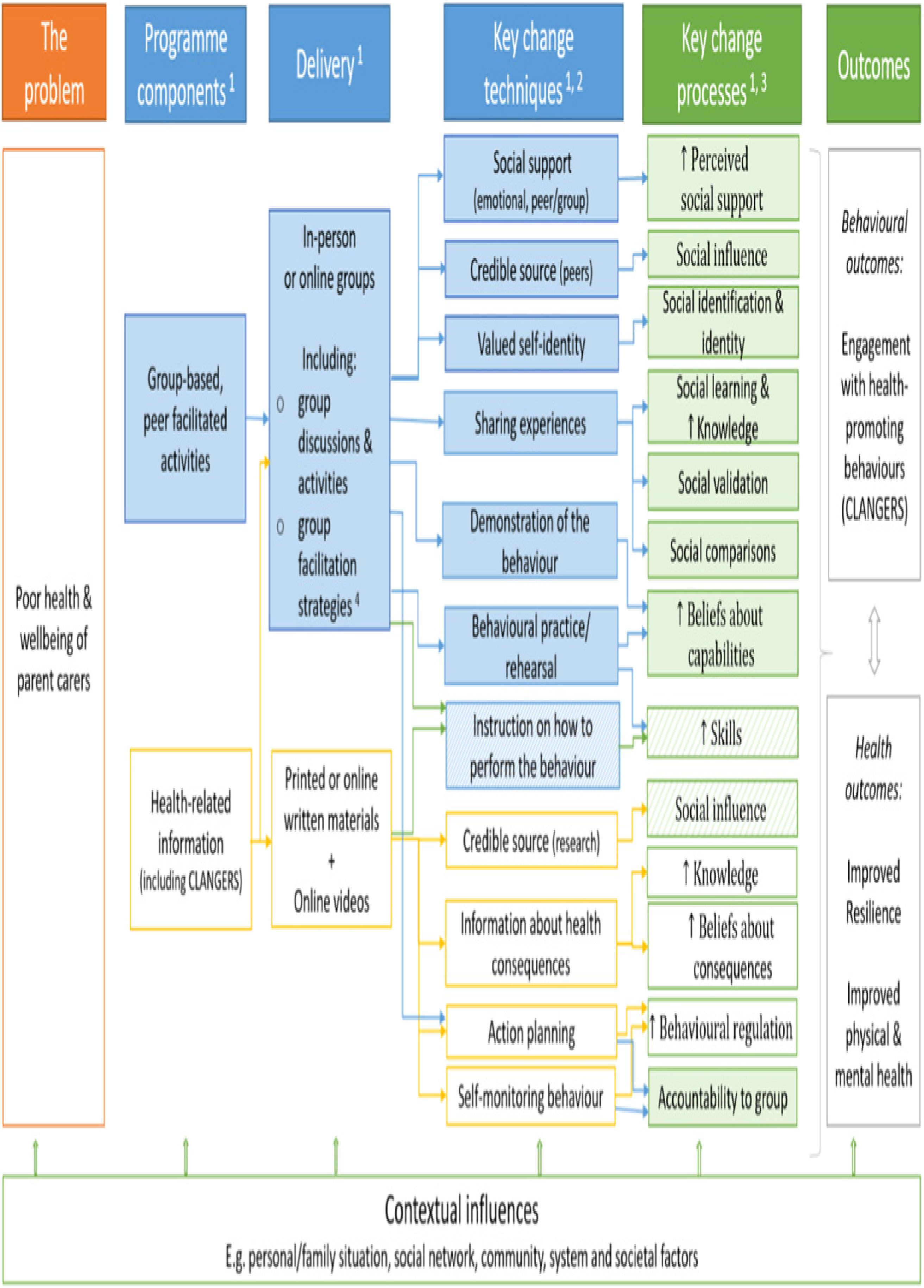
FULL TEXT

INTRODUCTION

Parent carers of disabled children are at increased risk of physical and mental health problems.[1–13] They often experience greater challenges in maintaining good personal health, which has implications for their own wellbeing and their ability to care for their children.[14] Individual, family and environmental factors affect parent carers' health. Social disadvantage, gender, ethnicity, sexual orientation and/or other personal factors may intersect to increase the health impacts of being a parent carer.[15] Population-based studies suggest that parent carer health problems persist and may worsen over time.[3] The COVID-19 pandemic exacerbated this problem, disproportionately affecting parent carers, with lockdowns, school closures and limited services leaving many families feeling abandoned.[16,17]

Our consultations with parent carers suggest existing public health interventions are perceived as insensitive to the challenges that parent carers experience. Interventions to promote health equity are urgently needed.[18] The Healthy Parent Carers (HPC) programme was developed specifically to promote the health and wellbeing of parent carers. It aims to improve health and wellbeing by engagement in behaviours associated with better health— Connect, Learn, be Active, take Notice, Give, Eat well, Relax, Sleep (CLANGERS). Intervention development and programme components and delivery strategies were described comprehensively in our previous papers.[19,20]

The updated intervention logic model of the HPC programme outlines that parent carer engagement with health-promoting activities (CLANGERS) will foster resilience and improve health and wellbeing (Figure 1). The programme facilitates behaviour change by providing opportunities for and prompting, social (peer) support, development of a shared social identity, sharing of experiences and the practice of health-related behaviours. This is achieved through (i) facilitated group-based activities and discussions, and (ii) providing health-related information and resources.



Enlarge this image.

The HPC programme is delivered to groups of 6–12 parent carers, led by pairs of trained peer Lead and Assistant Facilitators, following procedures in the Facilitator Delivery Manual. Participants also receive written materials (printed/online), mirroring the content discussed in groups, to refer to and use outside of the group sessions. These include information about CLANGERS, links to videos and useful resources and action planning and self-monitoring sheets.

Previously, researchers recruited facilitators, set up delivery sites, advertised for and screened potential participants, prepared resources and supported facilitators during delivery. However, outside of the research context, these tasks need to be done by licensed delivery partner organisations. The transition from academic to real-world settings is a common challenge for many evidence-based interventions.[24,25] The present study was, therefore, designed to establish and test a strategy to enable successful implementation by delivery partner organisations, which includes charities, social enterprises and voluntary groups.

Although the HPC programme has not yet undergone a definitive effectiveness trial, we wanted to explore barriers to implementation in nonacademic community settings, to ensure as early as possible that the intervention (if proven effective) would be implementable. The HPC programme is a complex intervention by virtue of the range of behaviours targeted, expertise and skills required by those delivering the intervention and other programme contextual factors. The recent Medical Research Council framework for complex interventions highlighted the nonlinearity of addressing important questions related to feasibility, effectiveness and implementation of interventions.[26] Thus, following intervention development and a feasibility study,[19,27] we considered it critical to explore potentially feasible and sustainable implementation strategies. This is particularly important as reaching vulnerable individuals and those facing health inequalities presents numerous unique issues which are not well documented.[28] This paper reports on the first steps towards translating the HPC programme to delivery in real-world settings, preceding a pragmatic evaluation of effectiveness.

The study was designed before the Covid-19 pandemic. Social distancing mitigations in the pandemic meant that HPC could not be delivered in person, as initially designed. It was necessary to first adapt the programme (before implementation) so that training of facilitators and delivery of the programme could be done remotely using Zoom™. Details of the adaptations to online delivery are reported in Supporting Information: File 1. Therefore, this study serendipitously enabled our first evaluation of the acceptability and practicability of online delivery.

This implementation study had the following aims:

- 1.
  To identify feasible and acceptable strategies for wider implementation of HPC with delivery partner organisations from the perspective of the organisations, facilitators and participants.

- 2.
  To explore barriers and enablers for implementation of the programme by two delivery partner organisations who work with families with disabled children.

- 3.
  To systematically develop and refine the implementation strategy, including the Implementation Logic Model, Implementation Package and the terms for future licensing, to optimise the programme for delivery with nonacademic organisations.

Additionally, due to the need to move the facilitator training and the HPC programme online, we explored the acceptability and practicability of online delivery.

METHODS

The Replicating Effective Programs (REP) framework was developed specifically to provide a systematic process for implementing health interventions outside academic settings by community-based organisations.[29] The framework aims to help maintain fidelity while maximising the transferability of interventions when they are translated from academic to community settings. As this was our aim of exploring the delivery of HPC by community-based delivery partner organisations, the REP was considered a particularly relevant framework. The REP framework consists of four phases: preconditions, preimplementation, implementation and maintenance and evolution. This study focused on the first two stages outlined by the framework (Table 1).

Table 1 Study method mapped to REP phases 1 and 2.

Task	Activity	Output
	Phase 1—preconditions	
Identify barriers	Establish a Community Working Group including representatives from Peninsula Childhood Disability Research Unit, Public and Patient Involvement groups; delivery partner organisations. Workshop 1—orientation meeting.	Partnership building between intervention developers and delivery organisations. Identified barriers and processes of implementation. Developed Implementation Logic Model.
Identify need	Funder workshop—determine local need and appetite for commissioning HPC.	Identified interest from commissioners and possible challenges to programme delivery.
Draft implementation	Draft implementation processes—in collaboration with delivery organisations and key stakeholders.	Co-created a draft Implementation Package and Logic Model.
	Phase 2—preimplementation	
Optimising implementation	Workshop 2—further refinement of the Implementation Package and Logic Model, including costs and any data that will need to be collected.	Implementation package reviewed. Contents developed to include additional key processes.
Pilot test	Train facilitators to deliver programme. Pilot test implementation and delivery. Parent carers take part in two pilot groups (6 or 12 weeks in length), implemented by delivery organisations.	Piloted the Implementation Package.
Evaluate and reflect	Workshop 3—review experiences of staff from delivery organisations and strategies undertaken during pilot testing. Workshop 4—discuss with potential future funders around sustainability and roll-out of the programme.	Identified key roles, processes and knowledge required to implement the programme. Revised the Implementation Logic Model. Developed a greater understanding of possible challenges and appetite for delivering the programme in different organisations.

Abbreviations: HPC, Healthy Parent Carers; REP, Replicating Effective Program.

We collaborated with two national organisations as delivery partners. The Council for Disabled Children (CDC) is the umbrella body for over 300 voluntary and community organisations in England. Contact carries out a range of activities supporting families with disabled children in the United Kingdom. Both organisations are commissioned to deliver programmes for the Department of Education and/or the Department of Health and Social Care. Both organisations offer a range of training, support services and consultancy to parent carers, health professionals, social workers, local authorities and service providers in the childhood disability sector. Therefore, they were perceived as having the right reach, infrastructure and connections to implement the HPC programme.

We also continued to work in partnership with parent carers in our Family Faculty Patient and Public Involvement group who advise on our research. A series of meetings were coordinated to support the adaption of the programme for delivery online and reflect on the findings from implementation.

We established a Community Working Group (CWG). Delivery partner organisations selected key personnel to attend based on their knowledge of who would be able to support the implementation of the programme within their organisations. Two parent carer co-investigators attended the meetings. Both had been involved in the programme and its development since the start and therefore could share their knowledge and expertise about the programme. One parent carer who had been a facilitator in the feasibility trial also took part. They were invited as they had also been previously employed by both of the delivery partner organisations as a facilitator. All co-investigators were invited to attend the group meetings.

REP phase 1: Preconditions: Identifying barriers, need and drafting implementation package

In workshop 1, we introduced the HPC programme and our previous research to the new delivery partners. Discussion centred around necessary delivery tasks including site set-up, recruitment of Lead and Assistant Facilitators, training of facilitators, preparation of training materials, recruiting participants, preparing delivery materials, orientation for facilitators, liaising with facilitators and participants, supervision, administration and facilitating delivery support calls. Delivery partners then presented how they delivered comparable programmes within their own organisations. The group also discussed sustainability, quality assurance, safeguarding and signposting.

REP phase 2: Preimplementation: Optimising implementation

The preimplementation stage involved pilot testing the package of the Implementation Manual, license agreement, contracts, Online Facilitator Training Manual, Online Delivery Manual, and management of postdelivery support calls.

Workshop 2 with the CWG involved discussions on the proposed Implementation Package, including implementation costs, which data would need to be collected, and the terms of a licensing agreement. Devising the Implementation Package involved key roles and responsibilities and the specific personnel who would be able to fulfil these roles within the Delivery partner organisations.

REP phase 2: Pilot testing the implementationFacilitator recruitment and consent

Delivery partner organisations identified parent carers to train as Lead and Assistant Facilitators using our predefined person specifications for each role.

Prospective peer facilitators were screened by a researcher and invited to document consent for participating in the study. They completed a pretraining baseline questionnaire, which included age, sex, motivations to be a facilitator, relevant experience and expectations of delivering the programme.

Facilitator training

Trainers followed the Online Training Manual to train new facilitators. Trainee facilitators attended a 1-h, pretraining session with the two trainers and study coordinator, which allowed everyone to meet as a group and to be briefed about the study and training. The session prepared facilitators for the online aspects of the programmes, which included specific online software: Zoom™ (video-calling) functions and methods of using Jamboard™ (online whiteboard). The training was delivered in two ‘Blocks’. Each block consisted of 3 days of training in total. Block 1 was just for Lead Facilitators, and Block 2 was for Lead and Assistant Facilitators. Each Lead and Assistant Facilitator was given their own copy of the Online Delivery Manual to support their training and subsequent delivery.

HPC programme participant recruitment and consent

We shared an exemplar advert which organisations used to advertise the programme. The advert was adapted by organisations to include specific information on the times, dates and contact details of their organisation. Their advertising strategies sought to reach a diverse range of parent carers. These included utilising local contacts and organisations, such as voluntary and community partners, local education authorities, health and statutory services, support groups for parent carers and social media, including Parent Carer Forums (www.nnpcf.org) on Facebook or Instagram.

Both delivery partners used the Eventbrite™ online platform for potential participants to register expressions of interest.

People who registered interest were initially contacted by a member of the organisation to complete a screening call and confirm eligibility and understanding. Participants' contact details were uploaded onto a password-protected screening spreadsheet to track screening and recruitment.

Eligible parent carers were then invited to a screening meeting with a researcher to learn about the research aspects and what participation would entail and to check participants' familiarity with and access to Zoom™. Participants could opt out of research participation and still participate in the HPC group. If participants were happy to take part in the research, the researcher emailed a copy of the Participant Information Sheet ahead of a subsequent meeting to document consent.

HPC programme delivery

Both delivery partner organisations delivered the 12 HPC programme modules through 2-h online group sessions, twice per week, over a 6-week period. The two courses were run in two separate localities in England, with participants and facilitators recruited from two different areas, one rural and one urban. Contact ran a daytime course, which took place at the same time and days each week. CDC ran a mix of day and evening sessions, which took place on the same days weekly. After each session, facilitators completed attendance registers and self-reported fidelity checklists to indicate the specific content they covered (adherence), the duration of the sessions (dose) and parent/carer engagement (responsiveness). A minimum of 6–8, and a maximum of 12, participants per group were suggested based on findings from the feasibility trial.[27]

REP phase 2: Evaluate and reflectHPC programme participant baseline measures

After consent, participants were emailed a link to the baseline questionnaire, which asked questions on parent carer demographics and the About My Child (AMC) questionnaire.[30] The AMC is a valid tool that measures the impact and complexity of the disabled child's medical condition. For this study, we used impact scores. Scoring ranged between 0 and 19, with higher scores indicating a greater impact. A £25 electronic shopping voucher was emailed to the programme participants on completion of the baseline and end-of-programme feedback forms.

HPC programme participant feedback forms

Participants in the HPC programme who consented to take part in the research were emailed a link to the End of Programme Feedback Questionnaire as a secure *Microsoft Form* during their final session. The questions asked for information about how they heard about the programme, the course delivery and their experiences of participation.

Questions were asked about attendance and any reasons or perceived barriers to this.

As this was the first time the programme had been delivered online, it was particularly important for us to seek participants' experiences of this delivery format. Therefore, questions were asked about online facilitation and any barriers to accessing online platforms.

Stakeholder workshop 3

CWG members and facilitators both attended workshop 3, which aimed to gain postimplementation insight into the roles, expectations, gaps and tasks involved in the implementation of the HPC programme.

Workshop attendants were divided into two small groups that met online on different days. Groups comprised a mix of roles from both organisations. Roles included a senior manager, responsible for the strategic and budgetary decisions; personnel who coordinated the day-to-day delivery tasks, Lead and Assistant Facilitators, trainers and researchers. The interactive group-based format of the workshop allowed for greater cross-role discussions into the challenges of implementation led by nonprofit organisations. Experienced qualitative researchers facilitated the workshops.

The workshops explored the key roles, processes and knowledge required to implement the programme. During the workshop, we used the online platform MIRO™ which is a large, interactive and collaborative board to collect data. Those attending the workshop could simultaneously add notes, discussions and diagrams to the Miro board. Postworkshop, the data were organised into different categories based on what they referred to.

Stakeholder workshop 4

Workshop 4 focused on longer-term sustainability strategies. Members of the CWG met with commissioners, representatives from other delivery partner organisations and Parent Carer Forums to discuss potential wider rollout. These new stakeholders were engaged in a consultation capacity and their consent for research was not formally documented. The agenda included core themes for discussion based on information generated from workshop 3 and pilot testing, including sustainability, and hopes and barriers to delivering the programme in the future. The workshop was facilitated by the study's principal investigator. Members of the study team met afterwards to identify core learning and themes from the workshop.

Analyses

Descriptive statistics were used to describe the flow of HPC participants through the study, summarise baseline demographics, baseline scores for the AMC,[30] and responses to follow up. SPSS was used to analyse descriptive statistics, including the numbers and percentages of HPC participants choosing each response option in the follow-up feedback questionnaire.

Qualitative data collected in stakeholder workshops, including notes on the Miro board and field/meeting notes, were analysed descriptively. We used pragmatic content analysis and sorted the comments and quotes into categories relating to different aspects of the implementation.

RESULTS

Across the series of four workshops, a range of personnel attended (Table 2).

Table 2 Role and number of personnel attending each workshop.

Role	Workshop 1	Workshop 2	Workshop 3	Workshop 4
Delivery partner manager/coordinator	2	3	4	3

Lead/Assistant Facilitators	2	2	6	1
Research team/co-investigator	7	6	4	3
Business Development Manager University of Exeter	0	1	0	1
Parent Carer Forum representative	0	0	0	2
Commissioner/funder	0	0	0	4

REP phase 1: Preconditions: Identifying barriers, need and drafting implementation package

Workshop 1 was attended by members of the CWG. Members gained a shared understanding of similarities and differences in terms of the set-up and training needs for the HPC compared to similar programmes run by partner organisations. This enabled the implementation package to be developed and possible gaps in training and resources identified. After this workshop, a draft of the Implementation Logic Model was developed. The model was further refined after each workshop.

REP phase 2: Optimising implementation

Members of the CWG met again in workshop 2 to discuss the proposed Implementation Package and add additional information on costings, data collection and the terms of a licensing agreement. Key roles and responsibilities were assigned to specific personnel, these included advertising, preparation of materials, support calls and supervision. Specification for the Lead role includes having knowledge and understanding of the issues affecting disabled children, young people and their families and the key challenges that parent carers face; the ability to work with parents in a sensitive and empathic way and experience in delivering training or support to others. Assistant Facilitator role descriptors include knowledge and understanding of how being a parent carer can impact on personal health and wellbeing, and experiences or aspirations to improve the health and wellbeing of other parent carers. Four freelance facilitators (two Lead Facilitators and two Assistant Facilitators) were recruited by the delivery partners and they consented to take part in the research. Facilitator characteristics were collected via the pretraining baseline questionnaire, which included age, sex, motivations to be a facilitator, relevant experience and expectations of delivering the programme.

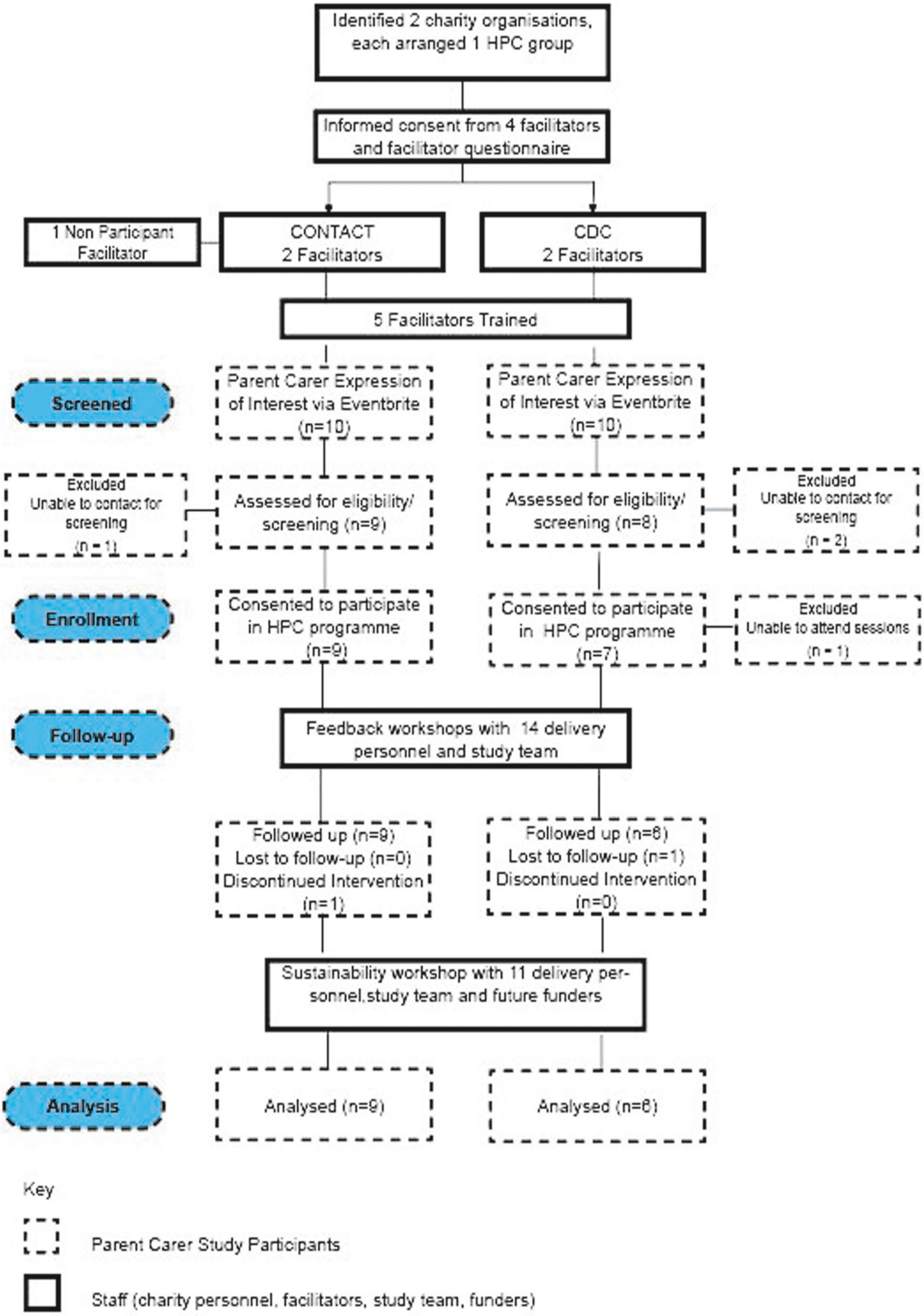
REP phase 2: Pilot testing of the implementationFacilitator recruitment and training

All facilitators approached by the organisations agreed to participate. Contact trained a ‘reserve’ Lead Facilitator, who also participated in the CWG. These five facilitators completed the online training to deliver the programme. Lead Facilitators attended 36 h of online training, and Assistant Facilitators attended 18 h in total. The training was delivered in two ‘Blocks’. Each block consisted of 3 days of training. Block 1 was just for Lead Facilitators, and Block 2 was attended by all facilitators.

HPC programme participant demographics and feedbackHPC programme participants' demographics

Twenty parent carers expressed an interest in the programme (Contact *n* = 10; CDC *n* = 10). Three parent carers did not respond to further contact after initial enquiries; 17 were formally assessed for eligibility (Contact = 9; CDC = 8). One programme participant (from CDC) was unable to attend the programme at the available dates or times. All 16 remaining participants consented to participate in the research and completed baseline questionnaires. Fifteen participants completed a follow-up questionnaire after the programme finished. One programme participant withdrew after the group had started but remained in the study and was able to complete the follow-up questionnaire. Programme participants had a mean (SD) age of 44.1 (3.9) years, 15/16 (94%) were female, 6/16 (38%) were

Asian/Asian British, 6/16 (38%) were White and 4/16 (25%) were Black/African/Caribbean/Black British. Sixty-three percent (10/16) of participants were married, or in a civil partnership, 11/16 (69%) were unemployed and 10/16 (63%) had two or more Advanced-Level qualifications (recognised for entrance to higher education) or above. Nineteen percent (3/16) of participants lived in a postcode ranked in the most deprived quintile based on the index of Multiple Deprivation 2019.[31] The total mean score for participant's index child on the AMC was 53, with a range of 37. Participants' demographic characteristics at baseline are summarised in Supporting Information Materials: Table S1. Figure 2 illustrates the study design and the flow of participants.



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HPC programme participants' feedback

Fifteen participants who completed the end-of-programme questionnaire reported hearing about the study via Parent Carer Forums (*n* = 5), social media/word of mouth (*n* = 6) or via delivery organisations (*n* = 3). All reported that the initial pre-meeting with the facilitator was helpful in making them feel comfortable to attend. Most participants, 14/15 (93%), were happy to access an online group, were satisfied with how the programme was delivered and reported that they found it useful in helping them to improve their health and wellbeing. Sixty percent (9/15) of participants stated that they would not have been able to attend an in-person group. All respondents stated that they would recommend this programme and felt included and part of the group.

Ninety-three percent (14/15) of participants did not experience any issues with their internet connection during the programme. Eighty-seven percent (13/15) of participants felt that the date and times of the sessions were fine, and 11/15 (73%) felt that the length of the sessions was about right. Ninety-three percent (14/15) of participants said that they were able to, and confident in accessing the online platforms used in the groups (Zoom™, JamBoard™).

Ninety-three percent (14/15) stated that they had missed a group session, with 7/16 (44%) specifically reporting that they attended 10/12 sessions in total. All participants reported attending at least one session. The most commonly reported reasons for missing sessions were due to work commitments (*n* = 3), illness/medical appointments (*n* = 4) and caring responsibilities (*n* = 5).

Workshops 3: Delivery partners' experiences of implementing HPC

During workshop 3, key considerations for implementation were identified. These included coordination and administrative roles to support implementation activities and the acknowledgement of the time commitment required by staff from delivery organisations. Furthermore, online delivery was perceived to enhance accessibility by reaching more people more expediently and inexpensively. Specific topics raised in this workshop included: (i) key aspects of successful implementation, (ii) the specific resources the research team utilised to achieve this, (iii) what, if any, equivalents the delivery partners had to achieve this or (iv) if there were any potential barriers or different ways to deliver within different contexts.

Clear roles within the delivery organisations were also identified around the different tasks involved in implementation; these included: strategic management, to support the integration within the organisation, identify staff and costs to support the delivery of the programme; Project Management, to identify facilitators and coordinate programme set up and recruitment; Supervisors, who have knowledge of the programme but also are skilled in supporting with risk and the emotional wellbeing of the facilitators where required; Administration, to support with posting and printing resources, setting up Eventbrite and calendar invites for programme participants to attend groups; Trainers, who are skilled facilitators, with in-depth knowledge of the programme; Lead Facilitators, who are experienced, with the required level of skills to support parent carers and Assistant Facilitators, with some knowledge and understanding of how being a parent carer can impact on personal health and wellbeing. Four categories related to roles and tasks were identified: Coordination of the Programme; Knowledge of the Programme; Governance and Strategic Direction (Box 1).

1:**BoxSpecific tasks, knowledge and skills required for delivery, identified by participants in workshop 3**

Tasks/roles

•-

Coordinating admin tasks/streamline admin processes

•-

Choosing dates

- Design recruitment plan
- Design advert/marketing
- Arrange supervision
- Supporting the facilitators
- In-depth understanding of the programme
- Set up and monitor Eventbrite™
- Contacting parent-carers who sign up
- Send out Zoom™ links
- Emailing resources to facilitators
- Printing/getting quotes for printing
- Arranging support calls

Knowledge of programme

- Identifying appropriate facilitators—with necessary skills and competencies
- Knowing what the facilitator needs

Governance (safeguarding, GDPR, quality assurance)

- Quality assurance of delivery and training
- Ensure the knowledge of the programme is and stays ‘in house’

- Memorandum of Understanding—adding detail to the manualised template relevant to Delivery partner organisations (facilitator: organisation; funder: organisation)
- Managing consent/GDPR considerations/GDPR considerations and control
- Monitor/communicate safeguarding/safeguarding training—need shared understanding of this—piece of work to agree on this
- Monitoring and evaluating—reporting and collation
- Insurance and DBS up to date
- Considering intellectual property, not for profit sharing but maintaining quality
- Accountable for safeguarding policies
- Trademark/Certificate of facilitation/recognise delivery programme)

Strategic direction (funding, staffing negotiation)

- Determine if fundable/secure funding to support delivery/negotiate with funder/monitor if self-sustainable
- Make decisions about how much money to spend
- Create staff capacity
- Negotiate payments/agree on rates for facilitators
- Prioritising and opportunity/cost planning: Situate within strategic aims (and is it fundable/deliverable)
- Strategic planning

As a result of this workshop, the Implementation Logic Model and Implementation Package were further refined.

Coordination of the programme

Stakeholders discussed the specific tasks required to implement the programme, these included choosing dates, creating an advert, contacting participants and printing resources. It became clear that there was a need to distinguish between coordination and administration tasks. One delivery partner coordinator stated that they recognised the importance of having specific administrative support to successfully deliver the programme: ‘Admin is a separate role and is essential for the successful delivery of HPC’.

It was apparent that providing the organisations with the manuals and introduction to the programme through the initial workshops and premeeting was insufficient to manage concerns and expectations around the implementation of the programme, independent of the study team. One workshop participant stated that, ‘There was a lot of anxiety from the facilitators about the newness of the programme and the coordinators felt unsure about their roles and what was required’. Delivery partner staff also reported that they did not always feel able to make autonomous decisions, and noted the importance of ‘feeling empowered to make decisions around budgets, paperwork, date, etc’.

Knowledge of the programme

Delivery partner staff noted that in-depth knowledge was required to ensure successful implementation. For example, one manager commented that it was important to be able to ‘Identify appropriate facilitators with the necessary skills and competencies’, which required a level of knowledge about the programme to find the appropriate people.

Governance

The importance of maintaining fidelity to the model and quality assurance was discussed by delivery partner staff, who expressed that it needed to be, ‘ensured that the knowledge of the programme stays “in house”’. Participants also noted the need for governance processes to be clear; for example, one member of the delivery partner organisation noted that organisationally there needed to be a consideration around the ‘quality assurance of delivery and training’.

Strategic direction

The cost of delivering the programme on an ongoing basis and how it aligned to the strategic aims of their organisation was discussed by senior management, who explained the need to ‘prioritise the opportunity and cost [of running the programme] and how to situate it within its strategic aims’.

Consideration was given to the longer-term sustainability of the programme, with a senior manager commenting, that ‘[they needed to continue] monitoring whether the programme is self-sustaining’. They also noted that they needed to ensure the programme was sustainable from a resource and cost perspective: ‘[we need to] secure funding to support delivery and ensure it's over and above the minimum needed’.

Workshop 4: Sustainability strategies for a wider rollout

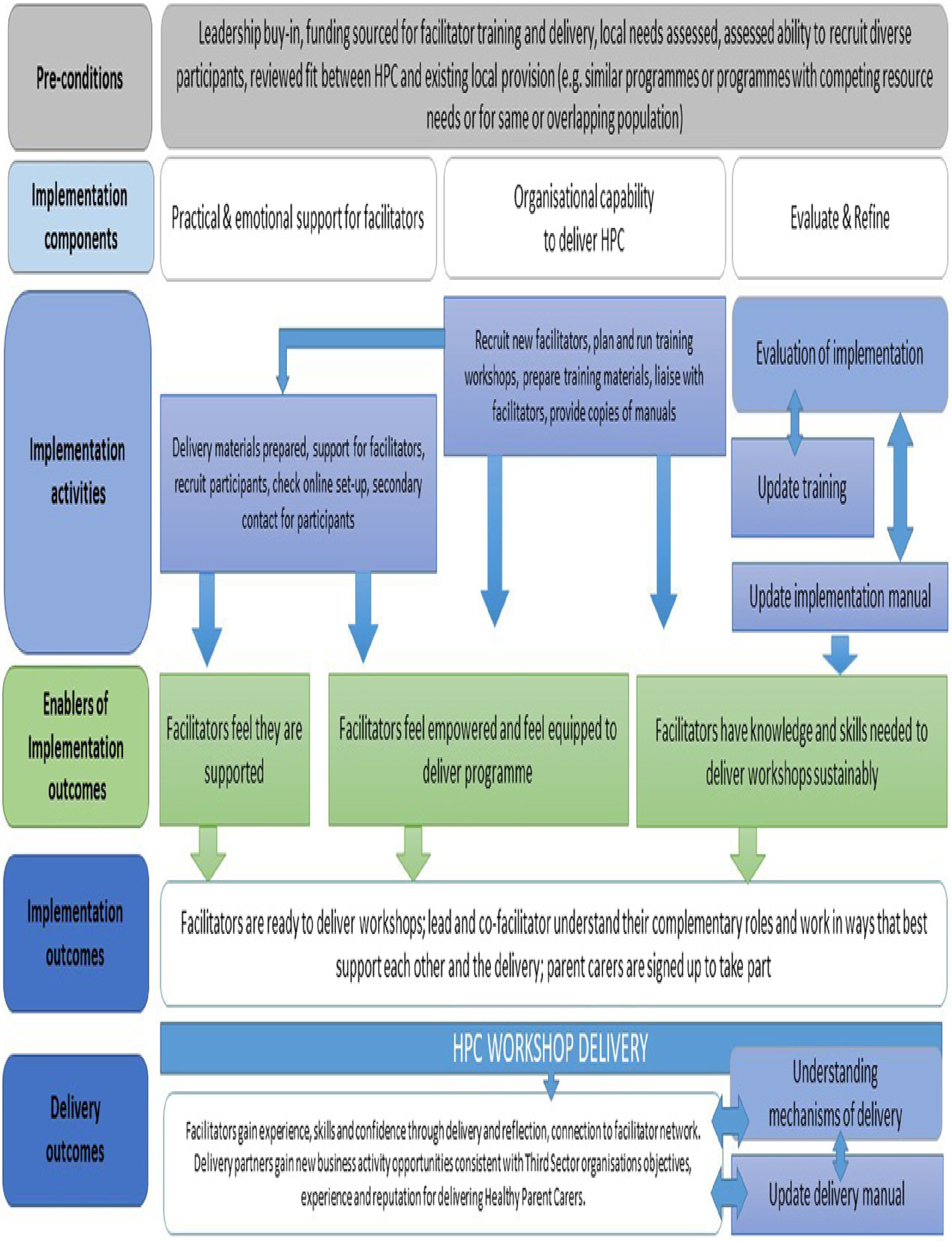
Workshop 4 presented an opportunity for a wider group of stakeholders to express views around the sustainability, hopes and barriers of delivering the programme now and in the future. It was attended by 14 participants, including three members of the research team, one commissioner, the Head of Service for Disabled Children, two members of an independent nonprofit organisation, two Parent Carer Forum chairs, the Business Development Manager from the University of Exeter, and the Director of Participation of Contact, and the Principal Officer of the CDC (see Table 2).

During the workshop participants discussed how impactful the programme could be for parent carers. One facilitator discussed the transformational effects it had on parents. The commissioner perceived the potential impact of the programme in potentially reaching and benefiting a larger number of parent carers. Discussions also took place around the potential economic advantages of delivering the programme online, including the potential for less overheads such as the hiring of a venue, time and payments for travelling.

However, challenges were noted specifically around how to maintain quality assurance, while increasing the number of courses delivered. A senior member of one organisation discussed their enthusiasm to deliver the programme but was concerned about not losing the quality when delivering on a much larger scale. A key point raised during the workshop was the recognition of the time commitment for parent carers to be trained and to deliver the programme on an ongoing basis. Workshop members shared opinions on the potential challenges of identifying parent carers with enough time and commitment available to deliver the programme.

Figure 3 is the final version of the HPC Implementation Logic Model that was developed iteratively over the course of the study. We found that the components associated with the successful implementation of the programme include ensuring that partner organisations felt empowered to deliver the programme by equipping them with the necessary skills, knowledge and expertise to enable delivery. The Implementation Logic Model indicates how organisational buy-in, funding and assessment of existing provision and local needs are required to be in place before delivery partner organisations sign up to implement delivering HPC programme as well as access to the right skills mix of staff and level of expertise within their team. A shared understanding of the complementary roles, including strategic management, coordination and administration supported successful delivery. Practical considerations, such as the preparation of materials, access to appropriate recruitment mechanisms, such as *Eventbrite™* and a mailing list of parent carers, or social media links with parent carers proved to be effective recruitment strategies.

Logic model: Successful Implementation of the Healthy Parent Carer Programme, to ensure organisations and facilitators feel supported, empowered, and have the skills and knowledge to sustainably deliver the programme



Pre-conditions

Leadership buy-in, funding sourced for facilitator training and delivery, local needs assessed, assessed ability to recruit diverse participants, reviewed fit between HPC and existing local provision (e.g. similar programmes or programmes with competing resource needs or for same or overlapping population)

Implementation components

Practical & emotional support for facilitators

Organisational capability to deliver HPC

Evaluate & Refine

Implementation activities

Recruit new facilitators, plan and run training workshops, prepare training materials, liaise with facilitators, provide copies of manuals

Delivery materials prepared, support for facilitators, recruit participants, check online set-up, secondary contact for participants

Evaluation of implementation

Update training

Update implementation manual

Enablers of Implementation outcomes

Facilitators feel they are supported

Facilitators feel empowered and feel equipped to deliver programme

Facilitators have knowledge and skills needed to deliver workshops sustainably

Implementation outcomes

Facilitators are ready to deliver workshops; lead and co-facilitator understand their complementary roles and work in ways that best support each other and the delivery; parent carers are signed up to take part

HPC WORKSHOP DELIVERY

Delivery outcomes

Facilitators gain experience, skills and confidence through delivery and reflection, connection to facilitator network. Delivery partners gain new business activity opportunities consistent with Third Sector organisations objectives, experience and reputation for delivering Healthy Parent Carers.

Understanding mechanisms of delivery

Update delivery manual

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DISCUSSION

Using the initial phases of the REP framework, we engaged a wide range of stakeholders to explore the implementation of the HPC programme by a delivery partner organisation in the community rather than being managed by researchers. This is consistent with existing research, which shows following an evidence-based formation such as REP is an easy and accessible framework which can help to support the identification of barriers and address implementation strategies.[32] The two partner organisations involved in this study were able to recruit facilitators, participants and deliver the programme online to parent carers within different geographical regions and with participants from a wider range of ethnic backgrounds than in our earlier studies.[27] Although the sample is small and thus the results are preliminary, feedback from staff, facilitators and participants was positive.

The study provides a further contextual understanding of the programme's implementation in different settings, taking a range of diverse perspectives, motivations and drivers into account. It provides key considerations for implementation at different levels, such as the importance of coordination and administration roles to support implementation activities effectively, and acknowledgement of the time commitments involved for delivery partner organisation personnel and facilitators, particularly when considering parent carers' responsibilities to ensure the future-proofing of the programme and its implementation. It also highlights important governance considerations, including ensuring quality assurance to ensure fidelity when delivery is scaled up. The results also indicate the need for staff to be knowledgeable about the programme and its delivery when implementing it for the first time, potentially beyond a manualised format.

This study not only identified barriers and facilitators to implementation but also used that information to develop an implementation package that addresses these issues. Similar studies show that identifying and documenting effective strategies can help to improve uptake[33] and increase the chances that the intervention is sustainable, scalable and adaptable to local service provision. It also highlights any specific local resources which may need to be priortised, and further provides a foundation from which the effectiveness of a scalable version of the programme can be tested.[34,35]

The HPC programme was originally designed to be delivered in person. COVID-19 presented both challenges but also a serendipitous opportunity to develop an online delivery version of the programme. Every aspect of the study was adapted to be delivered online, including facilitator training, workshops, meetings, recruitment, consent meetings and data collection. This provided invaluable learning around how to deliver the programme online and thus has changed our strategies around implementation moving forward.

An online format appears both an acceptable and practicable form of delivery. Online delivery provides a valuable alternative to in-person delivery and potentially increases the programme's accessibility. For example, 7/16 participants, (44%) specifically reported that they had attended 10/12 sessions, compared to 57% of participants in our previous feasibility study, who attended 8/12 sessions. Furthermore, all participants in the current study reported attending at least one session, compared to the previous feasibility study, where 34% did not attend any sessions.[27] Participants reported missing sessions for similar reasons, with the only addition of distance to travel being a reason for nonattendance in the in-person feasibility study. These results could indicate that an online delivery format may be beneficial to parent carers to help increase their ability to attend sessions more easily. Nevertheless, we were mindful of potential safeguarding issues as the world moved online in the pandemic and took account of published recommendations on digital safeguarding principles.[36] The online format also increases the sustainability and scalability of the programme by reducing the costs involved in face-to-face delivery, such as travel and venue hire, and may provide access to parent carers in remote areas or who cannot get to an in-person group on a regular basis. However, further research will compare face-to-face and online delivery in terms of acceptability, engagement, and effectiveness. We are also considering how personal and contextual factors might influence engagement with the HPC programme and how we can ensure acceptability and equity, especially as online interventions may worsen inequality.[37]

In line with the findings from our previous study, participants reported that taking part in the programme helped to improve their health and wellbeing, and felt included and part of the group, suggesting that the specific strategies we adopted enabled the online groups to build positive connections.[38] We believe that completing the programme modification work in collaboration with our Family Faculty public involvement group and giving attention to the group processes in the training and delivery manuals were key to maintaining these benefits.

Strengths and limitations

The strength of this research was that it followed systematically the REP framework, which provided an iterative, collaborative process with extensive stakeholder engagement to revise implementation and delivery strategies and processes in real-world contexts.[29]

The current study has some limitations. The small number of delivery partners and participants involved is not necessarily representative of all potential delivery partners and eligible participants. In addition, research staff were more involved than initially intended. However, this is consistent with other studies during phases 1 and 2 of the REP framework.[39] Further work to incrementally hand over responsibilities for training and delivery to delivery partner organisations is needed. In addition, future research across a larger number of and more diverse organisations, for example, local authorities and smaller delivery partner organisations, would allow us to continue to refine the implementation model for scalable rollout both nationally and internationally.

Implications and optimal implementation strategies

There is a growing field of parent-carer-focused interventions that either aim to teach parents about their child's condition, offer practical parental support, including advice and self-care for their child's needs or self-empowerment to interact with professionals.[40,41] However, none of these interventions specifically target the health and wellbeing of all parent carers. The HPC Programme was designed specifically in response to this need and gap in current provision.

Online recruitment seemed to work well and therefore similar strategies could be employed in the future to advertise and recruit to the programme. Other strategies that could be considered in future implementation included the use of Eventbrite™ and a template poster, which can be adapted by organisations. Specific consideration may be required in terms of the information provided in the advert, and the screening information collected via Eventbrite™, as this could help to ensure that people are adequately informed about the commitments involved and the aims and objectives of the programme. This may help to ensure higher retention rates. Advertising through online Parent Carer Forums provided a quick and effective means of recruitment; therefore, this method should be considered again when running future programmes. However, consideration should also be given around how to ensure parent carers who are not connected to these forums can be reached.

Despite organisations and facilitators having access to detailed manuals to support implementation, there was a lot of intrinsic knowledge required to run the programme. Facilitators and implementation staff preferred a dual approach, where information was provided both verbally, through in-person meetings and through reading the manuals. Other comparable, REP-based studies, similarly suggest that implementation with an independent, experienced facilitator, alongside standalone manuals could be a useful model to help community-based organisations feel more confident to deliver, while they build up knowledge and further confidence to deliver the programme independently.[32] Offering this approach potentially creates a more efficient implementation strategy and optimises early engagement, while allowing closer monitoring of the quality and fidelity of the programme. We will explore this as an option in the future evaluation of the programme. However, this does have an associated cost implication. The costs are likely to reduce over time, as materials and knowledge within organisations can be built upon and reused.

Evaluating the costs and benefits of running the programme is an important consideration in terms of its long-term sustainability. Within the current study, two trainers, with equal responsibility, co-delivered the training. However, since the programmes rollout, in the spring of 2022, this model changed to Lead and Assistant Trainers being employed with different remuneration rates. This is to optimise the likely affordability of the programme, as well as acknowledge the importance of modelling the different Lead and Assistant Facilitator roles. This model also creates training and employment opportunities for parent carers and may be more sustainable.[27]

CONCLUSION

Building on our earlier findings, which established satisfaction with the in-person programme and programme and workshop participant reports of improved health and wellbeing, the current study demonstrated that it was feasible for trained staff from two different Delivery partner organisations to implement a programme developed by a research team.[27,38] This research suggests that delivering the programme online is a feasible and acceptable mode of delivery and potentially creates more accessibility and reach and may reduce costs. This study enabled the creation of a promising Implementation Package and logic model. Further evaluation with organisations from a wider range of contexts and sectors is now needed within an implementation, or hybrid implementation-effectiveness trial.

AUTHORS CONTRIBUTIONS

All authors contributed. Christopher Morris led the development programme and was the principal investigator. Alice Garrood managed the project, including overseeing day-to-day recruitment and data collection. Gretchen Bjornstad, Alice Garrood and Christopher Morris drafted the initial study design with input from Sarah Brand, Jenny Lloyd, Annabel McDonald, Mary Fredlund, Aleksandra Borek, Mark Tarrant, Annie Hawton, Vashti Berry and Stuart Logan. Aleksandra Borek, Annabel McDonald, Mary Fredlund and Christopher Morris designed the original programme. Annette Gillett, Annabel McDonald and Mary Fredlund revised the online version of the Facilitator Delivery Manual, with input from Aleksandra Borek, Christopher Morris, Gretchen Bjornstad and members of the Peninsula Childhood Disability Research Unit (PenCRU) Family Faculty. Aleksandra Borek coordinated the family's faulty stakeholder involvement. Sarah Brand designed the implementation elements and workshops along with Jenny Lloyd. Gretchen Bjornstad and Alice Garrood analysed the baseline and outcome data. Council for Disabled Children (CDC) and Contact recruited programme facilitators and arranged delivery sites. Annabel McDonald and Mary Fredlund planned, prepared and delivered facilitator training and support. CDC and Contact, with the support of Alice Garrood, recruited participants and facilitated data collection. All authors served on the Project Management Group, contributed to drafting this paper, and approved the final manuscript.

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Department of Health and Social Care.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

The University of Exeter Medical School Research Ethics Committee approved the study (UEMS REC 20/09/258). Delivery partner staff, facilitators and HPC programme participants all documented their consent to participate. Workshop 4 was a stakeholder consultation event so formal consent was not sought or documented.

DETAILS

Subject:	Health problems; Behavior; Children with disabilities; Facilitators; Context; Charity; Intervention; Health status; Caregivers; Sustainability; Personal health; COVID-19; Working groups; Workshops; Disability; Mental disorders; Stakeholders; Commissioners; Learning; Recruitment; Health care; Pandemics; Medical research; Implementation; Physical training; Mental health; Support groups
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Reconsidering patient-centred care: Authority, expertise and abandonment

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ProQuest document link

ABSTRACT (ENGLISH)

Patient-centred care is commonly framed as a means to guard against the problem of medical paternalism, exemplified in historical attitudes of ‘doctor knows best’. In this sense, patient-centred care (PCC) is often regarded as a moral imperative. Reviews of its adoption in healthcare settings do not find any consistent improvement in health outcomes; however, these results are generally interpreted as pointing to the need for more or ‘better’ training for staff, rather than raising more fundamental questions. Patient autonomy is generally foregrounded in conceptualizations of PCC, to be actualized through the exercising of choice and control. But examining healthcare interaction in practice shows that when professionals attempt to enact these underpinnings, it often results in the sidelining of medical expertise that patients want or need. The outcome is that patients can feel abandoned to make decisions they feel unqualified to make, or even that care standards may not be met. This helps to explain why PCC has not produced the hoped-for improvement in health outcomes. It also suggests that, rather than focusing on scoring individual consultations, we need to consider how medical expertise can be rehabilitated for a 21st century public, and how patient expertise can be better incorporated into co-design and co-production of services and resources rather than being seen as something to be expressed through a binary notion of control.

Patient and Public Contribution

This viewpoint draws on research conducted by the author across a range of settings in health and social care, all of which incorporated patient and public involvement when it was conducted.

FULL TEXT

BACKGROUND

‘Patient-centred care’ (PCC) is a term first adopted by the psychoanalyst Michael Balint in the 1950s, in his work with English General Practitioners.[1] However, Balint sometimes used other terms, such as ‘patient-oriented’, and even at the outset, definitions were tricky; he defined it largely in terms of what it was not- the strictly biological, reductionist approach of illness-centred medicine—rather than what it was. Balint was an advocate for holism, invoking the ‘pathology of the whole person’; in accordance with his psychoanalytic background, his emphasis was very much on relational matters. However, he also stressed to the practitioners that he worked with that they were participants in a ‘lop-sided’ relationship, because of the asymmetrical distribution of medical knowledge between patient and doctor, and the fact that the patient sought consultations because they were unable to understand or resolve medical problems independently. The first empirical application of the concept of PCC was in the 1970s, in Patrick Byrne and Barrie Long's work; they audio recorded the consultations of 60 UK GPs.[2] Analytically, they drew distinctions between doctor or patient-centred behaviours, with the implication that patient-centred behaviours were to be aspired to and doctor-centred ones avoided. An example of this analysis in practice is that asking broad questions was seen as patient-centred, whereas closed ones were seen as doctor-centred.

Beginning contemporaneously with Byrne and Long's work, the 1970s and 1980s also saw the development of highly influential sociological work focused on the doctor/patient relationship, with sociologists such as Elliot Mishler and Howard Waitzkin conceptualizing the practice of medicine as a conflict or a struggle, through which patients were suppressed. This work brought ideas about medical paternalism to a wider audience, highlighting it as a problem that needed to be solved. And from the 1980s onwards, patient-centred medicine began to be promoted both as an approach in its own right, rather than as a feature of other approaches, and as the way to address this problem of conflicting agendas between doctor and patient. The specific approach was developed by Joseph Levenstein and colleagues working in the Family Medicine Department at the University of Western Ontario in Canada[3]; for Levenstein and colleagues, patient-centredness is a clinical method to address conflict.

HOW IS PATIENT-CENTRED CARE DEFINED NOW?

Since the 1980s, there have been a range of attempts to further specify, define and measure PCC, but without any clear consensus. While there are now a variety of definitions and measuring tools (the UK charity The Health Foundation says there are more than 160), what seems to unite them is an emphasis on the importance of a transfer of control from doctor to patient. This is seen as a necessary counter to the problem of medical paternalism, as exemplified by the historical attitude that ‘doctor knows best’. However, as researchers have shown, commonly used measurement tools can produce quite different results as to whether the same healthcare consultation can be judged patient-centred or not,[4] which casts some doubts on their utility.

PATIENT-CENTRED VERSUS PERSON-CENTRED?

It is worth noting here that the term patient-centred is sometimes used interchangeably with the term ‘person-centred’. For example, updates in UK health policy documents have sometimes replaced the former term with the latter, without any other changes. However, the terms have different roots: 'person-centred' originates in the work of the psychologist Carl Rogers and describes a particular approach in psychotherapy. Person-centred therapy gets its name from the fact that its focus is on the client's subjective view of the world. But as the sociologist Nikolas Rose has illustrated so well, vocabularies taken from therapeutic contexts are increasingly used across a much wider range of contexts and practices.[5] This can be problematic because the basis of psychotherapeutic work is an individual's own internal thoughts and feeling states. While it is widely acknowledged that an individual has privileged access to these, it is also widely accepted that there is not usually an equal distribution of clinical knowledge between a healthcare professional and their patient or client. Indeed, this was one of the key features of Balint's description of the 'lop-sided' relationship between doctor and patient. A person's expert status in talking about their feelings cannot be straightforwardly transferred to understanding their symptoms, for example. This is one reason why using the terms interchangeably is problematic; another is that personhood as a philosophical concept used by authors such as Kitwood,[6] and patienthood as a practical one (e.g., in an acute care appointment), are not easily or straightforwardly substitutable by simply swapping one word for another in an otherwise unchanged policy context.

WHAT IS THE EVIDENCE FOR PATIENT-CENTRED CARE?

The widespread adoption of PCC in NHS policy for service delivery might suggest a strong evidence base. However, examining the empirical evidence for the effectiveness of PCC tells a different story. While there are individual studies which report positive impacts, wider research (including Cochrane systematic reviews of PCC interventions) does not show a clear link between the adoption of PCC in a setting, and a corresponding improvement in health outcomes.[7] Some reviews have been able to demonstrate increased patient satisfaction where PCC is practised, but even this is not universally true. The only consistent finding is a circularity: that where practitioners are trained to use a particular PCC intervention, this increases the practice of PCC as measured by that specific intervention. However, this lack of evidence for the impact of PCC has not prompted a more critical re-evaluation. Instead, the problem is usually laid at the door of professionals, with an assumption that if only we could give them more or 'better' training in PCC, we would obtain the missing evidence.

WHY DOESN'T PCC WORK IN PRACTICE?

As I have shown, the pervasiveness of PCC is not grounded in empirical evidence. Instead, it is based on a moral position that makes intuitive sense. But I analysed a large corpus of audio and video recorded healthcare interactions collected over a 25-year period from a wide range of healthcare settings that were underpinned by a commitment to practise PCC.[8] In all of these settings I had observed that attempts to practice PCC sometimes ran into difficulties, and I wanted to understand why. Examining these interactions as they actually unfold on wards, clinics and consulting rooms shows that there is not generally the struggle for control that PCC assumes. PCC is underpinned by the language of patient autonomy and choice, but a focus on control as a property that rests with only one or the other party can obscure the way that choice and control are negotiated and constructed collaboratively. The issue that I came across repeatedly in my data was that, if choice and control are seen as properly belonging exclusively to patients, there is no longer any clear place for medical expertise in healthcare decision making. There are two potential consequences of this, and both are problematic for patients. The first is that medical decisions can become cast as purely private matters that patients must deal with alone, based on how they 'feel' about the options or how much they 'worry' about the alternatives. Whilst such an approach undoubtedly preserves patient autonomy, it does not necessarily bring about the empowerment promised by PCC. Instead, it can result in patients feeling abandoned, and trying to elicit medical advice indirectly, through questions such as 'What would you do in my situation?' or 'What do most people do?'.

The second potential consequence of giving control to the patient- and perhaps its logical end point, if this is assumed to be the ultimate aim of PCC- is in practices of affirmative care. From an affirmative care perspective, the professional's role is to empathetically support the assertions of the client, and client understandings of their situation are not to be challenged or questioned. Sociologically speaking, this kind of approach has its roots in a wider cultural movement where the revelation of inner experience leads inexorably and unproblematically to truth or authenticity.[9] However, in practical terms, it officially removes dimensions of the resources that professionals might otherwise bring to bear in healthcare consultations, such as their knowledge of how different courses of action have impacted different patients in different contexts. As Hilary Cass's current UK inquiry into the provision of gender identity services for under 18s has highlighted, the end point of this approach may potentially be in practices that do not meet care standards.

WHAT IS THE ALTERNATIVE?

I argue that there are two things that we need to make happen. We need to begin by recognizing the difference between medical *expertise* (meaning the right to knowledge in a particular area) and medical *authority* (meaning the right to decide what should happen based on that knowledge). PCC has rightly highlighted that medical authority can be problematic, in rejecting the ‘doctor knows best’ attitude of unilateral medical paternalism. Successive investigations into high profile medical scandals, such as the Francis Inquiry in the United Kingdom, have shown the role that a culture of unchallenged medical authority can play in these, and the need to address this. However, with its emphasis on choice and control, PCC has inadvertently problematised medical expertise as well. All the evidence from my data shows that medical expertise is important to patients; a large part of why they consult with a healthcare professional in the first place is because they don't treat all sources of healthcare information as equal, and they lack the knowledge, or the ability to apply that knowledge, to solve their own problems. This suggests that instead of continuing existing training endeavours in the hope that professionals will practice ‘better’ PCC, it would be more fruitful to recognize that professionals are sources of knowledge that patients both want and need, and to think about how we can re-centre medical expertise in the practice of contemporary healthcare in ways that are productive for and acceptable to patients. This does not mean that patient expertise is not important- far from it- but it also means we need to think about how this can be best elicited, incorporated and utilized. Rather than using different tools to score the extent to which individual consultations allow patients to express this (and in the knowledge that different PCC measurement tools have been shown to produce quite different results for the same consultations), we need to shift our focus to how this patient expertise can be incorporated on a wider and more fundamental level. Co-design of services and co-production of healthcare resources are important ways in which the central importance of patient perspectives and experience can be recognized and incorporated in a collaborative rather than conflict-based model of healthcare.

The second thing we need to do is to recognize that, wherever patient-facing healthcare policies are formulated, most will depend on being talked into existence at the point of care delivery. This means that, without an understanding of how healthcare interaction works in practice, they are potentially set up to fail. PCC is founded in a moral position, rather than empirical evidence, but as the constant search for ‘better’ training in an attempt to evidence an impact on healthcare outcomes shows, the problem with this is that it becomes very difficult to step outside the moral shelter of the position, even in the face of contradictory evidence. If control is simplistically conceptualized as a consumerist property, then it belongs only to one or other party, but in real-life healthcare interaction it is negotiated and constructed collaboratively. Studying healthcare delivery as it happens shows us how practices that we might imagine will promote patient empowerment, or even those that might work to promote empowerment in other settings, often don't function this way in healthcare. It is common for interaction to be studied as part of post hoc-policy evaluation. However, the example of PCC shows the need for an understanding of interaction being used to inform healthcare policy making, rather than simply using it to judge the success or failure of these policies after their implementation.

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CONFLICT OF INTEREST STATEMENT

The author declares no conflict of interest.

DATA AVAILABILITY STATEMENT

This is a Viewpoint article drawing on a range of previous research and so data sharing is not applicable.

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COVID-19 in Western Australia: ‘The last straw’ and hopes for a ‘new normal’ for parents of children with long-term conditions

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ABSTRACT (ENGLISH)

Background

Children with long-term conditions are vulnerable due to the treatments required for their conditions. Since the start of the coronavirus disease 2019 (COVID-19) pandemic, Western Australians experienced restrictions that changed daily life activities but were able to return to some of their previous routines due to the restrictions.

Aim

The study explored the stress experiences of parents caring for children with long-term conditions during COVID-19 in Western Australia.

Design and Participants

The study was codesigned with a parent representative caring for children with long-term conditions to ensure essential questions were targeted. Twelve parents of children with various long-term conditions were recruited. Ten parents completed the qualitative proforma, and two parents were interviewed in November 2020. Interviews were audio-recorded and transcribed verbatim. Data were anonymised and analysed using reflexive thematic analysis.

Findings

Two themes were produced: (1) ‘Keep my child safe’ describes the children's vulnerabilities due to their long-term conditions, the adjustments parents' made to keep their children safe and the various consequences faced. (2) ‘COVID-19's silver lining’ covers the positives of the COVID-19 pandemic, including their children having fewer infections, the availability of telehealth appointments, relationship improvements and the parent's hopes for a new normal where behaviours prevent transmission of infectious (e.g., hand sanitising).

Conclusion

Western Australia provided a unique context for the COVID-19 pandemic due to no transmission of the virus severe acute respiratory syndrome coronavirus 2 at the time of the study. The tend and befriend theory aids in explaining the parents' stress experiences, and the application highlights a unique aspect of this theory. Parents tended to their children during COVID-19, but many could no longer rely on others for connection, support and respite, and became further isolated in attempting to protect their children due to COVID-19 consequences. The findings highlight that some parents of children with long-term conditions need specific attention during times of pandemics. Further review is recommended to support parents through the impact of COVID-19 and similar crises.

Patient or Public Contribution

This study was codesigned with an experienced parent representative who was part of the research team and involved throughout the research process to ensure meaningful end-user engagement and ensure essential questions and priorities were addressed.

FULL TEXT

INTRODUCTION

The coronavirus disease 2019 (COVID-19) emerged in December 2019 and was declared by the World Health Organisation as a pandemic on 11 March 2020.[1] COVID-19 is caused by severe acute respiratory syndrome coronavirus 2 and can result in respiratory distress.[2]

Western Australia (WA) is Australia's largest state, with 33% of the total land mass.[3] Approximately 610,000 children and young people, of which 40,000 are Aboriginal, live in WA and make up 23% of the state's population.[4] It is estimated that around 262,300 children aged 0–14 have one chronic condition, and 122,000 have two or more chronic conditions in WA.[4,5] The first WA case of COVID-19 was recorded on 21 February 2020,[6] and the first death on 1 March 2020.[7] On 15 March 2020, WA was declared a state of emergency.[8] Gyms and indoor sporting facilities, playgrounds, skate parks and outside gyms in public places were closed.[8] Australians were told to stay home unless shopping for food and necessities or to address health and medical needs.[8] From 26 March to 9 April 2020, families were encouraged to keep children home.[8] One of the government's critical strategies in minimising the impact of COVID-19 was to close the national and WA state borders to travellers in March 2020.[9] Other measures included lockdowns, isolation, social distancing[8] and masks.[10] WA enforced the strongest COVID-19 border controls in Australia.[9] In May 2020, all school students were required to return to school, and restrictions started to ease.[9]

COVID-19 has significantly affected how everyone lives.[11] Previous research has confirmed that since the COVID-19 crisis, parents have experienced stress regarding social distancing, remote learning, financial difficulties and space for themselves.[12] Yet, there is a lack of literature on parents' experiences caring for children with long-term conditions, which is already known to cause stress.[13,14]

Long-term or chronic conditions among children are rising[15] and refer to a wide range of conditions, illnesses and diseases that tend to be long-lasting with persistent effects.[16] Children with long-term conditions are a vulnerable population dependent on health and education services that have been impacted by the pandemic.[17] Their parents already face higher mental health burdens as well as higher rates of work loss and financial strain due to COVID-19.[13,18] These families and children have been affected as most services required often cannot be delivered outside of a specialist setting, and it is difficult for parents to replace the support their children usually receive.[19] Families with a child with disabilities are already marginalised. Therefore, consideration of the study context is essential.[20] For example, it has been stated that the pandemic has further challenged the already difficult situations experienced by parents and their children.[18]

Stressful events may cause discomfort or trigger a stress response, but may also promote family strength and resilience.[21,22] COVID-19-related restrictions have been considered as potentially enhancing stressful events.[22] Many families have had to learn new ways of adapting to further isolation and profound unpredictability. While many will adapt and grow in resilience, others may experience stress-related disorders that are previously unknown.[23] Over time, an accumulation of financial loss, poor sleep, social isolation and unresolved fear may overload the neurobiological pathways that help people adapt to stress.[24,25] As a result of this overload, the anticipated mental health burden due to COVID-19 is vast, described as a new type of mass trauma with unprecedented public exposure.[23]

Research is therefore needed to gain insight into the impact of COVID-19 on the lives of parents caring for children with long-term conditions and their needs. WA provided a unique context to investigate the effects of COVID-19 as there was no sustained community transmission at the time of this study, but the threat had been experienced. This study was conducted in November 2020, just before the controlled interstate border was introduced, allowing very low-risk states and territories in Australia to travel to WA.[26] WA, at this time was operating at some level of normality with no community spread. Therefore, this study aimed to explore the experiences and needs of parents caring for children with long-term conditions concerning the COVID-19 pandemic and provide recommendations to improve services in preparation for possible future pandemics and crises.

METHODSDesign

This study used a rapid qualitative approach.[27–29] The study was codesigned with L. J., a parent representative who is a parent caring for children with long-term conditions. Codesign in this research study included L. J. being part of the research team and involved throughout the research process to ensure meaningful end-user engagement[30] and essential questions and priorities were addressed for this parent group. The importance of collaborating with parents caring for children with long-term conditions has been described previously.[13,31] L. J. did not participate in the study.

Participants

A purposive sample was recruited from an existing study on parents' experiences of stress caring for a child with chronic conditions,[13] conducted before COVID-19 was known and a prominent threat in WA. Parents had been previously recruited via a recognised family support organisation they were registered with.[13] Inclusion criteria were the parents' children: (a) had at least one long-term condition, (b) were aged 0–19 years, (c) diagnosed/started treatment within the last 5 years and (d) 6 months postdiagnosis/treatment. Parents were contacted via email and offered the option to complete the open-ended proforma attached to the email, or if they would prefer to be contacted by telephone and be asked the same questions by a researcher (Box 1). If no response from the email was received within 1 week, a follow-up telephone call and email were made. If no response was received from the follow-up, it was assumed that it was not a possibility for the parent to take part. An email template and telephone interview script were used to ensure the participants were provided with standardised guidelines.

1**BoxProforma/interview questions**

- Please tell us about your experience of caring for a child with chronic conditions during the coronavirus disease 2019 (COVID-19) pandemic (e.g., negative or positive impacts to you, your child and family such as access to services/support improvements/barriers).
- If your situation is different now compared to before the pandemic—please tell us how it is different (if you like, please provide examples).
- Please use this space to tell us anything you'd like to add (e.g., recommendations of improvements to services experienced during COVID-19).

Twenty eligible parents were invited to participate; one declined and seven did not respond. A final 12 participants took part in the study. A ‘parent’ was defined in this study as a person with the care responsibilities of the child.

The parents (seven mothers and five fathers) were aged between 31 and 63. One parent identified as Aboriginal Australian, nine as White Australian and two as White British. Two parents were a married couple, and three parents lived in regional WA. Three parents worked full-time, three worked part-time and six were full-time carers. Four parents had more than one child with long-term conditions.

All names have been changed and do not link to the previous article's pseudonyms[13] to further protect the parent's anonymity. The children's conditions are also categorised for anonymity purposes. A range of diagnoses was provided; most included more than one health diagnosis and required specialist care from two or more specialist health teams. Table 1 outlines the participants' profiles.

Table 1 Participant profiles.

	Parent	Child
Gender	7 Mothers and 5 fathers	8 Girls and 4 boys
Mean age (range)	43 (31–63)	10 (1–19)
Age at first diagnosis		Prebirth to 10 years
Examples of diagnoses		ADHD Autism spectrum disorder Cerebral palsy Cystic fibrosis Hydrocephalus Intellectual disability Epilepsy Genetic syndrome Tracheostomy

Abbreviation: ADHD, attention deficit hyperactivity disorder. **Data collection**

Data were collected using a proforma that consisted of three open-ended, text-box survey/interview questions (Box 1). This approach was the best option to collect rapid qualitative data before the interstate borders opened and not overburden parents. Proformas have been used successfully in other qualitative research[32,33] and are designed to encourage expansive answers from participants.[33] Interviews were also offered. The questions were developed by S. S., E. M. (experienced qualitative researchers) and L. J. (an experienced parent representative). The questions were open-ended to allow the participants to write or speak freely about their experiences. The questions were not piloted. For parents completing the questions by email, implicit informed consent was obtained when the participant completed and returned the form by email. Consent was provided verbally on the recording for parents who chose to be interviewed. Ten parents completed the open-ended proforma, and two parents opted to complete the questions via an interview with a female qualitative researcher, S. S. Interviews were semi-structured, audio recorded and transcribed verbatim. The two interviews were 26 and 44 min long. As expected, the amount of data was larger from the interviews. Yet, data were found to contain rich information in both the interviews and proformas allowing exploration into WA parents' stress at the beginning of COVID-19.

Ethical considerations

Ethical approval was obtained from the Child and Adolescent Health Service Human Research Ethics Committee (RGSS0000003233), and reciprocal approval was obtained from two universities in Perth, Australia. Research Governance approval was obtained from the tertiary children's hospital in WA.

Data analysis

The data were analysed using Braun and Clarke's[34,35] reflexive thematic analysis. This is a method for identifying, analysing and reporting themes and patterns within data and is an appropriate approach for qualitatively exploring the life experiences of underrepresented groups.[36] This study is positioned within the interpretivist paradigm, using a reflexive approach.[37] Since the lived, subjective experiences of parents caring for children with long-term conditions was an interest, and understanding the meanings that participants attributed to their stress experiences, and the subjectivity of the researchers' perspectives is acknowledged,[34] reflexive thematic analysis was an appropriate methodology. Braun and Clarke's[34,35] six phases (familiarisation with the dataset, coding, generating initial themes, developing and reviewing themes, refining, defining and naming themes and writing up) were followed. S. S. and E. M. were involved in the analysis process. The two analysts each familiarised themselves with the responses independently. Data were read and reread and initial notes and thematic labels were recorded based on initial impressions. An inductive approach was followed with semantic (surface, obvious, overt) and latent (implicit, underlying, hidden) meanings generated from the data.[37] NVivo[38] was used to manage the data. Noticeable patterns were collaboratively discussed. Eight open-ended proforma responses were doubled coded and the coding compared, and themes were refined and defined through regular meetings to advance interpretation. S. S. finalised the coding on the remaining four datasets, and any new insights were discussed between S. S. and E. M. Themes were continually reflected on and refined through this iterative process and through team discussions that involved returning to the proformas and interview transcripts. Themes were assigned that conveyed the shared meaning experienced by the participants. For example, the subtheme ‘hopes for a new normal’ was initially considered for a theme title but was revised to a subtheme as ‘COVID-19 silver linings’ captured the theme. Thematic maps were used to collate codes and data items relative to the respective themes and aided to review the connections and implement revisions[37] (see Supporting Information). All authors reviewed the final interpretations. Feedback assisted further engagement with the data and the final interpretations. The review and refinement also continued into write-up.

FINDINGS

Two themes were produced. ‘Keep my child safe’ covers the parents' fears due to their children's health vulnerabilities, the adjustments made and the consequences experienced to protect their child. ‘COVID-19's silver lining’ highlights the positives that resulted from the COVID-19 pandemic, including their children having fewer infections, telehealth appointments provided, relationship improvements and the parent's hopes for a new normal.

Key themes and related subthemes are outlined in Table 2.

Table 2 Key themes and related subthemes.

Theme 1: Keep my child safe
Subthemes
Vulnerable children
Adjustments to stay safe
Consequences
Theme 2: COVID-19's silver linings
Subthemes
Fewer infections
Telehealth
Relationship improvements
Hopes for a ‘new normal’

Abbreviation: COVID-19, coronavirus disease 2019.

Keep my child safe

Vulnerable children

The parents in this study had children with long-term conditions of which some, according to the parents, were more vulnerable to infections. Therefore, the parents were afraid and feared COVID, especially at the beginning of the pandemic, when little was known about the virus:

When Covid first hit, it was a very worrying time for our family, as we were very concerned for the health/life of our medically fragile child if he was to get COVID. (Sadie)

The parents became afraid of running out of medical supplies and medication their children depended on. Ruth highlighted the negative impact that could occur with missing just one dose of medicine for her son:

Because you've got to have medication…If he misses one dose, it increases his thing [condition] to happen more…So, if I can't get hold of his medicine…then…you're a bit dire straits [state of extreme distress].

Another fear was that their children would need hospital care for reasons other than COVID because they could not trust that the hospital was a safe place due to the pandemic. For example, one child had to attend the hospital monthly for blood transfusions. Parents mentioned that in the early stages, there was not enough hand sanitiser and masks and a lack of social distancing, as described by Emma:

Every day I'd walk in when my son was admitted and there would be piles of people standing in a group waiting to have their temperature checked and sign in online.

Similarly, there was frustration with others who did not follow the rules when attending hospital appointments which put their children at risk. Ruth described the seriousness of her child's condition and her anger at others dismissing the hospital rules:

I don't want to lose my child because somebody who I was sitting next to just can't be arsed…we'd enter into clinic and be sat out waiting with people that obviously had like common colds and stuff. But on the [hospital name] form, it said, do not enter if a cough, cold, or been in contact with someone with COVID.

The parents noticed that in the beginning, the staff at the hospital also expressed stress about the situation. According to the parents, the staff treated all children as infectious and demanded they wear masks. This behaviour made the parents feel that their children were contagious rather than vulnerable to catching the virus:

Drs and Nurses speak to him like he's a walking biohazard and not a patient. They don't consider their choice of words and can be quite offensive whether they meant to or not. (Emma)

The fear took other turns later during the pandemic, and the parents mentioned various worries, as outlined by Bronwyn:

The stress of caring for our child with complex needs was significantly increased…how we would manage in continuing to care for our daughter if either of us caught the virus but more importantly what it would mean if she caught the virus and the unknown outcome…a vaccine also presents its own concerns related to the risk of potential side effects as our daughter has previously had reactions to other forms of immunisation.

Adjustments to stay safe

Many families were used to being isolated, keeping their vulnerable children away from crowds and minimising visitors due to their children's normal sensitivity to infections. For these families, COVID-19 was not a huge difference. However, many parents like Brad stated that they had become even more 'vigilant' to try and continue to protect their children. For example, Emma described the precautions she took when shopping:

…it was a bit stressful in the early months just going to the supermarket and worrying that you could be taking coronavirus home on a box of [soda name]. I managed to get through this time though by wiping everything with [disinfectant name] wipes.

The adjustments parents made to feel safer during the pandemic included taking the children and their siblings out of daycare and school to minimise contact with other families. Some also stopped assistance with their child's physical and practical support with daily living:

Firstly, the need to stop all contact with our in-home support workers to minimise our daughter's exposure to the risk of contracting COVID-19. (Bronwyn)

Families undertook different daily activities due to the restrictions and social distancing that represented space and concealment:

…visit the ducks or play with a ball in the field during the pandemic. (Ella)

…we ended up going for some more drives really. (Brad)

Due to the closing of borders and isolation, some parents lost the usual support from grandparents or other extended family members who used to assist with the children's care and provide respite for the parents:

We relied heavily on family assistance before COVID and now have very little support from them. (Blake)

To handle home-schooling and the children's daily care needs, some parents took leave from work to stay home and care for their children. Other parents could work from home. Parents who could do neither managed by taking turns and working in shifts. Doing so ensured that someone could always be at home with the child. Yet, one parent felt like they had become a single parent when their partner was kept away due to restrictions.

Consequences

The consequences of the adjustments were that the parents became the sole carers of the children, who needed extensive help with daily living activities. In combination with isolation from family and friends, this increased anxiety and stress and decreased psychological well-being and mental health for both parents and children:

This put quite a lot of stress on us as a family. (Sadie)

In all the effort to make the family stay safe, one parent described the impact on their daughter who had struggled with low mood, had dropped out from school and developed severe anxiety and self-harming behaviour. Similarly, one father described how COVID-19 resulted in him needing to take antidepressants as the additional stress he was now under was unbearable:

COVID's the final straw.

This highlights the additional burden that COVID-19 brought to the already stressful environment of parental caregiving.

The new restrictions parents had to follow including one parent attending hospital appointments was challenging. Brad described his trials with needing his carer to attend the appointments, which allowed him to focus on the consultation:

I emailed ahead to say…I need to have an assistance with me…she [daughter] needs two people to hoist, she needs two people to change her etc…So, I got permission via the email. But still, when we went into clinics, I was met with abrupt, ‘one person only’. And I said, ‘No,’…‘I've already emailed her medical team. I've got permission for my carer to be here to help me’. And some people were ‘ok’, and some people just want to stress the point to the point we were at loggerheads.

Other consequences included delayed development and progress with some of the children's medical conditions. Moreover, parents worried about delayed or cancelled appointments with the healthcare. This concern was very much about problems that are not life-threatening but important for the child's quality of life, for progress with speech and learning and for hindering regression. Delayed appointments resulted in delayed diagnoses and nonacute surgeries, thus impacting the child's daily life. Especially hard was not knowing for how long the delay should continue:

My son's [condition] appointments seem to have gone out the window. We were inpatients in July and we still have not been followed up [four months later]. (Annette)

Many parents were left wondering about the direction when the appointments were cancelled or delayed and received a lack of advice to help them care for their child during COVID-19. Bronwyn highlighted the additional responsibility on parents when face-to-face appointments stopped:

…meant they were unable to directly observe or interact with our daughter and relied solely on us communicating all relevant information.

Likewise, the additional responsibility continued with the parents' new and unexpected role of home-schooling their child, as Ruth described:

he had to be home schooled, which was a rude awakening for me. And I had to be up to date with where he was at school…Even though I'm a stay-at-home carer for him, learning all about what he's doing in school, progress and all that was even more intensive.

A few parents revealed that their children struggled with being out of routine with school and sports, and one struggled to get their child to wear a mask due to their sensory issues. When shops and supermarkets were left bare through panic buying, this caused difficulty for parents when they could not get specific products for their children:

there was no food at all really, it just went overnight…trying to get the toilet roll that he's used to because he only likes set ones, as you can imagine, no toilet rolls. (Ruth)

Couldn't get access to our regular hand gel and masks. (Hollie)

COVID-19 impacted and heightened issues for some children, which caused added pressure on parents. Getting ill for some of the children could trigger their conditions, as Ruth outlines:

For him, it made him paranoid, which then I've got to keep a child having a meltdown next to me [at a hospital appointment] who thinks he's going to get sick, have a high fever.

When the closed borders were in place, and there was no transmission in the state, parents relaxed and let the children return to school and daycare. Due to the closed borders, many families felt safe. Being able to meet with family and friends again increased their well-being. However, due to the closed border, some families were still left without the usual support from extended family living in other states.

Similarly, parents could not also visit ill relatives in other states and countries as they could not risk the possible barriers of not being able to return:

…my Mum died in [Country]…I could fly to [Country] for the funeral but I wouldn't get back. And if I could get back, I'd spend two weeks in quarantine away from [Child's Name] and the house, which is more added pressure on the wife and stuff, and funding for carers. (Brad)

When the interstate borders were planned to open, the threat of COVID-19 came back, and the parents started to worry about their child's safety again.

Covid-19's silver liningsFewer infections

Keeping the children out of daycare and minimising contact kept the children healthier due to fewer infections and colds. This was a positive side of COVID-19 and something the parents mentioned as a welcoming change:

We did notice that while our child wasn't attending daycare it has been the best health we have ever seen him have. He didn't have any cold or flu symptoms, and no sickness. (Ella)

It also helped that more people washed their hands regularly and used hand sanitiser and masks, as outlined by Emma:

The positive impact was seeing the general public using hand gel as they walk into hospitals. We all hope that this becomes the norm, as it should be.

Parents felt it was okay to now talk about hand hygiene and encourage and remind guests to use hand sanitiser before entering their home, which had been a difficult conversation before.

Telehealth

One of the good things about isolation and physical distance was that the children could have more telehealth appointments (telephone and virtual) instead of needing to go to the hospital for a face-to-face meeting. This saved a lot of time, especially for families living outside the metropolitan area. It also saved money and energy when they did not have to travel:

The main change is the reduction of travel as we are now able to access telehealth and we have been able to negotiate more [treatment] via [online platform] or similar, freeing valuable time and reducing stress. (Elliot)

Telehealth did not suit all kinds of appointments, which was disappointing for some parents:

We attempted to link in with [various therapy] sessions using online meeting platforms, but this was not very useful for our daughter and her condition which is generally benefitted from face-to-face sessions to retain attention and maximise learning. (Luke)

Yet, despite this, parents were pleased that the sessions were available. Some of the services did not offer virtual appointments which at times was hard for parents to receive a satisfying experience in their child's care. Brad described the difficulties he experienced and the need for all modes of telehealth to be available for parents:

My daughter…was meant to have a follow-up for her dental surgery she had, and they wanted to do the dental over the phone. And I said, well, ‘how are you going to see?’ you know, cause obviously it's a follow-up to having teeth removed and gums cut into to remove teeth…I said how you gonna see anything wrong over the phone, when you're not even doing a video call?

The parents also emphasised the importance of using equipment that the parents could access from home instead of equipment that had to be accessed at the local healthcare clinic. The necessity to go to a healthcare facility instead of accessing telehealth from home hindered them from keeping physical distance:

They want us to attend a Community Centre [town name] for our next video conference which is a place where a lot of small kids and babies attend. (Emma)

Relationship improvements

While COVID-19 was a worrying time; it also provided time to review life and a bridge for relationship barriers. One of the positive outcomes of COVID-19 was that families had more time together:

…we stopped to appreciate the small things and enjoyed quality time together. (Sadie)

For Ruth, the restrictions had made her change general practitioners (GPs) as she wanted to attend a GP service that was implementing social distancing for her son's safety. This resulted in receiving unexpected additional support for her child and improved care that she had not experienced before:

…more of a relationship with the new GP. I found out through him that my son didn't have [an additional condition], which was a good thing because I was told by the old GP that he did. But the new GP was more proactive with getting him referrals to [hospital].

Many parents praised the various professionals that had assisted them in general, from healthcare professionals who provided reassurance for their child, pharmacists ensuring medications were available and schoolteachers ensuring their child was kept up to date.

For the first time, the parents expressed a relief that others could now have a better understanding of their lives:

Awareness. Our smaller and broader community understands the isolation and fear that WE LIVE during Flu season. (Hollie)

Hopes for a ‘new normal’

The parents reflected on several recommendations to continue to keep their children safe. It was suggested that the hand sanitiser needs to be available at various locations rather than just in the clinics:

I was quite disappointed when I posted on [hospital opinion website] asking that we could have hand gel at the entrances to [hospital] and still even during COVID this wasn't done. (Emma)

There should also be more hand sanitiser stations at [hospital] around car parks, lifts, etc. (Sadie)

To reduce exposure to COVID, parents recommended that there be one entrance and one exit at hospitals and safety measures to continue:

We would like to see a continuation of many of the safety/security measures (social distancing, hand health, numbers, screening etc) continue on into the future. (Elliot)

Similarly, better safety measures at the hospital were mentioned by several parents:

During the pandemic there needed to be better policing of public places such as throughout [hospital]. Throughout the pandemic, measures set up to monitor and control the public's access to various areas of the hospital were inconsistent and often ad hoc. (Bronwyn)

A few parents mentioned having advice available to reduce panic and having an advocate. Byron hoped that the previous experiences with COVID-19 may help in the future:

Everyone was making policy on the run. If ever the situation arises again, I'm sure things will be better communicated and executed.

Parents also wanted the possibility of telehealth to be a sustainable option:

Clearly for us the continuation of telehealth and [online platform] [condition] [treatment] would be a great assistance. (Elliot)

Online home schooling and new technologies for teaching opened new possibilities. The parents could see opportunities with these new ways of teaching and how they could continue to use them in the future. For instance, the children may not need to stay out of school the whole day because of a hospital appointment in the middle of the day. Or they could do home-schooling from the hospital bed:

We now have systems in place for keeping up with school and perhaps attending appointments with minimal disruption to [daughter's name] learning journey. (Hollie)

Parents also suggested similar interventions that were set up for the elderly with special shopping times to also be done for parents with vulnerable children. Some parents did not have the support available and had to take their child shopping with them, risking exposing them to the virus. Similarly, it was recommended to streamline hospital appointments to prevent multiple visits to reduce exposure.

DISCUSSION

The findings from this exploratory qualitative study reveal insights into how the initial stages of COVID-19 impacted parents caring for children with long-term conditions in WA. Parents experienced more stress during the start of COVID-19 when much was unknown about the virus. It was revealed that the main course of action for the parents was to keep their child safe which resulted in various adjustments (e.g., keeping their child home from school) and experienced various consequences from the pandemic (e.g., further isolation and access to healthcare services). Yet, positives were also noted during the start of COVID-19, including their children having fewer infections, some appointments being via telehealth which helped with the often difficult task of getting their child to hospital appointments, and relationship improvements within healthcare (professionals and services) and more broadly. For some families, there was the hope that these improvements would continue and become the ‘new normal’.

Understanding parents' stress responses is essential, especially when caring for vulnerable children where experiences of stress are likely to be enhanced due to COVID-19.[39] Stress in parents caring for vulnerable children during the COVID-19 pandemic has been related to diagnosis, prescribed medication of the immunosuppressed child, geographical location, household composition and employment status of the parent.[39] In the current study, additional stresses were found to be caring for their child while home-schooling, working from home and having increased parenting demands (e.g., absence of partners who could not return to WA due to the border restrictions and/or support services stopped).

The 'tend and befriend' theory[40] is an interesting approach applicable to the current study's context. It focuses on children and states that when faced with a perceived threat, people tend to their young and rely on others for connection and support. It was initially stated that females tended to their children and sought social connection,[40] whereas males were more likely to follow the fight-or-flight response.[41] There is much debate about gender and stress when caring for children with long-term conditions.[13,42] The current study did not aim to study gender differences. However, participating fathers and mothers both tended to their children by attempting to keep them safe, as noted previously.[13]

The theory implies that stress levels may decrease when social interactions are comforting.[43] It is well known that parents caring for children with long-term conditions can experience a lack of support from family, friends and healthcare services.[13,44] Social isolation was a common theme on the impact of COVID-19 with family caregivers of individuals with end-stage heart failure and lifestyle changes were noted in the United States study.[45] The parents in the current study were limited in befriending others due to COVID-19 consequences, which caused further feelings of isolation. Despite many parents feeling that border restrictions were needed to protect their children, the impact of this was that families were alienated from their key social support which they relied upon. This theory aids to highlight the greater level of stress parents experienced. To keep their children safe, they were unable to access vital social support via friends and family. Yet, a few experienced unexpected support from healthcare professionals (e.g., obtaining medications) and professionals (e.g., teachers help in home schooling) who assisted them during stressful times. These positive experiences were helpful to parents and beneficial in moving forward at this time of crisis.

While the parents described that others now had a better understanding of their daily lives, the fear of their child getting COVID persists. The parents provided many recommendations, including separate entrances and exits at the hospital to avoid unnecessary queues, having hand sanitisers and masks available and staff monitoring who was entering. Procedures and staff were unprepared at the start of the pandemic, and these recommendations have since been implemented at the children's hospital. More than ever during COVID times, additional support is required to access healthcare online or at the hospital to ease the burden for these parents.[13,14] Parents also need to protect themselves to prevent passing COVID to their children and to be able to care for their children, especially when support may be limited. Similarly, the implications of long COVID need to be considered. Further research into parents' COVID experiences and long COVID is necessary to explore parents' stress experiences when caring for children with long-term conditions to assist this group.

Telehealth was a benefit for some of the parents and something they would like to continue. Telehealth assisted with prompt appointments and reduced the travel and difficulties most encounter when taking their child to the hospital. It also enabled parents and their children to keep safe from COVID. In support, telehealth has been found to improve the provision of health services and be a critical tool.[46] However, the current study highlights that not all appointments were suitable for telehealth. Previous research has also noted reduced hospital admissions for children with long-term conditions in paediatric wards.[47] The current study highlights that suitable adjustments need to be in place for parents caring for children with long-term conditions (e.g., appropriate telehealth appointments and allowing a support person to assist a parent at hospital appointments) for future outbreaks and pandemics.

The current study suggested that some children had become distressed with the threat of COVID and the changes to their routines. Child and family distress have been noted to be heightened due to the messages about the use of handwashing, sanitisers, mask use, social distancing and so forth.[48] Children and young people's experiences in WA and internationally have been explored during COVID-19 through open-ended surveys and drawings.[48,49] An international study exploring the experiences of lockdown through children's artwork created an ebook reflecting children's experiences during COVID-19.[48] It was recommended that healthcare professionals need to support the child's health literacy, make them feel secure and take into consideration their hopes, fears and worries.[48] The authors suggest that the ebook may assist with starting conversations with children about the impact of COVID-19. Communication is key for keeping children informed and to promote wellbeing, but how best to do this for children with long-term conditions requires further investigation.

Each family in the current study is unique with personal backgrounds/histories and stressors. Still, their collective experiences at the start of the COVID-19 pandemic and support needs are alike. This is in agreement with previous research from WA, where families of children with medical complexity describe their support needs similarly despite the complexities.[13,14]

LIMITATIONS AND STRENGTHS

Participants were recruited from one family support organisation and English speaking, which may limit the applicability of the findings. No single parents were involved in the study; this group is expected to experience higher stress levels. Limitations can be attributed to the proforma via email, as further probing was not possible. However, the interview format was offered, and two parents chose this option. The study was conducted during the COVID-19 pandemic and captured the stressful experiences at a particular time in WA that was unique to other states and countries due to the border restrictions.

CONCLUSION

The COVID-19 pandemic increased stress on parents of children with long-term conditions, who were already psychosocially vulnerable. Policy makers, researchers, government and community services need to consider how to safely adjust restrictions and provide support to enable these families to better cope during a pandemic. Key areas include promoting safe access to their child's healthcare requirements and their social networks. COVID-19 also led to some welcome changes and outcomes for these families. Further research is needed to better understand how these ‘silver linings’ can be harnessed after COVID-19.

AUTHOR CONTRIBUTIONS

Stephanie Smith, Evalotte Mörelius made substantial contributions to the conception and design of the study, conducted the qualitative analysis and were involved in the interpretation of the data and writing of the findings. Stephanie Smith conducted and transcribed the interviews and drafted the manuscript. Mary Tallon, James Smith and Lauren Jones consulted on the study. Stephanie Smith, Mary Tallon, James Smith, Lauren Jones and Evalotte Mörelius critically reviewed the manuscript for important intellectual content and gave final approval of the version to be published.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because the data are based on sensitive information from parents' caring for children with long-term conditions. Requests to access the datasets should be directed to the corresponding author.

DETAILS

Subject:	Pandemics; Parents &parenting; Social distancing; Severe acute respiratory syndrome; Long term; Chronic illnesses; Families &family life; Severe acute respiratory syndrome coronavirus 2; COVID-19; Viral diseases; Interviews; Attention deficit hyperactivity disorder; Children; Coronaviruses; Native peoples; Questions; Parents; Viruses; Stress; Activities of daily living; Ostomy; Children &youth; Mental health; Audio data; Qualitative research; Telemedicine; Disease transmission
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A qualitative exploration of the psychosocial needs of people living with long-term conditions and their perspectives on online peer support

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ABSTRACT (ENGLISH)

Introduction

Approximately 20% of people with a long-term condition (LTC) experience depressive symptoms (subthreshold depression [SUBD]). People with SUBD experience depressive symptoms that do not meet the diagnostic criteria for major depressive disorder. However, there is currently no targeted psychological support for people with LTCs also experiencing SUBD. Online peer support is accessible, inexpensive and scalable, and might offer a way of bridging the gap in psychosocial care for LTC patients. This article explores the psychosocial needs of people living with LTCs and investigates their perspectives on online peer support interventions to inform their future design.

Methods

Through a co-produced participatory approach, online focus groups were completed with people with lived experience of LTCs. Focus groups were audio recorded and transcribed verbatim. Reflexive thematic analysis (TA) was conducted adopting a critical-realist approach and an inductive analysis methodology that sought to follow participants' priorities and concerns.

Results

Ten people with a range of LTCs participated across three online focus groups, lasting an average of 95 (±10.1) min. The mean age was 57 (±11.4) years and 60% of participants identified as female. The three key emerging themes were: (1) relationship between self and outside world; (2) past experiences of peer support; and (3) philosophy and vision of peer support. Adults living with LTCs shared their past experiences of peer support and explored their perspectives on how future online peer support platforms may support their psychosocial needs.

Conclusion

Despite the negative impact(s) of having a long-term physical health condition on mental health, physical and mental healthcare are often treated as separate entities. The need for an integrated approach for people with LTCs was clear. Implementation of online peer support to bridge this gap was supported, but there was a clear consensus that these interventions need to be co-produced and carefully designed to ensure they feel safe and not commercialised or prescriptive. Shared explorations of the potential benefits and concerns of these online spaces can shape the philosophy and vision of future platforms.

Patient or Public Contribution

This work is set within a wider project which is developing an online peer support platform for those living with LTCs. A participatory, co-produced approach is integral to this work. The initial vision was steered by the experiences of our Patient and Public Involvement (PPI) groups, who emphasised the therapeutic value of peer-to-peer interaction. The focus groups confirmed the importance and potential benefit of this project. This paper represents the perspectives of PPI members who collaborate on research and public engagement at the mental–physical interface. A separate, independent Research Advisory Group (RAG), formed of members also living with LTCs, co-produced study documents, topic guides, and informed key decision-making processes. Finally, our co-investigator with lived experience (E. A.F.) undertook the analysis and write-up alongside colleagues, further strengthening the interpretation and resonance of our work. She shares first joint authorship, and as a core member of the research team, ensures that the conduct of the study is firmly grounded in the experience of people living with LTCs.

FULL TEXT

INTRODUCTION

An estimated 15 million people in England live with a long-term condition (LTC).[1] Of these people, approximately 20% screen positive for major depressive disorder (MDD) as defined by the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition) and a further 20% experience subthreshold depression (SUBD).[2,3] SUBD is the experience of depressive symptoms that do not meet the diagnostic criteria for MDD.[4,5] In those with LTCs, SUBD is associated with having a significant impact on people's lives, including reduced quality of life, poorer reported physical health outcomes and increased risk of MDD.[5–7] SUBD is also a key risk factor for major depression, with 42% of patients who have SUBD comorbid with type 2 diabetes or heart disease developing major depression within 2 years.[7,8] Currently, there is no targeted psychological support for people with LTCs who are also experiencing SUBD. To prevent the escalation to MDD, the needs of those with LTCs experiencing SUBD need to be more carefully understood.

Online health interventions reportedly increase self-management behaviours and improve wellbeing.[9,10] Studies in patients with LTCs have highlighted improved self-efficacy, adaptive coping and empowerment as benefits of participating in online support groups.[11] Peer support is defined as ‘a range of approaches through which people with similar LTCs or experiences support each other to better understand the condition and aid recovery or self-management’.[12] Peer support may take place face-to-face, over the phone or online.[13] Online peer support platforms often embed a psychoeducation element. Psychoeducation interventions are defined as a ‘professionally delivered treatment modality that integrates and synergizes psychotherapeutic and educational interventions’[14] and are considered more holistic than traditional medical model interventions.[14] However, there is currently little evidence exploring the effectiveness of online peer support combined with psychoeducation interventions to support people with LTCs experiencing SUBD.

Recent findings suggest that online peer communities may offer similar benefits to face-to-face support.[15] A qualitative systematic review considered how people with LTCs describe their experiences with online peer support. The main findings suggested that feelings of reciprocity, social support and access to experiential knowledge were experienced when accessing online peer support.[16]

To our knowledge, there have been no randomised controlled trials (RCTs) of online peer support and psychoeducation interventions available to people with a diverse range of LTCs and SUBD (i.e., platforms that are not condition-specific). However, RCTs of face-to-face peer support were shown to be effective on mental and physical health outcomes for those with LTCs, including people with diabetes, asthma and cardiovascular disease.[17,18] Other research suggests peer support interventions for those currently experiencing depressive symptoms or higher scores of psychological distress were more effective at reducing depressive symptoms compared to usual care.[19,20]

Online peer support platforms for varying health needs are abundant. Yet, there are no online peer support and psychoeducational interventions tailored to support those experiencing SUBD in the context of LTCs. This article is set within the context of a wider project aiming to develop an online peer support and psychoeducation platform for those living with LTCs and SUBD. Intervention mapping has been used to integrate theory and evidence and guide the development of the project.[21] The study reported in this article is nested within the step ‘Intervention Mapping: Needs Assessment’.[21]

This article aims to explore the psychosocial needs of people living with LTCs and investigates their perspectives on online peer support interventions to inform their future design.

METHODSDesign

A focus group study of the psychosocial needs of people living with LTCs and their perspectives on online peer support.

Patient and public involvement (PPI)

This article is set within the context of a wider project that is developing an online peer support platform for those living with LTCs and SUBD. An intervention mapping[21] and participatory, co-production approach has been embedded throughout. Three groups were established as part of the participatory design as follows: (1) focus group participants; (2) a Research Advisory Group (RAG); and (3) a Participatory Design Panel (PDP).

The focus groups were formed of participants from King's College London's Integrated Care Consultation Partners Group (ICCPG), the Guy's and St Thomas' PPI group and the King's College Hospital PPI group. These groups bring together patients with physical/mental comorbidities and create a space for collaboration on research and public engagement at the mental-physical interface.

A separate, independent RAG was formed of members also living with LTCs. They supported the study throughout by co-producing all study documents and by collaborating on key decision-making processes. They also co-produced the focus group topic guide with the research team.

The PDP was made up of an external design agency, researchers, clinicians, a co-applicant with lived experience (E. A.F.) and participants from the focus groups. The PDP will also be involved in the subsequently planned co-design stages of developing the peer support platform.

Participants

Participants with LTCs were invited to take part in this study through flyer advertisements circulated through established PPI groups (the ICCPG, the Guy's and St Thomas' PPI group, the King's College Hospital PPI group) and through snowball sampling via these groups (e.g., word of mouth). Inclusion criteria were over 18 years of age, living with an LTC and the ability to give informed consent to participate. Exclusion criteria were insufficient English to be able to engage in focus group discussions. Participants were aware that they were being invited to discuss issues such as how their physical health condition affects their mental wellbeing and that the platform was being developed for use among people with SUBD and LTCs specifically. Three focus groups, with 10 people in total, were conducted, exploring the psychosocial needs of people living with LTCs and their perspectives on online peer support. Focus groups were intended to shift the experience of power from the researcher to the group of participants, and to enable participants to feel supported by the group and not isolated in their experiences.[22]

Due to restrictions imposed secondary to the 2019 novel coronavirus (COVID-19) pandemic, focus groups were carried out online via videoconferencing platforms and group sizes were reduced due to the online shift. Consultations with the RAG and researchers with experience of online delivery of focus groups informed the choice of platform to ensure optimal engagement. Clear, standardised, step-by-step instructions were provided to participants on how to download, access and use the platform. All participants had the necessary equipment (i.e., a device to take part, a webcam and microphone) and were offered a practice call with a member of the research team before taking part. Full ethical approval was sought and granted by King's College London Research Ethics Office, PNM Research Ethics Subcommittee (HR-19/20-14938). Electronic informed consent was obtained from all participants before taking part in the focus groups. Participants were all reimbursed for their time and expertise.

Data collection

An experienced qualitative researcher (H. R.) facilitated the focus groups alongside co-facilitators—Aymie Backler for two of the focus groups and Gabriella Bergin-Cartwright for the final group. The co-facilitator supported participants with technological difficulties and implemented a distress protocol if required, which was drafted due to the sensitive nature of the discussions.

The focus groups were designed to investigate the psychosocial needs of people living with LTCs and their perspectives on online peer support. The topic guide was co-produced with members of the RAG, co-investigator with lived experience and researchers.

It included open-ended questions covering: the interaction of their physical and mental health, for example, ‘How does your health condition make you feel?’; efforts to access support, such as ‘Have you looked for information on living with a health condition?’; and what they might expect from using the platform, for example, ‘What concerns would you have about using this sort of online support platform?’ (Supporting Information: Appendix 1).

Analysis

Focus groups were audio recorded and transcribed verbatim. Transcripts were reread alongside listening to the audio recording to anonymise and check accuracy.

Reflexive thematic analysis (TA) was conducted (E. A.F. and H. R.) adopting a critical-realist approach[23,24] and an inductive analysis methodology that sought to follow participants' priorities and concerns.[25] This analysis was co-produced using a participatory approach and therefore reflexive TA was selected by the authors as most appropriate due to its accessibility and acknowledgement that the authors play an active role in the analysis.[23] The focus groups were not carried out in a social vacuum as our assumptions and experiences as researchers impact the research we conduct.[23] HR (White British female, research assistant) is a source of support to family members living with various LTCs. EAF (White British female, communication strategist) lives with multiple LTCs (cystic fibrosis, cystic fibrosis-related diabetes, adrenal insufficiency), and has carried out patient advocacy work for several years. EAF engaged with the research team in reflexive TA training.[23] The highly relevant experiences of participants and depth of discussion enhanced the information power of this sample.[26] Both authors (E. A.F. and H. R.) spent time independently reading and familiarising themselves with the transcripts and began to code and record key ideas from the transcripts. A process of member checking was also adopted by presenting an interim analysis of preliminary themes and codes to the PDP and, separately, the RAG. As all members of the PDP had participated in the initial focus groups, these interactive sessions offered a unique opportunity for post-interview reflection. Feedback was sought on clarifying, developing and amending the final themes using the online collaborative tool Miro (© 2021 Miro). E. A.F. and H. R. individually coded the transcripts in consultation with the wider research team using Microsoft Excel. E. A.F. and H. R. then met regularly to discuss the data in detail to develop their initial interpretations and incorporate the feedback from the member checking work. The final generated themes are presented in Table 2.

Reporting

Reporting was guided by the Standards for Reporting Qualitative Research (SRQR), which consists of a 21-item checklist.[27] The SRQR has been used to ensure standards for presenting qualitative analysis are met, while also allowing the flexibility and approach of this work to be maintained.

RESULTSParticipant characteristics

Ten people with a range of LTCs participated across three online focus groups. Table 1 provides an overview of participant characteristics. The mean age was 57 (±11.4) years and 60% of those taking part in the focus groups identified as female. The majority (80%) of the participants used technology daily, and 30% had used internet support groups before.

Table 1 Description of participant characteristics.

	n (%)	Mean (±SD)	Range
Agea (years)		57 (±11.4)	39–71
Female	6 (60)		
Male	3 (30)		
Ethnicitya			
Black British	2 (20)		
White British	6 (60)		
White European	1 (10)		
Do you have access to the internet at home?a			
Yes	9 (90)		
No			
How frequently do you use the internet?a			
Daily	8 (80)		
Weekly	1 (10)		
Monthly			
Never			
Other, please specify			
Have you used internet support groups before?a			
Yes	3 (30)		

No	6 (60)		
Long-term conditionsa			
Anaemia	1		
Arrhythmia	1		
Barrett's syndrome	1		
Chronic pain	4		
Compartment syndrome	1		
Dysphonia	1		
Emphysema	1		
Endometriosis	1		
Hypertension	1		
Irritable bowel syndrome	1		
Laryngopharyngeal reflux	1		
Lymphoedema	1		
Morton's neuroma	1		
Osteoarthritis	2		
Osteoporosis	1		
Peripheral polyneuropathy	1		
Rheumatoid arthritis	1		
Sciatica	1		
Scoliosis	1		
Severe allergic asthma	1		
Spondylolisthesis	1		

No response	1		
Number of participants living with multiple long-term conditionsa			
1 Long-term condition	3		
2 Long-term conditions	2		
3+ Long-term conditions	4		

a

One participant did not provide characteristic information.

THEMES AND SUBTHEMES

Throughout the focus groups, a range of experiences were described in relation to the psychosocial needs of people living with LTCs and their perspectives on online peer support. We present three themes: (1) relationship between self and outside world; (2) past experiences of peer support; and (3) philosophy and vision of peer support. Table 2 provides an overview of the themes presented, corresponding subthemes, definitions and evidencing quotations.

Table 2 Themes and subthemes alongside quotations.

Theme	Subtheme	Subtheme description	Quotation
Relationship with self and the outside world	Mind–body separation	Participants express that healthcare culture generally tends to adopt the lens that both physical and mental care are separate.	When I was diagnosed, mental health issues didn't come into it. You had your condition and that was your condition. But now when we're asked to talk about how we feel …I find it really hard. (focus group 2, participant 2)
			(…) healthcare, um, practitioners, they'll just mention, okay, um, okay, what you're doing with your condition, how you're coping and you know, it's not how do you feel? And, and that so important to me, just asking that one simple question. (focus group 3, participant 1)

			(…) there's not much out there in terms of my physical condition and the impact that that has, you know, on my psychological well-being (…) . (focus group 3, participant 1)
			Now I guess the culture doesn't really encourage that very much. There's this mind body separation. And also, I had to use the word spiritual, but I found a very good source to help me reflect and meditate and that's been enormously helpful. (focus group 1, participant 2)
			My mum was really tough with me. You didn't complain. You didn't cry. And she never let up on chores. (focus group 2, participant 2)
	Duality of health	When discussing their own health, both mind and body become entwined in the descriptions.	(…) physical health and, and, mental health colliding, um, because they, they both interlink with each other eventually. (focus group 3, participant 2)
			(…) my mental condition is something aside, but I think at some point the two did collide. (focus group 3, participant 1)

			I think I'll start with my physical health. Um, I've become fat, you know, staying indoors and lack of exercise, I've actually put on a lot of weight and it's impacted, um, the way I think or feel about myself in terms of, uh, wanting to go out. I'm thinking, I've put on so much weight and people are going to be looking at me saying, damn, you know. So, yeah, my confidence is a bit low when it comes to the weight issue. (focus group 1, participant 4)
	Predictable variability	Participants expect good and bad days with their health but the nature of when the bad days will occur is often uncertain.	But listening to the body and, listening to my body and finding out, um, when to take rests, when to get up and do something, how far to walk, uh, all those things. (focus group 1, participant 2)
			(…) my health has gone down to zero. I was on a scale of 100 and doing alright, I was coping on my own and then all of a sudden. (focus group 2, participant 2)
			(…) other people can make goals, long term goals and stuff but I just take each day as it comes. (focus group 3, participant 2)
			I overdo it on a good days and then have terrible days. (focus group 2, participant 2)

	Tension between self-reliance and needing help	Wanting to be independent but also the discomfort with having to ask for help when support from others is needed.	I've asked for somebody's help to help me go upstairs, um, in, in the tube station to go through the stairs (…) And the person said, oh, I haven't got any money. (…) Can be tough on, on, on your mental health eventually. Because then you feel even more self-conscious and anxious and, um …And, and, and paranoid in a lot of respect. (focus group 2, participant 3)
			Total strangers who are, like, loads older than me asking if they can help me which is extremely sweet but it makes me feel a bit pathetic. (focus group 2, participant 1)
			But the thing I, I've noticed the most in regard to mental health and that's sort of relationship within oneone's's self and the outside world, is, um, how would you say? The atmosphere, um, around one in the outer world, I find very unsettling. You know, the, the sort of vulnerabilities and the frailties and the suspicions and all these unsettling things, um, that seem to be within others, uh, affect me very deeply and I recoil. And it sort of re-entrenches that, um, removal if you like, if that makes any sense. (focus group 1, participant 1)
			I struggle with asking for help. I have to have a mental breakdown and then someone says, let me help you, and that's when I'll allow it. (focus group 2, participant 2)

	Behind the mask	Often attempt to hide living with an LTC.	So I can't go into work, you know, feeling sick and looking sick and stuff. So it's, it's like there's two different me …Um, the sort of outward me and the inward me. It's actually quite exhausting. (focus group 3, participant 2)
			I've had people before that said, oh, you've got your makeup and stuff on. You don't look like you've got a problem with your back. And it's just how do you respond to that? (focus group 2, participant 4)
			It's difficult and, and you're in between and you try to hide as much as possible your disability, yet again because you don't want to be picked on, but obviously, you know, there's just not much you can do. (focus group 2, participant 3)
			But when it comes to relationship, it's a no-go. Um, it's that fear that that person will run away. I've had that situation when someone realised what's wrong with me and they're like, oh, no I can't deal with that and stuff, and I always tend to hide things. (focus group 3, participant 2)
	Burden of increased self-management	Changes to usual care during the pandemic have felt stressful.	Well the best you'd get is talking to your physio or your doctor by phone which isn't the same. (focus group 1, participant 3)

			I miss it. I really miss hydrotherapy. I really …Do. And no matter …I mean, tried to do it in the bath, but then you've got the …My …I'm on a meter. (focus group 2, participant 2)
			And everything has changed, um, I'm on a biologic. So I normally go into the hospital and they give me my injection, and now I have to learn within seconds, like how to do it myself. There wasn't any, um, demonstration of how to do this, um [sighs], so, yeah. It was really stressful. (focus group 3, participant 2)
Past experiences of peer support	Sharing knowledge and resources	Distributing health-related information and experiences between peers is useful.	I think, again the element of peer support is more around, listen I've tried this and it's worked, or, I've heard someone that I know that has tried this and it has worked. (focus group 1, participant 4)
			Most powerful thing I've found is with the meet up groups, for example, on complex PTSD, um, it's being with other people who have similar experiences, and, um, there's a resonance there and just sharing resources and information. (focus group 1, participant 2)

			We'll have different discussions [in peer support group] about how, um, that impacted on them, you know, using that tool as well. And we might have slightly different experiences, but at least we know that it's something that works. (focus group 3, participant 2)
	A mutual validation	It was expressed that people with LTCs are best placed to understand how another person with a LTC may be feeling due to their personal experiences.	I've discovered that there are a few people out there who have the same issues that I do, um, so it's made me feel a little bit better. And with Facebook I've joined other groups, for example, with lung conditions like myself. And we're swapping ideas or I'm, not always contributing, but I'm reading and it does help in a way. (focus group 1, participant 3)
			I have a peer group for one of my long-term conditions …we talk daily to each other, motivate each other, keep each other calm. (focus group 3, participant 2)
			(…) [my brother] he's, um, he gets very focussed, and he goes to the gym and he said to me, and he said, god, he said, if I had arthritis I would be having an operation within seconds. And it's a totally different attitude because what I've learned from the pain is extraordinary. (focus group 1, participant 2)

			The preparation [of going out] before and, and the sorting it all out afterwards is a nightmare, but I just really value the online stuff because, especially when it's a group …. (focus group 2, participant 4)
	Fear of negative reinforcement	Some participants may disengage or not engage at all with peer support platforms due to concerns around feeling worse after.	So I've not joined any online groups before because …Um, I don't know. I've just not felt that there was the right group for me. I think we spoke about, um, condition-specific groups, and that really didn't help because everybody was comparing their back pain to your back pain and that just …Wasn't helpful. (focus group 2, participant 4)
			Cause I felt that [being a member of the Facebook peer support group], um, it was …Further, sort of underlining the fact that I did have, um, these conditions. And it just, I just sort of wanted to get away from it. And, you know, for a sense of normality. (focus group 3, participant 1)
			No size fits all. I think that sometimes a problem with, oh, well, we'll set up a peer group …And just assume that it's going to work and for everybody who's going to want to engage. (focus groups 3, participant 1)

Philosophy and vision of a peer support platform	A safe and credible zone	For peer support platforms to be a success they must be co-produced, secure and a confidential space.	And if you're in a cocoon and there's only certain people that know the ins and outs of your life. You then become quite protective about what's going on. (focus group 2, participant 2)
			Talking about how mental health affects your pain, whatever that is, I think this is something new and it seems safe. Somehow, we can do it from our homes, we can listen to each other, but you haven't got to think about how to get somewhere. (focus group 2, participant 4)
			But I mean it's interesting. I'd be far more likely to use this because I think there's some, there's credibility behind it. (focus group 3, participant 1)
			Um, within my culture, it's like a taboo …When it comes to mental health. Um, so it's making the site, um … There, there's easy access to the sites where you don't need to go for a long process to kinda get to the stage. (focus group 3, participant 2)
	Reflect lived experiences	Peer support platforms need to consider personal differences and similarities of those using them and should reflect a space that they can all access.	That the peer support, um, or supportive or, uh, situations tend to be too structured and not reflecting the, the more authenticity of actual experience. (focus group 1 participant 1)

			So, yeah, I think, uh, an online peer support, um, forum, or a, uh, service or whatever yeah, you want to call it, might actually be very, very beneficial. Especially in these times that we've now realised that a lot of the services that people, or the support that people are being referred to quite, to be honest, inappropriate, uh, for their, for their needs. So yeah, especially I think on co-morbidity, it's really quite difficult, um, to get the support you need. And you've got more than just one condition that you have to deal with. (focus group 1, participant 4)
			Absolutely. I think we have to, um, be very mindful of, um, [sighs] cultural sensitivity, and what is appropriate for one group might not be appropriate for another group …Culturally diverse references will increase engagement. (focus group 3, participant 1)
	Transparent motivations	Peer support platforms should not feel too prescriptive or corporatized.	And they frighten me terribly. I found them very presumptuous. Especially [name]. That was in such a structured, non experiential view um, it's, um, yes, it was, it was, um, quite contrived and synthetic. Um, and yeah. (focus group 1, participant 1)

			They're addressing business and businesses were talking. I mean, it's very good that people have more expansive sensitivities towards the mind, certainly, and I don't recoil from that, that's precious. But when it, things can get corrupted along the way by, um, um, scenario, other agendas, shall we just say. And it's very conspicuous in the commercial world I'm sure. But, but, in the sense it's a commercial gain to address it rather than the authenticity going to. You know, it's a completely different dynamic. (focus group 1 participant 1)
			That's another thing, actually, that I think is a benefit is that it's being run by [university name] [snapping sound] rather than a corporate entity or some even social enterprises, or even charities, that the, um, your ethics, at [university name], the ethics at [university name] are really, you know. (focus group 3, participant 1)
	Technology becomes an essential skill	Technological literacy is key due to the impact of remote living and working.	Well I've found, um, it's been a strangely positive experience in the way that, um, that, uh, I quite enjoy being on my own and it's given me a lot of time to reflect and to do a lot of Zooming around in different groups. (focus group 1, participant 2)

	And so since then [beginning of lockdown] I had, um, Zoom, uh like Microsoft Teams, uh, counselling sessions which I found a little awkward at times. Um, however, yeah they went well. Uh, so yeah, and, yeah. So yeah, you know, it was just weird at first having, uh, sessions, um, yeah. But, um, yeah. (focus group 1, participant 4)
	And trying to do the technology frustrates me because if I can't hear, if I can't see, or, uh, there's breaking up, and then I just throw myself outside and then I overdo it. (focus group 2, participant 2)

Abbreviation: LTC, long-term condition.

RELATIONSHIP BETWEEN SELF AND THE OUTSIDE WORLD

Mind–body separation

Participants felt that healthcare culture generally groups physical and mental care as separate entities, even in the context of LTCs. This separation was felt in previous experiences of treatments received in healthcare environments, ‘when I was diagnosed, mental health issues didn't come into it. You had your condition and that was your condition. But now when we're asked to talk about how we feel …I find it really hard’ (focus group 2, participant 2), and was reflected in the way some participants viewed their own health: as two distinct halves of mental and physical. Participants showed awareness of the complex nature of health in certain contexts (e.g., social situations, in the workplace). Despite this, they reported health discussions with clinicians as seeming reductive and more two-dimensional in nature, without acknowledgement from their doctor or nurse that their physical health status was likely to be affected by the condition of their mental health. The discussion of these interactions with clinicians was broad and varied according to participants. For some, the emotional side of living with an LTC was never discussed with their healthcare professional (HCP).

Participants reported that clinicians either did not discuss mental health issues and/or did not seem to consider themselves to be in an appropriate role to discuss them, though this was not the case for all. One participant reacted with surprise on the occasion their physical health consultant raised the topic of mental health without being prompted by the participant. Overall, participants considered joined-up care of their LTC and mental health to be rare. The importance of the simple question ‘how are you feeling?’ in the context of a consultation was highlighted.

The separation of mental and physical health was sometimes present outside of clinical contexts too. One participant recalled how despite feeling unwell when growing up, ‘you didn't complain, you didn't cry’ (focus group 2, participant 2) and their mother did not provide any emotional allowances for their health condition.

Duality of health

Despite the perceived separation of mind and body in the context of healthcare, when discussing their own health, participants' descriptions of both mind and body became entwined. During analysis, it was not possible to discern whether each participant considered mental distress as a distinct condition unrelated to their physical health, or distress as a direct result of their physical health. However, there was awareness of physical and mental health impacting on each other. The language used to describe this was striking: ‘my mental condition is something aside, but I think at some point the two did collide’ (focus group 3, participant 1), in reference to mental and physical health converging. In particular, there was an understanding of the role that lack of exercise or diet could have on mental wellbeing and physical health, ‘I've become fat, you know, staying indoors and lack of exercise, I've actually put on a lot of weight and it's impacted, um, the way I think or feel about myself’ (focus group 1, participant 4).

Predictable variability

This subtheme was strongly emphasised by participants and captures how participants expect to experience good and bad days with their health, but also find it hard to predict when the bad days will occur. This manifested in difficulties making plans and an attitude of ‘take each day as it comes’ (focus group 3, participant 2). Participants discussed the consequences of ‘overdoing it’ on good days, which subsequently led to bad days. Some demonstrated an awareness of how they might prevent a bad day, for example, taking preventative measures to alleviate physical limitations: ‘listening to my body …when to take rests …how far to walk’ (focus group 1, participant 2). For others, the onset of a bad day appeared suddenly without an obvious cause-and-effect relationship.

Tension between self-reliance and needing help

This subtheme captures the discomfort that can come with living with an LTC in environments and locations that are physically difficult to access or participate in due to the physical limitation(s) of a health condition or disability. Some participants sought independence and consequently experienced discomfort when asking for help. Sometimes this discomfort was clearly evidenced, ‘I struggle with asking for help. I have to have a mental breakdown …and that's when I'll allow it’ (focus group 2, participant 2), for others it was implicit, ‘I've asked for somebody's help to go upstairs, um, in, in the tube station to go through the stairs …. And the person said, oh, I have not got any money …[which] can be tough on, your mental health’ (focus group 2, participant 3). It was clear that these interactions with members of the public caused distress.

Behind the mask

This subtheme refers to participants' occasional attempts to hide from others that they are living with an LTC. Some described how exhausting it can feel trying to conceal living with an LTC in the workplace, ‘so I can't go into work, you know, feeling sick and looking sick and stuff. So it's, it's like there's two different me …Um, the sort of outward me and the inward me. It's actually quite exhausting’ (focus group 3, participant 2), all the while receiving judgements from others on their appearance and perceived level of sickness. For example, participants received comments such as ‘you don't look like you've got a problem with your back’ (focus group 2, participant 4) in their work environment. In more personal settings, such as in a romantic relationship, judgements by a partner about their LTC had led to feelings of rejection and a desire to hide their LTC and full identity in future: ‘when it comes to relationships, it's a no-go. Um, it's that fear that that person will run away’ (focus group 3, participant 2).

Burden of increased self-management

This subtheme illustrates the varied impact that COVID-19 lockdowns had on the treatment and management of LTCs. Most participants had experienced negative changes to both their self-management and to the standard of clinical care that they usually received, which was described as stressful. Some experienced a lack of usual care and oversight from HCPs. This had a knock-on effect of either increased self-management to cope with symptoms, ‘so I normally go into the hospital and they give me my injection, and now I have to learn within seconds, like how to do it myself’ (focus group 3, participant 2), or an inability to manage a treatment because self-management was not an option. Examples given were not restricted to pharmacological treatment, but also affected other types of treatment such as hydrotherapy for joint pain, which was not available during lockdown.

PAST EXPERIENCES OF PEER SUPPORTSharing knowledge and resources

Circulating health-related information and experiences between peers was considered useful and a key reason for participating in peer support. The reasons given for sharing knowledge were manifold. One participant explained, ‘being with other people who have similar experiences, and, um, there's a resonance there and just sharing resources and information’ (focus group 1, participant 2). Other participants mentioned sharing what had worked for them personally and the enjoyment and optimism that came with showing proof of personal benefit. Interestingly, even if a resource had not benefited them personally, participants still enjoyed hearing about it, as evidence of success for another: ‘we might have slightly different experiences, but at least we know that it's something that works’ (focus group 3, participant 2).

Mutual validation

This subtheme captured the sense of recognition and affirmation participants reported when encountering someone with similar symptoms through peer support. It was expressed that people with LTCs are best placed to understand how another person with an LTC may be feeling due to their personal experiences. Simply the act of finding another with the same or similar symptoms could have this effect: ‘I've discovered that there are a few people out there who have the same issues that I do, um, so it's made me feel a little bit better’ (focus group 1, participant 3). For others, the sense of validation was found in the ongoing actions of peer support: ‘[…] we talk daily to each other, motivate each other, keep each other calm’ (focus group 3, participant 2).

Fear of negative reinforcement

There were not always positives to be found through shared experiences; for some participants, encountering people with similar symptoms made them feel worse. For this reason, they had chosen not to engage with peer support in the past. *Fear of negative reinforcement* encapsulated the feeling of hearing about negative health experiences from others and ‘[…] wanting to get away from it’ (focus group 3, participant 1). Two rationales for this were given. First, the conversation itself was perceived as negative or not solution-focused, or second, it served as a reminder of the participants' own health when they did not want to focus on it. Traditionally, peer support in people with LTCs has been centred around a particular condition, but we found evidence that this approach did not work for everyone. Several participants described encountering attitudes of competitive comparison where symptoms were pitted against each other: ‘condition-specific groups […] didn't help because everybody was comparing their back pain to your back pain and that just wasn't helpful’ (focus group 2, participant 4). Finally, while acknowledging that a condition-specific approach could be successful for some, participants pointed out that ‘no size fits all’ (focus group 3, participant 1) and it was important not to assume a particular initiative could engage all those who wanted support.

PHILOSOPHY AND VISION OF PEER SUPPORTA safe and credible zone

According to participants, successful peer support platforms should be a secure and confidential space and their development should involve co-production with members of the patient group that they aim to cater for. The need for safety while accessing peer support was a key concern, although there were different definitions of what it meant to be safe in this context. We found that being in a safe space could mean, amongst other things, an expectation of privacy, shared standards of behaviour or code of conduct, an environment that appeared credible by promoting or following a code of conduct or standards of best practice, made visible to patients or service users. One participant described a desire for a closed or private space in relation to the sensitive nature of their health: ‘you're in a cocoon and there's only certain people that know the ins and outs of your life. You then become quite protective about what's going on’ (focus group 2, participant 2).

Interestingly, there was also an emphasis on accessibility to peer support, which in practice could result in a less private space, by virtue of online peer support being easy to find and participate in. The need for accessibility and privacy is concisely summed up here: ‘within my culture, it's like a taboo when it comes to mental health. So it's about making the site, […] easy to access’ (focus group 3, participant 2). The ease of participating in online peer support was also discussed: ‘we can do it from our homes, we can listen to each other, but you haven't got to think about how to get somewhere’ (focus group 2, participant 4).

Reflect lived experiences

Several aspects of lived experience were considered important in peer support interventions: individual circumstances, variations in the presentation of comorbidities and cultural diversity. The first factor is the perceived inability of existing peer support initiatives to meet the needs of those with co-morbidity. Participants felt it was difficult to provide the right support for someone living with more than just one condition, and this could result in something 'inappropriate for their needs' (focus group 1, participant 4). Participants were sensitive to online environments, which they saw as generic or standardised in relation to their health needs. It was felt this resulted in support that did not reflect their lived experience and was therefore perceived as less helpful or applicable. This type of experience was considered inauthentic because 'situations [which] tend to be too structured are not reflecting the authenticity of actual experience' (focus group 1, participant 1). Third, several participants raised the importance of visible cultural and social diversity. It was felt that this evidence of diversity determined what was relevant and positively perceived by each user and could increase engagement with a peer support platform.

Transparent motivations

Participants believed that peer support platforms should not feel prescriptive or commercial in nature. One participant explained that it could depend on the motivations of the platform creators (whether commercial or academic) that result in an unwanted and prescriptive user experience: 'But things can get corrupted along the way by […] other agendas, shall we just say. And it's very conspicuous in the commercial world' (focus group 1, participant 1). It was felt that a commercial imperative was not inherently negative but considered likely to impact the integrity or values of a platform, which participants were acutely sensitive towards.

Technology becomes an essential skill

Participants described how adapting to an increase in digital technology during the COVID-19 pandemic and having technological literacy was key to coping with the impacts of remote living and working. There was a mixture of positive and negative sentiments shown towards using technology. The transition from face-to-face activities to digital interfaces affected all spheres of living, ranging from remote counselling, consultation with HCPs, socialising, working and exercising. One participant described beginning to use the ubiquitous communication platform '*Zoom*', as a positive because it provided the opportunity for additional reflection and socialising in different circles: '[…] a lot of time to reflect and to do a lot of Zooming around in different groups' (focus group 1, participant 2). A downside to digital interactions became clear when equipment or technology operated suboptimally, leaving participants feeling frustrated.

DISCUSSION

This exploration of the psychosocial needs of people living with LTCs and their perspectives on online peer support further develops the understanding of these participants' experiences. Offering new insights that can inform the future design and implementation of online peer support and psychoeducation interventions for those living with LTCs and SUBD. Three overarching themes were detailed based on the participants' accounts of their experiences and needs: (1) relationship between self and outside world; (2) past experiences of peer support; and (3) philosophy and vision of peer support.

Although our participants were not formally assessed for SUBD, their experiences indicated difficulties with their mental health as a direct result of living with an LTC. Despite acknowledging their mental healthcare needs alongside their physical healthcare needs, participants did not experience integrated, coordinated care. There was a clear distinction between how health was conceptualised in a clinical context versus personal experiences and descriptions outside of this clinical context. This indicates that the nonintegrated nature of the clinical contexts in which people with LTCs engage does not align with their needs. People living with LTCs are less likely to access psychological interventions aiming to reduce depression.[28,29] As a result, services such as Improving Access to Psychological Therapy (IAPT) Pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms are aiming to coordinate IAPT services, providing psychological therapies embedded in physical healthcare pathways.[28] Integrating these services is imperative, but more consideration also needs to be placed on the importance of supporting those with SUBD to prevent the worsening of their mental health difficulties. This is where interventions such as online peer support and psychoeducation could play a potentially cost-effective role.

The focus groups were conducted in the first six months of the COVID-19 pandemic in the United Kingdom. The themes generated must be viewed in the context of the chronology they occurred in during the COVID-19 pandemic and findings cannot be fully decoupled or extricated from the unique circumstances of the time. A recent article explored the experiences of service users with mental health difficulties during the COVID-19 pandemic. They concluded that service users found changes to their usual mental healthcare worrying, particularly when these changes were not effectively communicated.[30] Participants recognised that online peer support and psychoeducation did not require them to leave home and could therefore reduce the burden of self-management by helping people to feel more connected and supported by others in similar situations. This links closely with Griffiths et al.,[18] who found that a layperson-led, self-management programme for Bangladeshi adults with various LTCs led to significant improvement in self-efficacy and self-care behaviours when compared to usual care. This is also in line with the National Institute for Health and Care Excellence (NICE) report showing that digitally-based health and behaviour change interventions can support people to increase their self-management behaviours and improve their wellbeing.[9] Again, although participants were not formally assessed for SUBD, many shared mental health challenges and expressed a need for increased psychosocial support to address these needs. The subthemes of ‘predictable variability’ and ‘behind the mask’ shed further light on the psychosocial difficulties and the commonalities in physical symptoms experienced by those with LTCs. The fatigue induced by attempts to conceal physical health conditions from others, in addition to fluctuations in physical health symptoms, were shared as common occurrences by people with LTCs. Providing more support for the self-management of common experiences, such as these for people with LTCs, in addition to providing a platform to voice these shared experiences could improve the lives of people with LTCs who also experience SUBD, alleviating the strain on healthcare services, and ultimately preventing progression to MDD.

Participants expressed the view that peer support offers both an opportunity to share knowledge and resources and can provide a sense of mutual validation. They felt peers with similar experiences are best placed to understand their personal situation and provide valuable support. This chimes with the findings of a qualitative systematic review that considered how people with LTCs describe online peer support; key underpinning elements included reciprocity, social support and access to experiential knowledge.[16]

Whilst research assessing the efficacy of peer support for depression found that peer support interventions were more effective at reducing depressive symptoms compared to usual care,[19] mitigating the potential adverse effects of online peer support is also key. Easton et al.[31] suggest that further understanding potential adverse effects of online peer support is vital. Crucially, participants from the current article felt that online platforms must not have an over-commercial look as this can feel unsafe to interact with, presumptuous and untrustworthy to use. Participants also expressed concerns surrounding possible negative interactions with other users, leading to wariness and potential disengagement. Previous research has also suggested that negative experiences of online peer support could be related to the impact of reading about other peoples' negative experiences.[32] For online platforms to feel safer, they need to reflect users' experiences—tapping into the importance of the authenticity of lived experience and cultural diversity and must be carefully moderated. Overly defined environments feel unrelatable to people with lived experience and thus unhelpful. The more organic and flexible the space, the more usable it is. Participants expressed that central to this is co-production, so that the people intended to use a service to steer its design and development. Robust data on adverse effects and safety are needed to better inform wide-scale adoption within health systems.

Finally, pathways of referral to online peer support platforms also need careful exploration. This is especially pertinent in settings where integrated care and screening of mental health are not regularly practiced in secondary care. Alternative referral pathways might be required, such as through primary care practice and/or self-referral pathways.

Strengths and limitations

This work is nested within a larger project aiming to develop an online peer support and psychoeducational platform for those living with LTCs and SUBD. This project adopts a theoretically driven intervention design using the Intervention Mapping Framework.[21] This article provides evidence for the first step in the framework of identifying the needs of the group. The nature of adopting a Reflexive TA methodology and a participatory approach allows for flexibility and acknowledges the researchers' active roles in analyses.[23] This is an important strength of this article, as an interim analysis was presented to two PPI groups and their feedback was used to develop the final analysis.

This allowed us to develop our understanding of the data and check the resonance of experiences.[33] The co-investigator with lived experience (E. A.F.) also undertook the analysis and write-up of this article alongside colleagues, further strengthening the interpretation and resonance of our work.

It should be noted that 80% of participants described their technology use as daily, demonstrating a limitation in the transferability of these findings among people with lower technology usage. Future work should therefore explore the potential barriers which may play a role in preventing access and usability of online peer support platforms, for example, digital competency and technology literacy.

While the majority of the participants used technology daily, over half had not used internet support groups before. There was quite a range in confidence with technology described upon recruitment and some participants required further technological support to take part in the focus group. Conducting the focus groups remotely facilitated the participation of people living with LTCs who can face physical barriers to attending in-person research. To prevent a digital competency divide, tractable solutions should also be explored to ensure accessibility to online peer support for all those with LTCs. These solutions could include a dedicated onboarding process and perhaps assistance with acquiring digital tools where the individual does not have access to, or ownership of, the required technology. Most participants were actively engaged in research relating to the psychological and physical interface as some were recruited from well-established PPI groups. To develop our understanding of the psychosocial needs of those living with LTCs, it would also be key to engage those that are less involved in research and those who have little or no access to technology, as they may have varying needs that are important to explore.

Additionally, future work should explore the potential role that HCPs may have in facilitating online peer support. Their role(s) may be multifaceted, from screening, referral and signposting, to moderating the platform and contributing to the psychoeducational material. Therefore, future work is needed to explore these potential roles and what people with LTCs would view as the most valuable role HCPs may play. Also, a limitation of this work that should be recognised is that we did not use a clinical measure to assess the mental health of participants, so the findings are not specific to those with SUBD. However, the recruitment flyer was framed under the title of ‘Online peer support for preventing depression in people with LTCs: focus groups’ and all people recruited to this study were aware that they were being invited to discuss issues such as how their physical health condition affects their mental wellbeing.

Future implications

This article provides the needs assessment element in the larger context of this body of work. The findings from this work will directly inform the development phases of an online peer support and psychoeducational platform for people with LTCs and SUBD. This work details the shared experiences of people with LTCs, highlighting the lack of integrated care available to address both physical and mental healthcare needs. This is an area of concerning unmet need as people living with LTCs recognise how their mental and physical health influence one another. Online peer support is accessible, inexpensive and scalable, and might offer a way of bridging the gap in psychosocial care for LTC patients. Intervening earlier could improve lives and reduce the burden of comorbid mental illness on families, the NHS and society. This is particularly important given the known increased risk people with LTCs have of developing MDD. The findings from the work will also inform the future vision and philosophy of platforms designed to help support the psychosocial needs of people with LTCs.

CONCLUSION

Adults living with a range of different LTCs expressed the potential benefits that online peer support may have on supporting their psychosocial needs. They also expressed potential concerns around negative engagement with online peer support, highlighted by their discussions that emphasised the importance of these spaces feeling safe. Based on the shared experience of those who took part in this work and the value of co-production, careful, collaborative consideration is essential to develop the guiding principles of a future peer support platform, to explore potential moderation processes, and co-produce a moderation policy. That participants expressed that any online peer support platform needs to be a safe and credible zone highlights the need for platforms to be co-designed with the people that will ultimately use them to ensure this is a priority throughout. These findings evidence how important identifying needs in the pre-intervention design stage is to promote a more purposeful intervention design that is user-led.

AUTHOR CONTRIBUTIONS

Initial conceptualisation, methodology and funding acquisition of this work was undertaken by Lauren Rayner, Matthew Hotopf, Alan Simpson and Vanessa Lawrence. Investigation was conducted by Lauren Rayner, Hannah Rowlands and Elly Aylwin-Foster. Supervision, project administration and validation provided by Grace Lavelle and Lauren Rayner. Visualisation provided by Alan Simpson, Vanessa Lawrence and Grace Lavelle. Data curation and formal analysis were undertaken by Grace Lavelle, Hannah Rowlands, Elly Aylwin-Foster and Vanessa Lawrence. Finally, initial draft writing was completed by Grace Lavelle, Hannah Rowlands, Elly Aylwin-Foster and Vanessa Lawrence with the full authorship team reviewing and editing the final submitted manuscript (Hannah Rowlands, Elly Aylwin-Foster, Matthew Hotopf, Lauren Rayner, Alan Simpson, Grace Lavelle and Vanessa Lawrence).

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Pseudo anonymised participant data may be available for research purposes on request to the study authors, subject to approval.

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The experiences of psychiatric patients, their caregivers and companions in upholding patient

dignity during hospitalization: A qualitative study

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ABSTRACT (ENGLISH)

Introduction

The quality of care and patient satisfaction is closely linked with dignity, which is a crucial component of therapy and care. However, there is very little study on dignity in the context of mental health care. Planning for ongoing patient care might benefit from an understanding of the notion of dignity by exploring the experiences of patients, caregivers and companions of patients who have a history of hospitalization in mental health institutions. To retain patients' dignity while they were being treated in mental wards, this study sought to understand the experiences of patients, caregivers and companions of patients.

Materials and Methods

This investigation was qualitative. Semistructured interviews and focus groups were utilized to collect the data. The purposeful sampling method was employed for participant recruitment, which continued until data saturation. Two focus group discussions and 27 interviews were conducted. Participants included 8 patients, 2 patients' family members (companions), 3 psychologists, 4 nurses and 11 psychiatrists. Two focus group discussions were held with seven family members or companions of patients. Thematic analysis was used for data analysis.

Results

The primary theme that emerged was the infringement of patients' dignity, through negative guardianship, dehumanization and violations of their rights. Subthemes included dehumanization, worthlessness and namelessness, patient rights violations and stripping patients of authority.

Conclusion

Our results suggest that, regardless of the severity of the illness, the nature of psychiatric illness significantly compromises patients' dignity. Mental health practitioners, due to their sense of guardianship, may unintentionally treat patients with mental health disorders, thus compromising the patient's dignity.

Patient or Public Contribution

The research team's experiences as a psychiatrist, doctor and nurse informed the study's objectives. Nurses and psychiatrists who work in the healthcare industry designed and conducted the study. The primary authors, who are healthcare providers, collected and analysed the required data. Furthermore, the entire study team contributed to the writing of the manuscript. Study participants were involved in the data collection and analysis.

FULL TEXT

INTRODUCTION

Mental illnesses are a crucial global health concern,[1] affecting at least one in three individuals during their lifetime.[2] A meta-analysis revealed that 27% of adults in European countries experienced mental disorders within the past year,[3] while some studies in Iran reported a prevalence of over 29%.[4] Preserving patients' human dignity while providing quality care is a fundamental responsibility of any country's healthcare system,[5] particularly because individuals with mental disorders are vulnerable to losing their human dignity.[6] Dignity and respect are two main parts of the patient–caregiver relationship.[7] To underscore the significance of preserving dignity in mental health care, the World Mental Health Federation designated 2015 as the Year of Mental Health Dignity.[8]

The term ‘dignity’ is defined as the treatment of a person with honour, integrity and courtesy in a manner that is not condescending or patronizing, and with equality and the same respect as any other individual desires. It is a mutual respect that cannot be achieved without the participation of both parties. Patient dignity entails recognizing each person's uniqueness and emotions and granting them control over their decisions and actions.[9,10] Additionally, dignity encompasses how one presents oneself to others in terms of physical appearance and personal conduct. Ultimately, dignity is reflected in the attitudes and behaviour of others toward an individual. The framework of human dignity posits that dignity is a subjective notion that pertains to an individual's internal sense of self-worth. It is also influenced by a variety of psychological, cultural and social factors. Furthermore, human dignity is unique to each person and is shaped by their relationships with others. Additionally, there is a sense that human dignity is a comprehensive concept that extends beyond the sum of its components.[11–13]

Maintaining patient dignity is a fundamental part of providing quality care.[14] Patients recognize dignity as one of the most important aspects of care and make a direct connection between their sense of dignity and respect and the overall quality of their care.[15] There is a strong relationship between preserving patient dignity and their satisfaction with care.[16] Caregivers should be knowledgeable and skilled in how to preserve patient dignity in their work.[17] Ensuring that patients are cared for while preserving their human dignity is a crucial element of healthcare delivery systems.[18–21]

Preserving patient dignity includes upholding privacy, confidentiality, honest communication, involving the patient in their care, respecting their authority and control over the care process, respecting, viewing the patient as an individual and allowing them to make decisions.[21] The importance of preserving human dignity and status has been highlighted in the 1984 General Assembly Declaration.[22] The World Health Organization has also recognized human dignity as a key factor in promoting patient health, and identified the right to informed consent, access to health services, confidentiality of information and privacy as the most important rights in a 1994 Declaration.[22]

In recent years, considerable effort has been devoted to planning and policy-making to improve the delivery of mental health care globally. However, the experience of all stakeholders has not been sufficiently considered. Enhancing the quality of care and sustaining the dignity of patients with mental health disorders requires examining how to improve care across a range of scenarios, from the mild to the most extreme. Therefore, this study aimed to explore the experience of patients, caregivers and family members/companions in preserving dignity during hospitalization in the mental health department.

MATERIALS AND METHODS

This study used a qualitative research approach. Participants were selected through purposeful sampling to meet the research objectives. The participants were patients, caregivers and family members of patients with mental health disorders hospitalized in a psychiatric ward of a University Medical Center over the past year. Patients were selected in consultation with psychiatrists. Inclusion criteria for patients were stable mental condition and ability to provide informed consent. Psychiatrists and nurses had at least 6 months of experience in the psychiatric ward. Family members were first-degree relatives present during admission and regularly through the hospitalization.

Data were collected through face-to-face focus groups and face-to-face semistructured interviews based on an initial interview guide. Patients were asked about hospitalization experiences, experiences maintaining and harming dignity, and factors impacting dignity. Caregivers were asked about experiences in the psychiatric ward, hospitalizing psychiatric patients, situations preserving or damaging patient dignity and factors impacting dignity. Family members were asked about experiences during admission and hospitalization, situations preserving or damaging patient dignity and factors impacting dignity. Twenty-six participants were interviewed, with one interviewed twice. Interviews lasted 24—63 min. Two focus groups of 83 and 74 min were conducted with the same family members. Conducting a focus group discussion is an effective approach to obtaining detailed insights into the perspectives and viewpoints of a community regarding a particular subject matter.[23] Preserving the dignity of study participants, including patients and their families, was a primary focus throughout the data-gathering process in our study. The participants were selected with the assistance of their respective psychiatrists, who first explained the study's purpose and nature to them. Following this, patients and their guardians provided written informed consent. Throughout the data gathering and analysis phases, the participants were referred to as study colleagues and addressed by their appropriate title and last name as a sign of respect. We communicated to them that their contribution was highly valuable and that their involvement was greatly appreciated, emphasizing the importance of their dignity and worth throughout the study.

Questions were refined based on emerging themes and categories. Probing questions clarified responses. Interviews were transcribed verbatim. Thematic analysis identified related features and subthemes until saturation, when new data matched existing data and no new data was added. The data were analysed through a combination of paper and pen methods, aided by Microsoft Excel 2016. The study participants were actively engaged in both data collection and analysis. They were given access to the transcribed interviews and focus group discussions and asked to provide input on the codes, categories and overarching themes. Their feedback was incorporated in the selection of relevant quotes, and they also provided commentary on the main findings of the study. Additionally, their insights were helpful in clarifying any misunderstandings that may have arisen during the data gathering and analysis process.

Ethical approval was obtained from the Iran University of Medical Sciences Biomedical Research Ethics Committee (IR.IUMS.REC.1395.121). Informed consent was obtained from participants and guardians. Confidentiality and anonymity were ensured using aliases. Findings were provided to relevant centres with proper referencing.

RESULTS

Upon completing data collection, 27 interviews and 2 focus group discussions took place. The participants consisted of 11 psychiatrists, 3 psychologists, 4 psychiatric nurses, 8 patients and 1 family member of the patients. Seven family members or companions participated in the focus group discussions.

The primary theme of this study was the violation of patient dignity due to negative guardianship. The subthemes identified were negative guardianship, custody and deprivation of rights. The results revealed that psychiatric illnesses impact a patient's dignity, regardless of the severity of the illness. Therapists may unintentionally violate the dignity of patients with mental health disorders because of their sense of guardianship, which threatens the patient's dignity. Table 1 presents the main theme, subthemes and primary codes of the study.

Table 1 Main theme, subthemes and main codes of the study.

Main theme	Subthemes	Codes
Violation of patient dignity through negative guardianship	Negative guardianship	Not being able to make decisions for oneself
		Waiting for a decision by the therapist on behalf of the patient or family

		There was no participatory approach Negative family reaction to being consulted by a therapist
		Consult with the family about the patient's discretion
	Dehumanization, namelessness and worthlessness	Not looking like a human being
		Not being respected
		A sense of worthlessness
		Feeling less than a human being
		Removal respectful titles
		Removal of the title to create empathy and reduce formality
	Violation of patients' rights	Talk about the illness with family
		Not being aware of your rights
		Not knowing the diagnosis
		Lack of insight into the patient at the time of hospitalization
		Not keeping patient information confidential
		Physical abuse
		Not getting patient consent
		Unprincipled hospitalization of the patient

	Deprivation patients of their authority	Hospitalization against the patient's wishes
		Ignoring patients' decision
		Ward restrictions
		Deprivation of the right to choose a therapist
		Ignoring the patient's wishes
		Lack of access to the main therapist

Meaning of dignity

At the start of the interview, the participants were asked to define the concept of dignity, and their responses were as follows:

Patient, a 33-year-old single male, believes that dignity is the genuine respect that every person is entitled to.

Patient, a 28-year-old single female, views dignity as being treated with respect and as a healthy human being, equal to others.

Patient, a 46-year-old divorced male, draws from his personal experience to define dignity as being trusted and receiving the respect one deserves.

The psychiatrist, a 61-year-old female, considers dignity to be the foundation of care, where both the patient and healthcare provider should be respected to achieve a healthy life.

The psychologist, a 40-year-old female, sees dignity as a more comprehensive and detailed form of respect.

Lastly, the psychologist nurse, a 31-year-old female, defines dignity as the core principle of care where the patient is viewed as a deserving and respected human being who should receive quality care.

They saw dignity as a wide and comprehensive concept related to respect and being treated respectfully.

Negative guardianship

The first theme was negative guardianship. Participants believed that a reason for overlooking patients' dignity is the sense of negative guardianship that some therapists have toward patients. Therapists thought that patients with psychiatric disorders were incapable of making their own decisions or might be exploited for various reasons.

Psychiatrist: ‘There have been cases where the family or relatives wanted to take advantage of the situation because of the patient's position, here the psychiatrist has a responsibility to defend the patient's rights’.

Psychiatrist: ‘One of the reasons our colleagues are so sensitive to these patients' rights is that they may make decisions that are detrimental to them or do something that affects their lives’.

Psychiatric nurse: ‘Many patients …do not have an insight into their disease and we are responsible for them’.

Healthcare providers often believe that patients cannot make decisions independently. Some therapists thought that asking the patient for their opinion would usually result in a negative response from the patient or their family, who expected the therapist to decide for them. In this respect, therapists believed they were better positioned to act in the best interest of patients who cannot act in their own best interests.

Psychiatrist: ‘If we ask them, the situation will get worse. They say we came here for your guidance, But I see you know nothing’.

Patient: ‘I expect my therapist to tell me what to do, if he does not tell me, what am I going to do?’

Companion: ‘We mostly expect him to be treated. We do not know anything about the treatment and they did not provide enough information so we go to someone who knows better than us'.

This decision-making process evolved from a sense of guardianship that regards patients as incapacitated individuals who are incapable of having any rights and are deprived of self-determination and decision-making.

Inpatient: 'I consult with my doctor or psychologist about most issues in my life because I think I made many mistakes in my life that would not have happened if I had consulted'.

Therapists, patients and family members or companions expected the psychiatrist to have the authority to make decisions about all aspects of the patient's life, making the participatory approach invisible.

Psychiatrist: 'We are asked whether he should be hospitalized or not, or they even ask if he (should) get married or not. We usually answer them according to the patient's condition, it is less common to ask their opinion'.

Companion: 'In the case of patients like ours, the doctor knows better what is better for him. We also trust him and it has been good so far'.

Psychiatric nurse: 'It is rare for a patient to be asked what he wants. Usually, his family makes decisions in consultation with a doctor'.

Decision-making on behalf of patients at a highly personal level was also not uncommon. Depriving a person of essential life decisions, such as choosing to marry or having relationships with others, was one aspect that did not occur during hospitalization. However, questions about these issues from the patient and their families at the time of hospitalization were not usually well answered. Some psychiatrists spent more time answering the patient's questions in this regard.

Psychiatrist: 'They ask us if he should get married. They also believe that if he gets married, it will be fine. I tell them that the other party must be aware of this person's condition'.

Companion: 'We ask the doctor whether he should get married or not, but usually, their answer is not straightforward'.

Many crucial life decisions may be taken away from patients and given to decision-makers like psychiatrists. In this manner, the patient is deprived of their rights, infantilized and unable to make critical life choices.

Decisions about who should be informed of the patient's diagnosis were also less frequently made in consultation with patients.

Patient: 'They did not ask my opinion whether to tell my family or not, …I was not good enough to decide. My family asked and they were told that this was probably the diagnosis'.

Psychiatrist: 'When the family asks and the patient cannot make a decision, I usually tell them'.

Psychiatrist: 'There are restrictions, for example, we are careful to tell their spouse'.

Assistant: 'Usually, the family insists on knowing the diagnosis, and we tell them the diagnosis; we typically do not ask the patient'.

Dehumanization, namelessness and worthlessness

Negative guardianship may lead to some degree of infantilization, depriving patients of their authority and ability to self-determine or collaborate in decision-making. This can result in feelings of dehumanization, anonymity and worthlessness, as experienced and observed by patients, practitioners and companions.

Patient: 'They referred to themselves as Mr. Doctor or Mrs. Nurse, but they addressed us by our first or last name without any titles like Mr. or Mrs.'.

Companion: 'Not all, but some staff members don't show much respect to patients'.

Participants believed that these behaviours made them feel less than human. They mentioned not being addressed by their usual titles.

Patient: 'The person in the hospital might have had a job before; I was employed. In the hospital, they called me by my last name only and talked down to me like I didn't understand anything, as if I were a child'.

This lack of respect, where patients are not given their due titles and are belittled, makes them feel disrespected, dehumanized and infantilized.

Companion: 'Generally, the treatment was respectful, but one could sense that they see the patient as lacking a complete personality like other people'.

Some psychiatrists and other healthcare teams believed that calling patients by their first name created empathy and intimacy. Others strongly opposed this practice and aimed to create empathy while maintaining the patient's respect.

Psychiatrist: ‘I believe it's disrespectful to call patients loudly from the waiting room’.

Psychiatrist: ‘I address patients by their titles and ask my assistants to do the same. I prefer being called by my title as well. I think it's the right way, but I see patients being called without a title. Maybe they want to get closer and create empathy’.

Psychiatrist: ‘If we call patients without titles, it's to lessen the formality and distance between us’.

Nurse: ‘In our department, calling patients without titles happens frequently, but it's meant to create intimacy’.

Psychologist: ‘I take it very seriously, but I've seen it happen. I think it's to strengthen empathy, but I don't find it appropriate’.

All three interviewed groups reported cases where patients' dignity was not observed during admission. The results revealed that patient dignity is a sensitive issue that many therapists pay special attention to, but hospital conditions and patients' lack of rights awareness make it challenging to respectfully. Although practitioners claimed to take this matter seriously, this was less evident from patients' and companions' perspectives:

Psychologist: ‘I always invite patients into the room or stand up when they arrive. I escort them out when they leave, giving them a sense of respect and dignity’.

Psychologist: ‘I explain patients' rights to all of them; this is one of the most important ways to respect their dignity’.

Nurse: ‘All our doctors show the utmost respect for patients and set a great example. I've never seen a case of patient disrespect.

Companion: ‘The overall treatment is good, and we're satisfied, but our patient's condition is special. They need more respect’.

Patient: ‘I've been hospitalized several times. The level of respect varies depending on the place, doctor and ward. I've felt both respected and unworthy as a person’.

There is a notable disparity in perceptions between practitioners and patients or companions concerning respect and honour, particularly in the theme of rights deprivation.

Violation of patients' rights: Rights to diagnosis knowledge, care choice, confidentiality and freedom from harm

Disrespecting the dignity of psychiatric patients often manifests as rights deprivation, particularly concerning their right to know their diagnosis. Psychiatrists usually prefer not to disclose the diagnosis to psychiatric patients for various reasons.

Patient: ‘For a long time, I didn't know my diagnosis. I only knew I had a mental illness and needed medication. My doctor eventually told me I had a mood disorder. I didn't follow up until they finally told me I was bipolar. Then I researched and learned what it meant’.

Companion: ‘We only knew that the patient had a psychiatric disorder; we didn't know the diagnosis’.

Psychiatrist: ‘Knowing the diagnosis alone doesn't help. They may search the internet, and it could confuse them’.

Patients' experiences also showed that they were not informed of their diagnosis even after a long hospitalization.

Patient: ‘I was hospitalized several times and took many medications, but I didn't know my disease's name’.

Psychiatrists cited several reasons for not disclosing the diagnosis, including the patient's lack of insight at admission, inability to understand the diagnosis and the patient not asking for it.

Psychiatrist: ‘I don't think knowing the diagnosis is very helpful, but if they ask, I'll tell them. There should be a system that provides the necessary education’.

Receiving other basic rights, such as choosing a therapist during hospitalization, was also reported. This was mostly related to the structure of patients' admissions during emergency visits.

Patient: ‘Dr …was my doctor, but when you come to the emergency room, you cannot choose your doctor. You are sent to another doctor; this makes me sad’.

Instances of physical abuse, lack of privacy and confidentiality were also reported:

Psychiatrist: ‘There were cases where health staff hit patients; we saw the video, and those staff members were punished'.

Psychiatrist: 'Like how maternal cases shouldn't be examined in front of students, we're doing the same with psychiatric patients. We don't ask for the patient's consent while ten students are sitting next to us. Would you be comfortable if I asked you this question?'

One of the patients' rights that were often overlooked was the right to confidentiality. Patient information was frequently shared with family members without consulting the patient, especially during emergencies. This was more likely when therapists were questioned by the family.

Psychiatrist: 'I usually tell the family because the patient doesn't have any insight, and someone has to decide'.

Patient: 'I didn't want my wife to know my diagnosis. I don't know how she found out, but it wasn't good for me'.

Depriving patients of their authority

One crucial aspect of diminished dignity for psychiatric patients is the loss of their authority. This study's findings indicate that psychiatric patients often lose their decision-making power on numerous matters in their lives. A key aspect is the inability to make decisions regarding their treatment process.

Psychiatrist: 'Patients with mental health disorders sometimes lack the authority to make decisions. They may struggle with decision-making, but we sometimes forget they can still make choices for themselves. For instance, a patient may say they don't want medication for their depression, and I might respond that if they don't want medication, they shouldn't come to me for help. Their manner of expression might not be respectful, but they're being honest. I don't offer psychotherapy, so I refer them elsewhere. If they don't follow my advice, I might get frustrated and refuse to see them anymore. I rarely see them asking about their preferred treatment options'.

Regarding hospitalization, patients mentioned that even when they had the authority to decide on their admission or were aware of their condition and did not want to be admitted, they were hospitalized against their will.

Patient: 'I knew I wasn't very sick, but when I argued with my brother, nobody listened to me and they took me to the hospital. No matter what I said, they got angry and put me to bed. I wasn't hospitalized for long and was discharged soon'.

In such cases, doctors also acknowledged that they sometimes had to treat patients due to family pressure, even when the patient was capable of making their own decisions. This situation exemplifies the deprivation of patient authority. Most of these forced hospitalizations occurred during night shifts by assistants.

Psychiatrist: 'The patient wasn't very sick, but the family insisted they were in a lot of pain. We admitted them, and they were discharged the following morning'.

Psychiatric patients also encountered challenges regarding admission, such as obtaining permission to leave the ward, not being allowed to have a cell phone on the ward, and needing approval for simple tasks. These restrictions exemplify the disenfranchisement they experience.

Psychiatrist: 'For instance, we take away their mobile phones. However, this patient is no different from other patients'.

Psychiatrist: 'Initially, there was significant resistance to allowing them to keep their mobile phones, but I advocated for their right to have them. Eventually, it became clear there was no issue'.

DISCUSSION

The current study's findings indicate that the dignity of psychiatric patients during hospitalization is not adequately addressed as outlined in the Charter of Patients' Rights. Our results reveal that healthcare providers exhibit a negative guardianship towards patients, leading to dehumanization, depersonalization, violation of patients' rights and stripping of patients of their authority. Consequently, patients in mental health facilities may suffer from a lack of dignity maintenance, negatively impacting the quality of care.

Our findings align with previous research. In a study by Chambers et al., 19 adults in a mental health unit in the United Kingdom were surveyed. Patients' experiences revealed that their dignity was impacted by factors including staff not listening to their concerns, lack of participation in treatment and care decisions, insufficient information about treatment plans and medications, limited access to therapists and an unsupportive physical environment for physical activities.[6] We also found that lack of participation in the decision-making and treatment violates the patient's dignity. This result was also supported by Scorpen et al. who conducted a study examining the experiences of patients, relatives and caregivers regarding patients' dignity in mental health departments. Their primary resulted theme was ‘the importance of small things for experiencing dignity’, with subthemes encompassing awareness of minor issues, a consciousness of spoken words and satisfaction and recognition of interpersonal relationships. Employees' behaviour directly impacted patients' and their companions' perception of dignity. When patients and families are treated with values such as equality and respect, imbalances in relationships can cause resentment.[24,25] Our results also showed that patients should be treated respectfully. They need to be seen as human and they compare themselves with patients with physical illnesses.

In 2012, Lindwall et al. published findings on preserving patients' dignity in psychiatric wards. This study aimed to describe nurses' experiences in handling situations related to patients' dignity in psychiatric wards. Findings demonstrated that when caregivers work according to their moral duty, patient dignity is preserved.[26] Gastfson's study identified seven primary themes: patients not being taken seriously, patients being ignored, disclosure of patients' secrets, violence against patients, victimization of patients, abuse of patients' trust and predefining patients.[27] Their results were in line with our study. We also found that disclosure of patients' diagnoses to their families and ignoring them made them feel undignified.

Maintaining a patient's dignity fosters a sense of comfort, confidence and worth, which can aid in treatment and care decisions. Conversely, when a patient's dignity is neglected, feelings of uncertainty, humiliation and shame can adversely affect treatment and care outcomes.[28] The foundation of care is respect for individual dignity, which is increasingly important every day.[22] Dignity is a fundamental concept in health systems and the focus of medical and nursing care.[29] In medical environments and hospitals, dignity encompasses independence, honesty, justice, respect for human rights, awareness and active defence of the patient.[30]

Preserving patient dignity in various hospital wards is crucial, and respecting rights related to individual dignity is a principle of work and professional ethics. Some studies have shown that hospital patients are susceptible to losing their human dignity.[31] Regrettably, evidence suggests that most healthcare workers view the world solely from their professional perspective, limiting their thinking, judgement and ultimately their performance. Expanding their understanding of the phenomenon in various ways is essential to achieving optimal performance.[32] The history of the healthcare system introduction demonstrates a shift from a biomedical approach focused on disease, signs and symptoms to a holistic approach emphasizing human values and experiences.[26] Treatment for patients with mental disorders may be performed without their consent, at the therapist's discretion and based on the principle of utility. The ability to participate in treatment decisions, have authority, provide informed consent and maintain confidentiality is sometimes overlooked by patients admitted to mental health wards.[33] This negligence can result in a sense of lost authority and helplessness in the patient, negatively affecting their recovery.[33–35] Furthermore, research has shown that a loss of patient dignity may even diminish their desire for recovery and survival.[36]

Enhancing human dignity is thus a critical consideration. Improving human dignity in medical care users can increase patient self-confidence while disrespecting dignity can lead to severe forms of physical and mental deterioration.[31,37,38] When a person with a mental disorder is admitted, stress can manifest as physical behaviour that may harm oneself or others.

Limitations

While our findings offer valuable insights into dignity within mental health settings and hospitalization, further research on the dignity of patients with mental health disorders in various contexts, such as family and workplace settings, would be beneficial.

CONCLUSION

Our study underscores the importance of conducting further research on the concept of dignity in varied settings to enhance our comprehension of it. We also recommend the development of quantitative measures to evaluate the preservation of dignity across multiple perspectives. Based on our findings, we suggest that psychiatrists, psychologists and nurses, who are at the forefront of providing mental health care, require additional education and improved attitudes toward dignity in mental health settings. They must view the care and treatment system from the patient's perspective and gain a deeper understanding of the significance of dignity and respect in enhancing patients' quality of life and well-being. One of the primary reasons for compromised dignity in mental health settings is the negative attitudes of healthcare providers toward individuals with mental health disorders. They must adopt a more positive outlook toward the abilities and lives of these patients. Our study reveals that despite the efforts of psychiatrists and therapists to empathize and safeguard patients' rights, the nature of mental health disorders causes some hospital staff to perceive these individuals as incompetent to make critical life decisions. This perspective leads therapists to make decisions on behalf of their patients, resulting in a disregard for their rights and a loss of decision-making authority.

AUTHOR CONTRIBUTIONS

H.R., A.S., C.B., and Y.R. wrote the manuscript draft. H.R. and F.A. designed the study. F.A., A.A. and M.A. did the data gathering. H.R., A.S., and C.B. conducted the analyses. All authors reviewed the final manuscript.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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Towards an Implementation-STakeholder Engagement Model (I-STEM) for improving health and social care services

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ABSTRACT (ENGLISH)

Background

The implementation science literature acknowledges a need for engagement of key stakeholders when designing, delivering and evaluating implementation work. To date, the literature reports minimal or focused stakeholder engagement, where stakeholders are engaged in either barrier identification and/or barrier prioritisation. This paper begins to answer calls from the literature for the development of tools and guidance to support comprehensive stakeholder engagement in implementation research and practice. The paper describes the systematic development of the Implementation-STakeholder Engagement Model (I-STEM) in the context of an international, large-scale empirical implementation study (ImpleMentAll) aimed at evaluating the effectiveness of a tailored implementation toolkit. The I-STEM is a sensitising tool that defines key considerations and activities for undertaking stakeholder engagement activities across an implementation process.

Methods

In-depth, semistructured interviews and observations were conducted with implementers who were tailoring implementation strategies to integrate and embed internet-based cognitive behavioural therapy (iCBT) services in 12 routine mental health care organisations in nine countries in Europe and Australia. The analytical process was informed by principles of first- and third-generation Grounded Theory, including constant comparative method.

Results

We conducted 55 interviews and observed 19 implementation-related activities (e.g., team meetings and technical support calls). The final outcome of our analysis is expressed in an initial version of the I-STEM, consisting of five interrelated concepts: engagement objectives, stakeholder mapping, engagement approaches, engagement qualities and engagement outcomes. Engagement objectives are goals that implementers plan to achieve by working with stakeholders in the implementation process. Stakeholder mapping involves identifying a range of organisations, groups or people who may be instrumental in achieving the engagement objectives. Engagement approaches define the type of work that is undertaken with stakeholders to achieve the engagement objectives. Engagement qualities define the logistics of the engagement approach. Lastly, every engagement activity may result in a range of engagement outcomes.

Conclusion

The I-STEM represents potential avenues for substantial stakeholder engagement activity across key phases of an implementation process. It provides a conceptual model for the planning, delivery, evaluation and reporting of stakeholder engagement activities. The I-STEM is nonprescriptive and highlights the importance of a flexible, iterative approach to stakeholder engagement. It is developmental and will require application and validation across a range of implementation activities.

Patient or Public Contribution

Patient contribution to ImpleMentAll trial was facilitated by GAMIAN-Europe at all stages—from grant development to dissemination. GAMIAN-Europe brings together a wide variety of patient representation organisations (local, regional and national) from almost all European countries. GAMIAN-Europe was involved in pilot testing the ItFits-toolkit and provided their views on the various aspects, including stakeholder engagement. Patients were also represented in the external advisory board providing support and advice on the design, conduct and interpretation of the wider project, including the development of the ItFits-toolkit.

Trial registration

ClinicalTrials.gov NCT03652883. Retrospectively registered on 29 August 2018.

FULL TEXT

INTRODUCTION

In implementation research, there is a growing recognition that effective implementation requires engagement of stakeholders in the design, delivery and evaluation of implementation strategies. A stakeholder can be defined as any 'individual or group who is responsible for or affected by health-and healthcare-related decisions that can be informed by research evidence'.[1] Comprehensive stakeholder engagement can lead to a better understanding of local needs and barriers, increased relevance and impact of implementation activities, improved implementation capacity and capability and increased research adoption.[2] Beyond these instrumental benefits, there are also wider normative and political reasons for engaging stakeholders, including a shift from a paternalistic 'science advice' model to a more democratic and inclusive model of knowledge exchange.[3]

The wider literature provides a range of approaches to stakeholder engagement. Research on patient and public involvement (PPI) focuses on a subset of stakeholders and emphasises the need for shifting power towards the beneficiaries of services to co-produce mutually valued outcomes.[4,5] Co-creation and participatory action research go beyond the usual stakeholder engagement by emphasising the development and maintenance of bidirectional relationships.[6] Implementation science can be informed by these literatures, to incorporate more comprehensive approaches to stakeholder engagement.

Stakeholder engagement is highly relevant for all stages of the implementation process (i.e., exploration, preparation, implementation and sustainment).[7] Engaging stakeholders across the implementation process can facilitate the identification of context-specific barriers and the matching of more acceptable implementation strategies. Most of the work to date often reports minimal stakeholder engagement in the implementation process.[8–15] Stakeholders are either not directly engaged in the implementation process (e.g., a core team, often the researchers, decide on the goals and strategies) or they are minimally engaged (e.g., through brief periods of formal or informal feedback). In other implementation work, stakeholders are formally engaged, generally through single methods, in discrete aspects of the process, either barrier identification or barrier prioritisation.[16–18] None of the work reported to date formally engages stakeholders in a more comprehensive manner, in all aspects of the implementation process—from barrier identification, to barrier prioritisation, to implementation strategy selection, to intervention design.

Within the implementation literature there has been a call for the development and validation of tools and guidance to facilitate more comprehensive approaches to stakeholder engagement.[19] Existing approaches to stakeholder engagement include guiding principles,[1,20] taxonomies,[21] mapping criteria[22–25] and other classification systems.[26,27] For example, based on existing literature and empirical insights, Boaz et al.[20] formulated 'design principles' to support stakeholder engagement in implementation (e.g., clarify objectives of stakeholder engagement). Similarly, Concannon and colleagues[1] formulated a framework for classifying stakeholders in comparative effectiveness research, followed by recommendations for how to engage stakeholders. While guiding principles are helpful for designing stakeholder engagement activities, they do not offer enough conceptual depth to support the monitoring or evaluation of such activities.

Some approaches used in implementation focus on mapping and prioritising stakeholders using predefined criteria. For example, an interest–influence matrix is often used to determine the potential influence of stakeholder groups in a project.[25] Others have used the criteria power, legitimacy and urgency to generate typologies of stakeholders and their importance to a project.[22] One of the limitations of existing mapping criteria is that they were developed in management research, which focuses on the strategic aims of organisations rather than on the potential benefits of stakeholder engagement in implementation research.

Other approaches have focused on classifying different degrees, rather than on qualities, of stakeholder engagement. For example, the Spectrum of Public Participation classifies stakeholder engagement on a continuum including inform, consult, involve, collaborate and empower.[27] Another classification system distinguishes nonparticipation, symbolic participation and engagement participation.[26] While these classification systems begin to offer some conceptual clarity, they are still limited to certain aspects of stakeholder work and do not cover the range of considerations needed across an implementation process (e.g., setting objectives or evaluating outcomes).

Lastly, we identified two approaches that offer more comprehensive guidance for stakeholder engagement in implementation, including the 'analytic-deliberative' model[28] and the dynamic adaptation process (DAP) model.[29] The analytic-deliberative model was developed with contributions from qualitative and quantitative research (literature review, expert panel and pilot study) and offers a simple process for engaging stakeholders including inputs, methods, outputs and processes.[30] Similarly, the DAP describes possible stakeholder engagement across the implementation process.[29] In the DAP adaptations to an evidence-based practice need to be planned and coordinated in close collaboration with an Implementation Resource Team (IRT) and other key stakeholders to preserve fidelity to core components.[29] While these process models provide clear 'how-to' guidance for stakeholder engagement, they do not provide much conceptual depth with regard to the different dimensions of stakeholder work across the implementation process.

In this article, we aim to advance current approaches to stakeholder engagement by describing the systematic development of an initial conceptual model for implementation-stakeholder engagement. As part of a multinational, Horizon 2020-funded study,[31,32] we conducted an in-depth qualitative investigation of stakeholder engagement activities undertaken by implementation teams who used a toolkit designed to support the tailored implementation of digital mental health services across nine countries. We developed an initial Implementation-STakeholder Engagement Model (I-STEM) through our investigation of what happens when implementers are structured into iterative cycles of stakeholder engagement across various phases of the implementation process, but where they retain considerable flexibility in how they approach this engagement work. We define a 'model' as a coherent conceptual arrangement that, when it is operationalised, makes possible a rationale description and taxonomy of a phenomenon. We have developed the I-STEM to support implementers with the planning, delivery and evaluation of stakeholder engagement activities when translating research into practice. The I-STEM guides implementers through the different phases of a stakeholder engagement process and can be used flexibly alongside existing theories, models and frameworks of implementation.[33]

METHODSStudy design and settings

This study was conducted alongside the ImpleMentAll (IMA) effectiveness trial comparing a toolkit for tailored implementation (ItFits-toolkit) with implementation as usual activities in a stepped-wedge study design.[31] Here we draw on the findings from a qualitative process evaluation, which was conducted alongside the effectiveness trial to understand how implementers engaged with the toolkit and how they worked with key stakeholders throughout the different phases of the implementation process. The study design consisted of qualitative interviews with members of the implementation teams and observations of meetings and events related to the implementation work. Members of the site implementation teams included: implementation leads (ILs; those responsible for coordinating the implementation work), core team members who were part of the teams working closely with ILs and other relevant stakeholders. The study settings included 13 implementation sites from nine counties—Italy, Spain, Germany, France, The Netherlands, Denmark, Kosovo, Albania and Australia. Even though each of the sites worked on implementing digital mental services, there was considerable variability with regard to the stages of implementation that sites were at. Some of the sites already had established regional expert centres and aimed to scale out their services, whereas other sites had only recently started their service and were still in the preparation phase. This variability provided us with a natural laboratory to explore how implementers worked with stakeholders across all stages of an implementation process. A detailed study protocol for the qualitative process evaluation can be found in Supporting Information: Additional File 1. A completed checklist of the 'Standards for Reporting Qualitative Research' can be found in Supporting Information: Additional File 2.[34]

ItFits-toolkit approach to stakeholder engagement

The implementation toolkit tested in the IMA trial had a build-it requirement for implementers to engage in iterative cycles of stakeholder engagement. The toolkit allowed considerable flexibility and did not specify how stakeholder engagement was to be undertaken. Instead, it provided implementers with a range of processes, principles and resources that they could use to enable stakeholder engagement activities, including:

- 1. *Core team*: A broad range of internal and external stakeholders who led and coordinated the implementation work locally using the ItFits-toolkit.

- 2. *Core principles*: Six core principles (including 'be open') that highlight the importance of listening and valuing stakeholders' knowledge and experience.

- 3. *Module steps*: All four modules of the ItFits-toolkit (identify, match, design and apply/review) incorporate three important substeps: (1) initialise; (2) verify and discuss and (3) finalise. First, the core team formulates the initial ideas in each of the modules (e.g., potential barriers to implementation). Next, they engage with a wider group of stakeholders to verify, discuss and potentially expand on those ideas. Lastly, the core team finalises each module (i.e., considering the inputs of all involved stakeholders).

- 4. *Consensus techniques*: Instructions on how to carry out brainstorming, structured group discussions, informal conversations, email discussions and surveys. An integrated online tool for creating custom surveys that can be sent out to stakeholders to collect information for tailoring implementation strategies.

Data collectionInterviews

Interviews with ILs, core team members and stakeholders within implementation sites were conducted repeatedly throughout the trial period using a theory-informed topic guide that evolved over time.[35] Core team members and stakeholders were sampled and interviewed to gain in-depth data on specific issues, and develop, test and then refine emerging analytic ideas. Interviews were mostly on a one-to-one basis and were conducted using video conferencing technology. All interviews were conducted in English by an experienced qualitative researcher (S. P.).

Observations

Meetings and events related to implementation activities were observed, either in real time or via video recordings made by site and project team members. These included technical trial support calls, on-demand technical support, follow-up calls and core team meetings. All support activities were delivered by the central research team either face-to-face or via videoconferencing technology. A member of the process evaluation team (S. P.) was present in these activities as a nonparticipating observer.

Data collected

Overall, 55 interviews were conducted with 30 individual participants across the study duration. The number of interviews contributed by each site ranged between 2 and 7 (median = 4). Interviewees were ILs (n = 19), core team members (n = 9) and other stakeholders (n = 2). The number of ILs exceeds the number of sites due to staff turnover. Some interviewees took part in more than one interview. IL and core team member participants were professionals (both clinicians and support staff) working within healthcare within both private and public sectors who were involved in the implementation of digital mental health services. Other individuals included stakeholders who had key roles in relation to the work undertaken through the ItFits-toolkit, but who were not considered part of the core implementation team, for example, key facilitators working in collaborating organisations that form part of the service delivery (e.g., insurance companies). In addition to interviews, we collected observational data during 19 calls: monthly support calls (n = 9); 1-month follow-up support calls (n = 5) and 3-month follow-up support calls (n = 5). The total number of sites participating in each of the recorded calls ranged from 1 to 5. The number of calls that sites took part in ranged from 1 to 4.

Data management and anonymisation

Participant written consent was taken for all data collection activities. Interviews were audio-recorded and transcribed verbatim for analysis. Meetings and events were observed and fieldnotes were taken. All data were carefully anonymised to prevent identification of either the individual participant or the participating study site. Qualitative software (NVivo) was used to support data management, analysis and documentation.

Data coding and interpretation

The analytical process for the interviews and observations was informed by principles of first- and third-generation Grounded Theory.[36] Sampling, data collection and analysis were iterative. Data were analysed and categorised using the *constant comparative method* of data analysis,[37,38] involving initial line-by-line coding, focused coding, theoretical coding and the production of memos (Figure 1). The ongoing analysis informed further rounds of sampling and data collection as concepts started to emerge (*theoretical sampling*). The research team discussed and refined the emerging codes and categories throughout the analytical process. They created, reviewed and refined analytical memos, conceptual maps and diagrams, integrating concepts over time. The resulting *initial* model for implementation stakeholder engagement is the outcome of an iterative model development process, which was conducted alongside the qualitative data analysis. This process involved building numerous iterations of models through diagrams and applying those models to samples of qualitative data, seeking out both conflicting and confirming examples in relation to the models. After each round of model application, the team worked collectively to refine diagrams and concept definitions, until we arrived at the most parsimonious constellation of concepts that represented the analytic insights developed from the data. To illustrate the iterative development process, we have included two early versions of the I-STEM in Supporting Information: Additional File 3.

Figure 1. Analytical approach applying the principles of the constant comparative method.

RESULTSI-STEM

We have developed the I-STEM (Figure 2) showing how stakeholders can be formally engaged in the implementation process. I-STEM builds on the idea that comprehensive engagement of stakeholders in all aspects of the implementation process can help (re)shape the work in constructive ways, increase ownership of the process and subsequent uptake of the innovation. The I-STEM is not prescriptive but rather highlights the importance of a flexible, iterative approach to stakeholder engagement. It is a sensitising tool that can be used alongside existing implementation theories, models and frameworks to support the planning, delivery and evaluation of stakeholder engagement activities by focusing on four key processes:

- Identify and prioritise engagement objectives.
- Map stakeholders using pre-defined criteria.
- Choose an engagement approach.
- And define qualities and logistics of the engagement approach.

DETAILS

Subject:	Mental health services; Collaboration; Cognitive-Behavioural factors; Mapping; Models; Empirical analysis; Cognitive behavioral therapy; Interest groups; Developmental stages; Stakeholders; Clinical outcomes; Toolkits; Objectives; Social care; Teams; Iterative methods; Interviews; Technical services; Participation; Conceptual models; Dissemination; Classification; Prioritizing; Implementation; Organizations; Social services; Cognitive ability; Qualitative research; Patients; Grounded theory; Mental health care
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Trauma-informed co-production: Collaborating and combining expertise to improve access to primary care with women with complex needs

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ABSTRACT (ENGLISH)

Introduction

Health, social care, charitable and justice sectors are increasingly recognising the need for trauma-informed services that seek to recognise signs of trauma, provide appropriate paths to recovery and ensure that services enable people rather than retraumatise. Foundational to the development of trauma-informed services is collaboration with people with lived experience of trauma. Co-production principles may provide a useful framework for this collaboration, due to their emphasis on lived experience, and intent to address power imbalances and promote equity. This article aims to examine trauma-informed and co-production principles to consider the extent to which they overlap and explore how to tailor co-production approaches to support people who have experienced trauma.

Methods

Bridging Gaps is a collaboration between women who have experienced complex trauma, a charity that supports them, primary care clinicians and health researchers to improve access to trauma-informed primary care. Using co-production principles, we aimed to ensure that women who have experienced trauma were key decision-makers throughout the project. Through reflective notes ($n=19$), observations of meetings ($n=3$), interviews with people involved in the project ($n=9$) and reflective group discussions on our experiences, we share learning, successes and failures. Data analysis followed a framework approach, using trauma-informed principles.

Results

Co-production processes can require adaptation when working with people who have experienced trauma. We emphasise the need for close partnership working, flexibility and transparency around power dynamics, paying particular attention to aspects of power that are less readily visible. Sharing experiences can retrigger trauma. People conducting co-production work need to understand trauma and how this may impact upon an individual's sense of psychological safety. Long-term funding is vital to enable projects to have enough time for the establishment of trust and delivery of tangible results.

Conclusions

Co-production principles are highly suitable when developing trauma-informed services. Greater consideration needs to be given as to whether and how people share lived experiences, the need for safe spaces, honesty and humility, difficult dynamics between empowerment and safety and whether and when blurring boundaries may be helpful. Our findings have applicability to policy-making, funding and service provision to enable co-production processes to become more trauma-informed.

Public Contribution

Bridging Gaps was started by a group of women who have experienced complex trauma, including addiction, homelessness, mental health problems, sexual exploitation, domestic and sexual violence and poverty, with a general practitioner (GP) who provides healthcare to this population, alongside a support worker from the charity One25, a charity that supports some of the most marginalised women in Bristol to heal and thrive. More GPs and healthcare researchers joined the group and they have been meeting fortnightly for a period of 4 years with the aim

of improving access to trauma-informed primary care. The group uses co-production principles to work together, and we aim to ensure that women who have experienced trauma are key decision-makers throughout our work together. This article is a summary of our learning, informed by discussion, observations and interviews with members of the group.

FULL TEXT

INTRODUCTION

Co-production is an approach where professionals and people who may use or are affected by public services collaborate, using the experience and expertise of all to form equitable partnerships to develop services/research and outcomes.[1–3] While co-production can help tackle inequities in health services by enabling those who are often excluded to help shape them,[1] there can be barriers that prevent involvement and perpetuate marginalisation.[1,4,5] There is increasing recognition of the needs of marginalised communities and the structural obstacles to involvement that they may face,[6] alongside support that might be needed by those who have experienced trauma.[7,8] Existing co-production approaches need to acknowledge and understand trauma and its potential impact on individuals, group dynamics and health inequalities.[8] The high prevalence of trauma in all sectors of society, and even higher prevalence among groups who experience health inequalities, mandates careful consideration of the impact of trauma within co-production work.

Trauma can be defined as ‘an event, …or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening’.[9] Complex trauma is prolonged and is often inflicted by an individual who should be trusted—for example, experience of child abuse or domestic violence.[10] The reduction in life expectancy for those experiencing complex trauma is well documented,[11,12] with higher rates of mental health problems, substance misuse, cardiovascular disease, diabetes, gastrointestinal disorders and cancer, amongst other conditions.[13] Complex trauma negatively impacts the ability to access healthcare services, experience of these services and ability to participate in research.[9] This compounds the existing direct physical and mental health impacts of complex trauma.

In recent years, there has been a move towards trauma-informed approaches to healthcare delivery.[9,14,15] An organisation/system that is trauma-informed:

> realises the widespread impact of trauma and understands potential paths for recovery; recognises the signs and symptoms of trauma in clients, families, staff and others involved within the system; and responds by fully integrating knowledge about trauma into policies, procedures and practices, and seeks to actively resist re-traumatisation.[9,p.9]

Inherent to a trauma-informed approach is the explicit consideration of the cultural, historical and gender factors affecting health, and redistribution of power in decision-making.[9] Although the involvement of those with lived experience of trauma is a core aspect of this approach and some research has highlighted the potential for co-production approaches to contribute to this,[16] there is no trauma-informed framework to guide collaborative processes between people with lived experience and other stakeholders (e.g., researchers, clinicians and managers).

In this article, we describe how we used co-production principles in the collaborative development of a trauma-informed primary healthcare intervention called Bridging Gaps. We start by reviewing trauma-informed and co-production principles, highlighting overlap as well as key differences. We then provide further details and aims of the Bridging Gaps project. We illustrate our co-production process to date, which involved using the principles of trauma-informed approaches as codes to analyse participant interviews. Findings are used to provide recommendations to those seeking to adopt co-production methods to work with people who have experienced trauma.

Comparative analysis of co-production principles and trauma-informed principles

While co-production has been described as a ‘vague’ concept, encompassing a range of different collaborative approaches,[17] this article draws on the principles of co-production from highly cited definitional material[2,18–20] that recognises the vital role of expertise from lived experience in developing services and research. Key principles of co-production include: sharing power and decision-making; adequate resources and shared ownership; equality; diversity of voice; accessibility and reciprocity; valuing all perspectives; and an appreciation of different knowledge and skills.[2] Principles of co-production substantially overlap with trauma-informed approaches. Collaboration with marginalised and less privileged communities is frequently a feature of trauma-informed approaches, which may provide crucial opportunities for building self-efficacy, confidence, skills and worth.[7] An emphasis on changing existing power dynamics through collaboration with and empowerment of individuals with lived experience of trauma is a key aspect of trauma-informed approaches. The six principles of trauma-informed approaches are listed in Table 1 and are compared to the principles underlying co-production approaches.

Table 1 Comparison of principles of co-production and trauma-informed approaches.

Aims and research questions

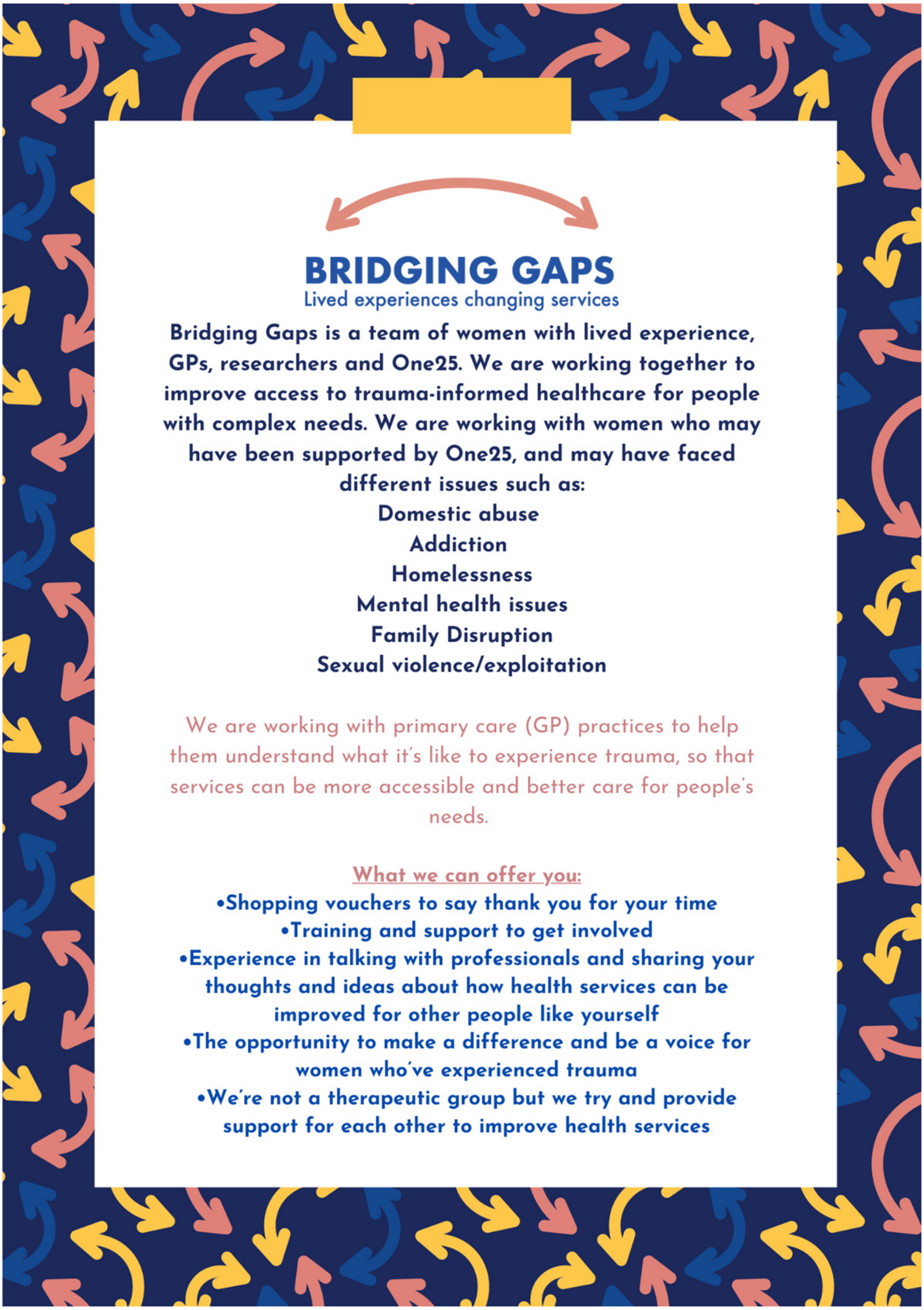
The aim of Bridging Gaps is to improve access to trauma-informed primary care with women with experience of complex trauma/needs. This work is ongoing. In this article, we focus on how we used co-production approaches to develop the project and reflect on how we learnt to tailor these to support people who have experienced complex trauma. Our improvement work with general practices is reported separately.[40] In this article, we investigate the following question:

- When working with people who have experienced multiple traumas, how do co-production approaches need to be developed to ensure safe, collaborative and effective working relationships?

Development of the co-production group

As a general practitioner (GP), co-author L. P. has delivered a once-a-week outreach clinic in the drop-in centre of support charity, One25, for 5 years. The outreach clinic is an attempt to provide more accessible healthcare to a highly marginalised group within a trusted community space alongside services delivered by One25 but is unable to offer the full spectrum of mainstream primary healthcare and only operates 1 day a week. The women that One25 supports have experienced complex trauma and face numerous adverse circumstances such as addiction, mental health issues, homelessness, trafficking, domestic violence, sexual exploitation, having children removed from their care and street sex work. All the women One25 works with have experienced trauma, and it offers specialist services alongside an ethos of nonjudgemental, unconditional love. Through her clinical work and conversations with staff and women attending the One25 drop-in centre, L. P. identified that the existing mainstream primary care system was largely not accessible to the women, despite high levels of clinical need. It was hoped that by bringing the right experts together (GPs, women with lived experience, One25 charity staff, researchers), better solutions could be developed. This led to the creation of Bridging Gaps.

Co-production meetings were held initially weekly then every 2 weeks and took place in well-known community spaces that One25 already used to provide services. Participants were offered shopping vouchers as a thank-you for their time and contributions following National Institute for Health and Care Research (NIHR) guidance.[41] The initial goal of these meetings was to discuss the ways in which women with lived experience of trauma could have their needs better met by primary healthcare. As the project developed, the group compiled some information about the project to encourage new members to join (Figure 1). During initial conversations about the project, it was stressed that participation or the choice not to participate would have no bearing on the healthcare received and existing support from One25 would continue.



BRIDGING GAPS

Lived experiences changing services

Bridging Gaps is a team of women with lived experience, GPs, researchers and One25. We are working together to improve access to trauma-informed healthcare for people with complex needs. We are working with women who may have been supported by One25, and may have faced different issues such as:

Domestic abuse
Addiction
Homelessness
Mental health issues
Family Disruption
Sexual violence/exploitation

We are working with primary care (GP) practices to help them understand what it's like to experience trauma, so that services can be more accessible and better care for people's needs.

What we can offer you:

- Shopping vouchers to say thank you for your time
- Training and support to get involved
- Experience in talking with professionals and sharing your thoughts and ideas about how health services can be improved for other people like yourself
- The opportunity to make a difference and be a voice for women who've experienced trauma
- We're not a therapeutic group but we try and provide support for each other to improve health services

Enlarge this image.

Meetings were attended by at least two professionals (GPs, researchers or staff from One25) to provide assistance, for example, if someone should become distressed and need to be supported within or outside the meeting. Over the period of operation (April 2019–to present) the core co-production group who met fortnightly has included a total of 29 women with lived experience of trauma, four researchers, two academic GPs, four GP trainees, and four One25 staff members, all of whom were women. Due to the longevity of the project, there has been significant variation in the membership of the group. At any one time there have typically been two to six women with lived experience, one to two academic GPs/GP trainees, one to two researchers and one staff member from One25 attending the groups. Group meetings happened on a fortnightly basis where possible, providing a sense of routine and continuity. Initial recruitment of women with lived experience of trauma took place in collaboration with One25, with L. P. and One25 staff directly approaching women who may have an interest in the project. Some of the activities of Bridging Gaps over the 4 years of the project are outlined in Table 2.

Table 2 Bridging Gaps activities.

Received training from a communications and story-telling expert

Co-developed and facilitated collaborative meetings with two general practices (face-to-face before the COVID-19 pandemic)

Co-developed a training session on trauma for GP trainees (face-to-face before the COVID-19 pandemic)

Created a new process to enable public contributors to own the IT equipment they needed to be able to be involved.[41] (This was because most women we worked with were digitally excluded at the beginning of the pandemic).

Received training in trauma-informed approaches

Co-developed and delivered online training on trauma-informed approaches at two GP surgeries and three online codesign meetings (during COVID-19 pandemic).

Co-delivered online training on co-production for the NIHR School for Primary Care Research.

Supported four GP trainee placements within fortnightly meetings to improve access to trauma-informed primary care.

Post-COVID-19 lockdowns, we facilitated three service improvement meetings at each of three general practices to improve access.

Successfully implemented service improvements at two general practices, including the development of a bespoke clinic, with ongoing work with a third subject to funding (see Potter et al.[40] for further details).

Co-delivered four conference presentations, including an invited plenary presentation for the International Symposium on Inclusion Health. Presentations at online professional meetings in Japan and the United States of America.

Invitations to present at two national NIHR Applied Research Collaboration online events on Community Engagement and Inclusion of Underrepresented Groups in research and Co-production in implementation.

Invitations to present at the international online seminar on Navigating Power, Building Relationships, and Fostering Trust in co-production and the in-person CoPro 2022 3-Day International Forum in Canada, both hosted by McMaster University.

Twenty-nine women with lived experience of complex trauma have contributed to this work, 20 practice staff have been involved in service improvement meetings, and 69 professionals have been involved in trauma-informed approaches/co-production training/workshops.

Abbreviations: COVID-19, coronavirus disease 2019; NIHR, National Institute for Health and Care Research.

METHODS

Methods used for this article were based on participatory action research and cooperative inquiry, where research is developed with people rather than on them.[42] Women with lived experience were much more motivated by practice and the possibility of change, than by theory or research. Where they had been involved in research before, they often saw little change following this. The Bridging Gaps group were focussed on ‘building participants' capacity to critique and question current arrangements, and innovate in the development of social practices',[17,p.86] aiming to improve access to trauma-informed primary care.

Ethics approval

The research was granted approval by the University of Bristol Faculty of Health Sciences Research Ethics

Committee, references 93802 and 110882.

Data collection

In traditional research, the roles of researchers and participants are mutually exclusive. Here all partners and women with lived experience contributed to the design and management of the work, and all were co-researchers and co-participants (e.g., researchers were also interviewed by more distant colleagues).[42] To understand, reflect on and document our approach to co-production, we conducted the following data collection and analysis.

Reflective notes

At the beginning of the project, an academic GP (L. P.) and researcher (L. W.) made reflective notes on 14 meetings, including project meetings (*n* = 11) with the women, one initial preparatory meeting with GPs not involved in Bridging Gaps and a member of the CCG, one storytelling workshop and one group visit to funders. Further reflective notes on their involvement in the project were made by a researcher and the four GP trainees involved in the project. Evaluation reports to funders included reflective questions on progress and included input from all members of the co-production group. While we have not quoted from these reflective notes, they provided a helpful record of project development.

Observation

Observations were conducted of three co-production group meetings and one storytelling workshop, by researchers (H. M., M. F. and H. C.) who were not at the time involved in group facilitation. Each observation was conducted by two researchers simultaneously with allocated time for discussion and comparison of field notes before these were combined for analysis. The storytelling workshop was one of four sessions led by a professional storyteller. These workshops included various interactive games and activities to help promote bonding as a group and develop skills and confidence in communication and public speaking.

Semistructured interviews

Twenty-nine women with lived experience have been involved in Bridging Gaps at some time to present (of the 29 members, five have joined since the interviews took place). At the time of the interviews (post-COVID lockdowns during summer–autumn 2021), due to life circumstances, reduced possibilities of engagement during lockdowns and very sadly one death, four women were contactable to be invited to interview. Interviews were also conducted with one researcher, two academic GPs and two One25 staff, all involved in the facilitation/management of the project. An additional researcher (T. S.) joined the project to conduct interviews with no prior experience of the meetings. This enabled triangulation between interview analyses conducted by H. M. and M. F. who had been involved with the project for over 1/3 years, respectively, with those from T. S. who had more of an ‘external’ perspective. All interviewees were women, ages ranged from 30 to 55. Interviews lasted between 19 and 81 min. Separate topic guides were developed for women, partners and researchers (Supporting Information: Appendix 1), which were developed and edited by researchers, academic GPs and discussed and agreed upon with the group. Informed consent (written for face-to-face, verbal audio-recorded for remote) preceded interviews, which were audio-recorded, transcribed, checked for accuracy and anonymised.

Data analysis

Initially the analytic process involved an inductive approach. H. M. and H. C. open coded observation notes with subsequent discussion to develop categories. Reflective notes were analysed in the same way. Discussion around emerging categories led to the identification of emergent categories relating closely to the six principles of trauma-informed approaches (Table 1) and a framework approach[43] was adopted in the subsequent analysis including interviews. These subsequent analyses were carried out using NVivo 12. Two researchers (T. S. and H. M.) double-coded two interviews, with subsequent discussion followed by T. S. coding the remaining interviews.

Bridging Gaps lived experience input

Bridging Gaps members have prioritised service improvements and achieving change in primary care over involvement in analysis and write-ups. In line with trauma-informed collaborative working, this focus was respected and supported while still offering opportunities to review drafts of key recommendations, learning and key points, which were discussed in our fortnightly co-production meetings. One lived experience member who met the co-authorship criteria wished to be named as a co-author. Others who would rather not have their real names identified come under the Bridging Gaps group title. Lived experience members have also co-delivered national and international presentations on the project and co-authored a book chapter where the women with lived experience wrote the majority of the words, and academic authors wove together their contributions.[44]

RESULTS

Results are presented using the overarching framework of the six trauma-informed principles, with additional themes developed inductively and example quotes presented in associated Tables.

Table 3 Illustrative data for cultural, historical and gender issues.

Themes arising	Data
Cultural, historical and gender issues	*Quote 1*: Well, what I like about it as well is because it's women who've been involved in—primarily, when it started, it was women who'd been involved in the sex trade, which I have, and I don't think them women's voices are heard enough; they're kind of forgotten about …the sex trade bit of it is kind of hidden and kind of looked down upon and I think it's really important to get them women's voices heard and make them feel that they are heard and have a voice in services because they don't have a voice in that enough. (Lived experience member 2) *Quote 2*: Women together and kind of just we have a bit of a giggle, have a cuppa and, you know, it just seems quite easy-going even though we're talking about quite—it can be quite traumatic, triggering things. Yeah, it feels like a safe space, definitely. (Lived experience member 1) *Quote 3*: I think women which have got experience at what they've gone through and the services that they are possibly using, to have their voices heard and to know that potentially you can make change is totally vital. Because for me, I was silenced for so many years. (Lived experience member 5)

Table 4 Illustrative data for Peer Support.

Themes arising	Data

Supporting each other	*Quote 1*: I've not given my kind of story yet but I've heard other people's and seen them do a presentation and it felt supported; it felt like, if it was too much, it felt like we'd all support each other …I've definitely got closer to the girls that do the meetings with me, definitely, yeah …I know that if I needed to, I could probably ring them up if I needed to. (Lived experience member 1) *Quote 2*: The sense of a family and the support from other women, knowing you're not alone, feeling empowered, building your confidence. I could go on, there's so many [laugh], so much, the friendships, not just service level friendships, you really get to know women on a deeper level and I class (Name) as my best friend. I think she changed my life. I could tell her anything. (Lived experience member 9) *Quote 3*: And so the women at those meetings connect with each other and even if you're not sort of formally kind of creating any peer support mechanisms, those are happening as people kind of walk out meetings together and chat or connect with each other. And I'm aware sort of different women have friendships with each other outside of the group. (Researcher 4)
Learning/sharing with each other	*Quote 4*: I felt like I got a lot closer to [academic GP] and [researcher] and [researcher] confided in me as well and yes, I felt very privileged. (Lived experience member 9). *Quote 5*: I just remember that actually the time that I did seek help around my own mental health. I was quite inspired by speaking to another member of the team who had talked to me about things she was struggling with … then I reflected on it myself and so it was the kind of bravery and strength that I see in women with lived experience who do share their stories that did prompt me to say 'okay …maybe actually I need to be brave and share some of my lived experience' and it was a real prompt for me seeking help for myself. (Academic GP 6)
Impact of providing support to peers	*Quote 6*: And then leaving and knowing they're going home alone as well, it stays on your mind. Well it stays on my mind for a bit …Yes, it's not nice to see that. Like one of the women broke down, yes and it was emotional. (Lived experience member 9) *Quote 7*: I felt like I had to stand up and be a kind of protector—not protector, that sounds like I'm making myself a martyr and I'm not—but I felt like I had to fight for them a bit more and fight for the kind of—to make sure things are all right for them a bit more. (Lived experience member 2)

Table 5 Illustrative data for trustworthiness and transparency.

Themes arising	Data

Trusting relationships	*Quote 1*: I think, because what helps with this, is a lot of the women know (Name), she's a doctor at One25 she does a clinic there, so a lot of the women would already know her, she would know the women and she understands the sex trade and what all that involves. (Lived experience member 2) *Quote 2*: The women have known her for a long, long time and she's done a lot to serve them really out of One25. That sort of trust, that's really hard to get in any other way because that's just through years of knowing people and showing up for them. (Academic GP 8) *Quote 3*: Just the level of trust that all women have really respected and all the women have really shared things as well that they wouldn't share so it's then made you feel like wow, like and if you all trust in me then I can trust you. If I'm trusting you, then you can trust me. (Lived experience member 9)
Longevity of relationships	*Quote 4*: Well. I think the longevity of it is really important …women felt that this was a long-term thing, that they weren't just involved in something for six months and then that ended. That was quite important in terms of women who have experienced a lot of trauma …It was quite important for there to be that time to build up that relationship and trust and then- because that takes ages and once that had been established you had time to deliver things through the project and women to feel, 'I am not just being used because of my lived experience.' (Support staff 7)
Members contributing equally to the project	*Quote 5*: And I think sometimes …you think, 'Oh, I'll just go get the vouchers, put in the bare minimum and I've got vouchers.' I can see it time and time again …if you're coming, just doing that, I think it's not fair on the other women who *are* putting in that kind of work. Sometimes I think a lot of the work can just land on a couple of people and then that's the—because I know, for me, at times I've felt resentment towards other members of the group …because I felt 'Well, I'm taking on all this …' (Lived experience member 2)
Transparency around roles	*Quote 6*: We need to acknowledge the actual existing power dynamics and roles that exist rather than pretending that they are not there and pretending that we are all equal, because I think that backfires and has an opposite effect from what it intended. We have to be really transparent about what everyone's roles are and the power in that everyone else's roles and try and mitigate that and try to balance it out a bit. Recognising that we can't fully flatten it because of the inherent roles that we are playing in the project. (Support staff 7)

Blurring boundaries	*Quote 7*: Like [support worker] she's really put her everything into it, like even her personal life. She was all about [Organisation] and the women and like it was more of a friendship. Like she did cross those boundaries with me anyway, I can't speak for other women. (Lived experience member 9).

Table 6 Illustrative data for collaboration.

Theme	Illustrative data
Group membership fluctuation	*Quote 1*: I think, going back to when it first started, for some of them women, it was their lifestyle, where they couldn't keep up the kind of commitment. (Lived experience member 2)
Too much email	*Quote 2*: There was a lot of emails, I think people felt overwhelmed, like it was a job and you were expected to kind of do this, do that. And I know a lot of women wasn't going to [Researcher] or [Academic GP] but they were coming to me, 'I can't handle [it], there's loads of emails.' (Lived experience member 2)
Challenges and disagreements on way forward	*Quote 3*: Creating a culture and a space where challenge can happen and conflict can happen and be resolved. That is to me the really interesting to learn about. (Support staff 7) *Quote 4*: We haven't had no disagreements as such. We have debates and I've walked off and I've gone away frustrated which I'm sure some of the GPs and that who are involved and (Name) have gone away frustrated from the way I've reacted sometimes but, as a group as a whole, we haven't had no massive disagreements or falling outs. We've managed to come to—once I get over the frustration—we manage to come, we do come to an agreement and kind of work things out. Yeah. And I know everyone's thing is to make sure the women are safe and in a safe space, to be able to speak about things … (Lived experience member 2) *Quote 5*: I think it's down to personality. Some women feel more confident to speak up. Other women are a little bit more reserved and perhaps don't say as much …For me personally, I wasn't that vocal, I think. I was quite happy to just go along with it …I think the thing is …if there were things I possibly didn't agree with or wanted to say, I knew that I could in confidence either call [Academic GP] or [Researcher] you know, so yeah, I did feel that I could air it with them. (Lived experience member 5)

Table 7 Illustrative data for empowerment and choice.

Theme	Illustrative data

Storytelling workshops	*Quote 1*: The work with [Storytelling facilitator] felt like it really brought lots of relationships closer as well …It was women with lived experience, GPs, researchers, all doing the same silly exercises …yeah, it was a real leveller, and it was enjoyable. (Academic GP 6) *Quote 2*: I think it really helped to do, is build a team, like give that team feeling? And what I liked about it as well—because we had trainee GPs involved—they took part in it as well so it wasn't 'Right, we're the service users over here and you're the staff.' That felt very—we was just all on the same level. And I think it's good it solidified us a group and kind of made us …and just to see the women chatting in a group. Some of them have never even sat in a group and spoke. (Lived experience member 2) *Quote 3*: Loved them. Every single one from day one, she's [storyteller] wicked, amazing. So I think mainly that was what got my confidence up I think, yes …I boob bounced [Researcher] [laugh]. That was wicked that was. You know what I look back on them and every time it makes me smile. Yes, those were straight bonding sessions. (Lived experience member 9)
Training in trauma-informed approaches	*Quote 4*: It was great …. So a lot of the stuff that we were taught …I'd already done a lot of it anyway doing the other training, but obviously some of the women coming through hadn't done any of the stuff, so for them it was a really important thing for them to do. (Lived experience member 5) *Quote 5*: I think because we've all experienced trauma, to then do that training and try and keep our head focused on actually what we're just trying to do …make it easier for women to access primary health care …we just got consumed by this trauma feeling …it felt like a slog at times …. But it wasn't no-one's fault; I think we just got carried away with the trauma side. (Lived experience member 2)

Integrating difficult experiences through sharing	*Quote 6*: So normally would have said talking about my past traumas but that's actually been like a self-counselling for me to be honest because before I couldn't talk about it without getting upset or being angry or just feeling loads of emotions that I guess now I can talk about it and I feel fine. It doesn't bother me in the slightest so it's kind of been—so I would have said that at the beginning but it's not that now …. I feel like I can talk about it now without crying or getting angry or going home and feeling, yes, like feeling depressed. (Lived experience member 9) *Quote 7*: Obviously when you're telling your own personal story, it can be a bit emotional because it's not conversations you have on a regular basis. I mean, like me personally, I don't talk about my trauma that I've gone through in the past, and then when you do talk about it, initially I found it quite sort of triggering for me because obviously it brings back a lot of very hurtful memories, but it's trying to sort of detach yourself from it. I know that I'm in a better place from the fact that I'm not going through any violence. (Lived experience member 5)

Feeling unable to say ‘no’- unrecognised power dynamics in the room	*Quote 8*: When you're in recovery—I know I've done it when I first got clean and people would say, ‘Oh, can you do that?’, I'd be, ‘Yeah’, I just wanted to do some[thing] …. We'd be in Bridging Gaps and everybody would be like, ‘Yeah’, and then we'd walk out and say, ‘Do you know, I don't want to do that’ …. So then I'd have to go and say, ‘Look, they're not really happy with that.’, and they'd be [saying] ‘But they said “yeah”’, and I'd be [saying] ‘Look, you don't understand. People will say “yeah” because they wanna please you and they're excited to be part of something and to have their voices heard but’—and it's not just on the staff, it's on the women as well and that's what I say to them, ‘If it doesn't feel right, you're allowed to say no and no one's going to say, “Right, get out”', so I think it was from both sides as well, but if that understanding was there that that's—and they did, I explained it and we all got through it—but I think there wasn't that kind of real understanding of how service users can behave. (Lived experience member 2) *Quote 9*: I think you need to be working together for a really long time and there needs to be significant trust to say, ‘I don't really like this’, or ‘let's go in a different direction.’ (Academic GP 8) *Quote 10*: Yes a lot of people are like yes people and just like to agree 'cause they don't want to hurt your feelings or they don't wanna be challenged on anything or debated on anything. I don't know what it is, it could be anything but I feel like people just say yes 'cause it's the easier option so it's always better to ask people first what they think. (Lived experience member 9)
Being empowered to choose what to share and when	*Quote 11*: Sometimes I feel I have to overly prove that I'm valid to be there, kind of thing. I've got this to prove, you know? So then I'll overshare, I'll say, ‘Well, I've gone through this.’ …I was speaking to [Academic GP] recently and she said she doesn't go nowhere and say, ‘Well, I've done this degree.’, she just goes in, and that kind of did flip a switch …really it's, ‘What's going to be helpful to *you* emotionally as well as to the project?’ and you don't have to divulge *everything* to make change! You don't have to prove that, ‘I've been through this and this and this.’ (Lived experience member 2)

Creating change	*Quote 12*: You feel like you've got, you've made a difference. Like got a little bit of purpose as well …you feel like you're becoming something and that's a good feeling rather than just sat and [sigh] what have I done today …Yes it helps you …it envisions you to do other things as well. Like you leave there and you can get things done like that you haven't been able to get done without coming here first …when I leave the meeting, it gives me motivation to do things as well. (Lived experience member 9)

Cultural, historical and gender issues

Group members chose the term *complex needs* over *severe and multiple disadvantage*[45] to describe their shared experience of surviving complex trauma. This included experiences of sexual and domestic violence, street-based sex work, trafficking, sexual exploitation alongside homelessness, addiction, having had children removed from their care and mental health problems (Table 3, Quote 1). The group wanted a female-only environment (Table 3, Quote 2) and we sought to create a nonjudgemental, open space where people came together on equal terms, sharing decision-making together and supporting each other: 'women can empathise and understand exactly where you are coming from because they've experienced similar things themselves' (Lived experience member 5). The group's aims were developed together with women with complex needs, who had a clear motivation to be heard and change services for others: 'we're a voice for other women being heard' (Lived experience member 9) (see also Table 3, Quote 3). The group reflected how historic experiences of trauma impacted their access to healthcare, which could be retraumatising, and that the needs of women with experience of trauma may differ from those of men. Traumatic experiences impacted the women's ability to trust and engage with healthcare professionals.

Peer support

Initial phases tended to focus on peer support and sharing of experiences. We aimed to enable women to support each other and form meaningful relationships and provided space for difficult and painful stories relating to past interactions with health and social care services to be shared. Early group meetings could involve both laughter and tears, with humour being used as a tool for processing difficult emotions and for group bonding. Women frequently encouraged and supported each other to continue group engagement (Table 4, Quotes 1 and 2). This highlights the intrinsic value of peer support in enabling women to empower other women. Peer support also extended beyond group meetings, with women informally meeting up separately outside of meetings and checking in with each other when going through difficult times (Table 4, Quote 3). Over time, researchers also shared things about their personal lives with the group, which helped to engender a sense of equality and community in the group and avoid 'othering' (Table 4, Quote 4). Listening to and working with each other also gave researchers a different perspective on their own help-seeking behaviour (Table 4, Quote 5).

We observed and discussed as a group how the peer support that existed between the women with lived experiences enabled them to challenge the researchers more confidently when there were things they did not agree with. Women would feed back that the peer support itself was healing, but listening and supporting each other also had an emotional impact: 'it was hard not to be able to take away the pain' (Lived experience member 9). We became aware that if group members took on too much of this peer support, it could become counterproductive for them and when this happened, we altered our ways of working to try and avoid this (Table 4, Quotes 6 and 7) (see also Section 3.5). For example, we developed sessions with general practices where lived experience members prepared personal examples in relation to trauma-informed principles. However, this sharing could become retriggering. Researchers first became aware of this when one lived experience member highlighted this for others, who may have felt less confident speaking about this. However, this added to her own concerns to make sure all voices were heard. On understanding this, the group changed its approach to focus less on trauma-informed training and experience-sharing, and more on developing bespoke service improvements with general practices.

Trustworthiness and transparency

Ongoing relationships and trust with One25 staff from the start enabled a safe space to be established in which collaboration could take place. The relationship between the GP who worked at One25 (L. P.) who initially conceived of the project and women with lived experiences of trauma who had been supported by One25 was integral in promoting a sense of trust within the group (Table 5, Quotes 1 and 2). Trust was also built between women in the group through the sharing of experiences (Table 5, Quote 3). Moreover, the longevity of the project helped in establishing longer term, more trusting relationships (Table 5, Quote 4).

As the project developed a group agreement was discussed and established in a collaborative manner. It was agreed that the group would follow existing One25 guidelines to protect the safety of those within the group, for example, maintaining the confidentiality of experiences shared and not being under the influence of substances when in the group. Through the project, some challenges arose with these. Initially when the group first operated on a more drop-in basis, where some women who were in a place of greater instability attended the group, they could talk over others, or kept coming in and out through the meeting. This led to some disruption, which was difficult for those who were consistently and meaningfully participating (Table 5, Quote 5). Occasionally, there were instances when women attended the group whilst using substances, potentially threatening the recovery of others. While drug use was not allowed, at times it was challenging to tackle this. Researchers had less experience in identifying signs of drug use and there were sensitivities around accusing or singling women out in the group. As the group established, there were rarely substance use issues arising. Although the aim was to move away from an 'us' and 'them' approach, professional roles maintained important boundaries that needed to be transparently kept to (Table 5, Quote 6). From a trauma perspective, lack of consistency in boundary enforcement could have a destabilising effect, safety implications and impair trust. In contrast, in other situations, some of the women in the group shared how the crossing of professional boundaries could also support relationships and trust, through the sharing of personal experiences and going beyond boundaries to provide support (Table 5, Quote 7). This relates to the co-production principle of *blurring boundaries*.[31,32]

Several structural issues complicated our striving to enable more equal relationships. Researchers and support staff held organisational positions, which meant that they were ultimately responsible for elements such as budgets, upholding organisational policies and procedures (Table 5, Quote 6). However, when these issues were discussed openly within the group, a greater feeling of trust was fostered. Furthermore, there were opportunities where we could minimise these power imbalances by using transparency. For example, although one of the researchers was the budget holder, decisions were regularly run by the group as a whole on how to spend the budget. These conversations were facilitated by flexible funders, who when asked about budget changes, were able to accommodate the group's wishes.

Collaboration

In the early stages of the project, there was more flux in group membership as individuals were more or less able to engage depending on what was going on in their life at the time (Table 6, Quote 1). The lead academic GP reflected that this led to her holding group plans and newer members inheriting plans made by others who had left, which may have led to the perception that they were *her* plans as she was the one restating them.

Communication was essential to building collaborative relations. Before the COVID-19 pandemic, all meetings were face-to-face and one funder required that the group attend training days to share learning with others. The car journey to these training days allowed an opportunity to deepen the relationships in the group. The neutral space of the car and no agenda for conversation may have reduced existing power dynamics, fostering openness and relationship-building. In contrast, the COVID-19 pandemic had a significant impact on our ability to collaborate by preventing meetings in person. We transferred to phone conferencing/online meetings and not all the women had access to e-mail/online conferencing initially, until researchers were able to provide IT equipment. When group members did have access to e-mail, people often did not want long emails as it could be too much information (Table 6, Quote 2). These challenges in communication then also had an impact on the relationships between people, where misunderstandings or differences of perspective may have been harder to air. Both support staff and researchers reflected on the substantial need for ongoing relationship maintenance, which could be fragile and had the potential to be broken. Existing hierarchies may have influenced the women's freedom to dissent from ideas suggested by the professionals in the team (Table 6, Quotes 3–5), which we discuss further in the empowerment section below.

Empowerment and choice

The project evolved from early phases where women spoke about their own personal experiences of trauma to a more focused problem-solving approach when collaborating with local general practices. Through initial group meetings, storytelling workshops and meetings with GP colleagues/trainees, we developed a series of activities to build confidence in interacting with professionals. Storytelling workshops were run by an external facilitator, and many of the exercises promoted empowerment and choice. The storytelling facilitator provided guiding rules of no self-criticism, creating a safe space in which all group members were ‘doing the same silly exercises’ and where all were free to make mistakes and develop new skills (Table 7, Quotes 1–3). After two workshops with general practices, the group themselves undertook training in trauma-informed approaches, to have a greater technical understanding of issues of trauma. Members of the group varied in their perspectives over whether this was helpful or had the potential to be triggering (Table 7, Quotes 4 and 5). As we developed the healthcare professionals' training, women shared their experiences to illustrate how trauma affects people when accessing general practice. Again, the group had differing perceptions on how sharing experiences felt, but at times it could be triggering (Table 7, Quotes 6 and 7). The combination of sharing experiences and then doing this as part of an online training event with GPs (due to COVID-19) could be difficult, especially when some professionals had their cameras off: ‘so you couldn't even see their faces’ (Lived experience member 9). The difficulties of interaction online made it difficult for the group to know they were being listened to. These experiences, combined with feedback from our partner One25 and the group, taught researchers an important lesson. While people might initially agree to something, on a later check-in people might change their minds. While the sharing of experiences had been discussed and agreed upon in group meetings, and we started further plans for training events, we then found that after the meetings, sometimes lived experience members would discuss among themselves that they were unhappy to do this. This then meant that one member expressed this on behalf of others who were less comfortable in speaking with the group. This directly relates to issues of peer support, where one member felt they needed to voice disagreement on behalf of others, which added to her own sense of responsibilities. There were unrecognised power dynamics operating where people might say yes to something in a meeting, when really they want to say no, or might change their minds at a later date. We found that when people agreed to propositions ‘yes’ might not always mean yes and on reflection people might decide differently. An initial ‘yes’ could cover disagreement, uncertainty and fear, which rose to the surface at later dates (Table 7, Quote 8–10). These dynamics could contribute towards misunderstandings or feeling let down or frustrated.

The combination of difficulties in communication over email, the inability to meet face-to-face during the pandemic and unseen power dynamics culminated in a significant turning point for the project. As soon as we were able to shift back to face-to-face meetings after COVID-19 lockdowns, we reviewed the training model and removed any need for the group to share any experience, unless they so wished to informally through general conversation. We found that working in a more trauma-informed way was about empowering people to get involved *and* having the choice to not get involved, moving away from people recounting experiences unless they choose to in the moment (Table 7, Quote 11). As we have progressed through the project and made changes within general practices, this has motivated group members to make changes in other aspects of their life (Table 7, Quote 12).

Safety

Having One25 support staff present within group meetings was essential to provide expertise and continuity, providing guidance to researchers and enabling support for the women if needed, including debriefs and space to discuss any issues or trauma that may have been triggered. Facilitators were responsible for initiating a check-in and a check-out at each meeting. This involved everyone sharing in turn how they are feeling in the moment, so that support could be offered where needed. In addition, support staff were aware of other issues that may be happening in group members' lives and how that might impact their participation (Table 8, Quote 1). There were varying levels of experience in working with people who have experienced trauma, with differences according to professional roles, training, knowledge and skills around safety (Table 8, Quotes 2 and 3). Researchers identified the need for funders to be more aware of the multiple skills, resources and time that this work takes (Table 8, Quote 4).

Table 8 Illustrative data for safety.

Theme	Illustrative data
Different staff training, skills and knowledge	*Quote 1*: I think it was difficult in the sense that we don't know people's backgrounds, and that's not appropriate for us to know, but there might be things that are coming up that we're not aware of, or issues that might potentially trigger, or there might be a lot going on in the background of someone's life that we might not be aware of. And that might affect people's involvement …how might people experience particular parts of the project. (Researcher 4) *Quote 2*: I suppose the main thing is about having that understanding of the seriousness of the risk that they are at in their daily lives and understanding that they might not want to discuss that but helping them to stay safe really. (Support staff 3) *Quote 3*: As lovely as (Researcher) and (Researcher) are, they don't have that understanding of that lifestyle and just the chaos of that lifestyle and the up and down of that whole …. (Lived experience member 2)
Resources to support the work	*Quote 4*: I think sometimes funders and systems are encouraging us to do this kind of thing, but, actually, the difficulties of doing it are quite extensive and probably not accounted for sufficiently, including researchers' own skills and time and resource to do this. (Researcher 4)

Remote working (during COVID-19 lockdowns)	*Quote 5*: When we're all together doing it face to face, we're very supportive of each other, we can support each other, we all kind of know what each other's feeling and going through but when you're kind of stuck at home on Zoom and then you're sharing all this stuff and then you're stuck with yourself and all the stuff. (Lived experience member 2) *Quote 6*: I think when we were able to meet [online] during lockdowns, that actually felt quite important because there was something there that people could kind of access, but then that also has become quite difficult at times in terms of ensuring safeguarding and confidentiality, if other people are in the house and shared spaces, and not being able to guarantee and know who is in a space, which made it more difficult to kind of operate through lockdowns as we as progressed. (Researcher 4)
Differing perspectives on safety and safeguarding	*Quote 7*: On safety, we have to consider safety of people and we are responsible for everyone's safety and so there are just some things that we have to dictate. That's just how it has to be. (Support staff 7) *Quote 8*: When we were on Zoom there were some things around actually there might be a perpetrator there in the background …. I think …we were a bit concerned at the beginning about the team's understanding of safeguarding and actually the fact that women come across as really presentable but actually they have got all these things going on in their background and that that needed to be acknowledged. (Support staff 3) *Quote 9*: We were discussing about putting some safeguarding information onto an application form and it immediately evoked a response and she explained that response really clearly as to why even the terminology or any illusions to safeguarding was something that was quite traumatic and something that many women responded badly to who had had bad experiences under the banner of safeguarding. (Academic GP 6)
External supervision	*Quote 10*: I was a bit like, ‘No, I think we really do need clinical supervision’, and so then, fortunately, kind of linked in to get some …got an external person involved. So that was great, and I think that was really important. We've now funded, kept into the funding mix that there is that. (Researcher 4)

When the pandemic and lockdowns began, the group first moved to a free phone-in conferencing system as not all members had access to Wi-Fi or IT equipment to access online conferencing. It became hard to avoid talking over each other, and once we had funders/IT agreement to buy mobile tablets for the group to own, we moved to online conferencing systems. Remote working led to challenges due to the loss of peer support from in-person meetings ‘you're just stuck at home with it’ (Lived experience member 2) and some safety concerns (Table 8, Quotes 5 and 6). When joining online meetings, finding confidential space in your own home is not always possible for women in abusive relationships, and homelessness often means a lack of privacy and safe space. There were varying opinions as to who might be best equipped to make decisions relating to the safety of group members. Support staff felt that they held responsibility for supporting group members' safety (Table 8, Quotes 7 and 8), and others questioned how to empower individuals and offer them choices while ensuring the safety of all group members. We resolved this situation through individual safety plans and asked some of the women to join the meetings from a community centre space to guarantee confidentiality for the rest of the group (and paused the project completely when community centres were shut in early 2021). These issues that we grappled with were reflective of wider tensions between safety and empowerment, which the women discussed in the group, where in the past professional actions described as safeguarding had become disempowering or traumatic for the person concerned (Table 8, Quote 9). Both support staff and researchers identified a need for external clinical supervision to help manage some of the more difficult dynamics to support everyone (Table 8, Quote 10).

Another psychological safety issue that arose through our work that was not covered within interviews was how to manage relational issues when working with new members or general practices where women may have had previous contacts. We developed a process whereby we asked for permission to share first names before a new member joined or discussed who might be at a general practice meeting. This provided some degree of protection but was not infallible as names may not initially be recognised, or triggers might unexpectedly occur at particular places. Debriefs and postmeeting support were essential where unanticipated interactions led to the triggering of past trauma.

DISCUSSION

While co-production processes are to some extent inherently trauma-informed, we identified various areas where additional considerations were necessary. The creation of a safe space is vital. This should include direct consideration of cultural, historical and gender issues, which may impact upon group processes. The group should include people already known to and trusted by members who have an understanding of the signs and symptoms relating to trauma. Facilitators should have experience in managing group dynamics and creating supportive environments, which empower all individuals to freely express their opinions. Including professionals from a diverse range of backgrounds and having groups based on shared protected characteristics may be of value. While *blurring boundaries* is a key aspect of co-production work, this may need to be approached slightly differently in trauma-informed processes. Transgression of boundaries is a key characteristic of trauma experience, thus maintenance of appropriate and healthy boundaries can be important in creating a safe space for some individuals. Transparency in discussing and agreeing upon group ground rules and how these should be managed is important from the earliest stages of the group. Balancing safety with empowerment and agency was complex. Lived experience members, who had the most experience in managing the risks they faced, previously sometimes had difficult experiences under the banner of safeguarding. Researchers had less experience in this field, and support workers felt that they held the responsibility for holding risk. Further work in this area is needed, incorporating all perspectives.

While the consideration of power dynamics is already an important component of co-production, this requires additional attention when working with people who have experienced trauma. Those in positions of power need to recognise that people saying ‘yes’ and agreeing to something, might not actually be a representation of people's true feelings. In her work with women who have experienced sexual violence, Ravi[46] highlights in her *Smile Spectrum* how a smile might be hiding deeper negative feelings and pain. Similarly, we found that when people agreed to ideas, ‘yes’ might not always mean yes, and on reflection, people might want to change their minds. An initial ‘yes’ could cover disagreement, uncertainty and fear, which rose to the surface at subsequent meetings. We encourage ourselves and others involved in co-production to explore how more safe room can be created on an ongoing basis for disagreement and uncertainty.

Partnership working is key due to the range of skills needed to carry out co-production work with people with lived experience of trauma. For those applying for funding, it is important that adequate resources should be provided for individuals to have flexible access to support between meetings from those with relevant expertise. Additionally, funding applications should consider that time is needed for trust to develop, and maintenance of projects over months and years will be more productive than short-term projects.

Our recommendations (Table 9) are consistent with the experience of other co-produced research with people who have experienced multiple traumas, vulnerability or complex needs.[5,6,25,47] Moreover, we add to and highlight existing knowledge in the following ways:

- 1. The importance of being aware of unseen power dynamics where people may be reticent about expressing dissent or agree to something where they may later change their mind upon reflection.
- 2. Moving away from any emphasis of the sharing of lived experiences to give people full control to choose how, what and when to share, and if they wish to share their expertise and/or experiences. An individual's lived experience qualifies and enriches their opinion as a valued voice in developing services. That is valid, valuable and enough. They should feel supported to choose to illustrate a point with a personal example if they would like to, or not.
- 3. The challenging dynamics between safety and empowerment. Safeguarding can sometimes mean power and choice is taken away from individuals, and this needs to be managed sensitively and carefully, and recognised and named transparently, explaining the issues and options for moving forward. Furthermore, this needs to be balanced with people's own expertise in how they manage their own risks.[48]
- 4. Being honest about where things go wrong and discussing these openly.
- 5. Greater accounting for the needs of safe and sometimes single-gender spaces, or subgroups based on shared protected characteristics.
- 6. The importance of having a safe reflective space for all co-production group members including people with lived experiences, support staff and researchers with external, independent clinical supervision available.
- 7. Reflecting on when you are blurring boundaries and why–what impact is it having and is it helping to provide support and connection, or is it potentially adversely impacting on safety and trust?

Table 9 Recommendations table.

Trauma-informed principles and experiences/lessons learnt	Recommendations

Cultural, historical and gender issues Having a women-only group enabled conversations to be held and experiences shared that could not have occurred in a mixed-gender group. Changing existing gender inequalities was a key motivator for individuals to become involved. We did not directly discuss racial inequalities within the group. Additionally, the professionals within the group were from white backgrounds. This may have acted as a barrier to ongoing participation for women from a diverse range of backgrounds.	In advance of recruitment, reflect on the cultural, historical and gender issues that may affect your work. Work towards the co-production group being demographically representative of the population you are serving. Consider how cultural, historical and gender issues will affect power dynamics in the group and how to mitigate against this. Ask people in the group what they need to feel safe, people may prefer to be in groups based on gender or other identities/characteristics which could facilitate freer discussions and sharing of experiences. It may be helpful to discuss how cultural, historical and gender issues relate to the experiences of trauma and accessing care. Consider whether the recruitment of professionals on the team can seek to include representatives of a diverse range of backgrounds.
Peer support Support from peers had a therapeutic value for all the members of the group. At times, some individuals were providing a lot of support to peers which could have the potential to be overwhelming.	Build in time for supportive conversations within sessions throughout the project and acknowledge the potential therapeutic value of this. Where sharing of difficult or traumatic experience may arise, provide appropriate space for this. Consider the impact on individuals in the group who provide a lot of peer support to others and put in measures to proactively support them.

Trustworthiness and transparency A prior relationship with those leading the project was vital in supporting engagement and enabling trust, particularly in the earlier phases. The long-term nature of the project enabled building of trust with new members of the group over time and maintaining trust of existing members that their efforts were making a tangible difference. Openness is vital to maintain trust. This includes the need for professionals in the group to admit and discuss when they get things wrong. We found funders to be very flexible where decisions came from people with lived experiences. Having agreed ground rules was important. Ensuring these were adhered to by all members of the group was at times challenging. Some individuals in the group contributed more than others for a variety of reasons. This did at times lead to a sense of unfairness from those who were participating a lot.	Seek to have key people who are known to and trusted by members with lived experience at all group meetings. Ideally, project funding should span years, not months. This is often difficult to achieve in practice within current structures. Lengthen projects to the maximum allowed by funders (i.e., span activity out rather than having short bursts of intense work). Be transparent about power differences and name them as issues arise, acknowledging that some cannot be overcome. Talk about things that have gone wrong and how to mitigate the impacts of these. Discuss decisions to be made and the parameters of these. Be transparent about how budget is spent and involve people in budget decisions. Explain to funders that where group decisions change project directions, that this has come from the group. Ensure ground rules are agreed upon by all members and shared at meetings. Identify who in the group is the most appropriate to ensure these rules are followed by all group members. Consider outlining a process whereby concerns can be raised about the behaviour of others in relation to the agreed ground rules. Consider as a group how best to manage differences in the level of contribution.

Collaboration Collaboration between third-sector organisation, experts with lived experience, researchers and clinicians was necessary to bring all needed skills and expertise to the group. Academic language can be a significant barrier to collaboration on written reports and publications—consider creative ways in which to overcome these. Too many e-mails during lockdown led to some in the group feeling overwhelmed. Remote collaboration made it more difficult to maintain human connection and peer support. However, some in the group preferred remote access as they found attending in-person meetings difficult. Effective collaboration included different people expressing differing and conflicting views. Ensuring ongoing trust, transparency and a sense of safety within the group was vital to air different perspectives and find a new way forward to manage disagreements constructively. Some women with lived experience were able to contribute to the project at certain points but not at others due to various life factors.	Consider the range of expertise needed for the project and embrace a partnership approach. Ensure costing covers adequate reimbursement for the time and resources from all partners involved, including partner staff time and experts with lived experience. Use creativity to facilitate group contributions to written reports and papers—flip charts, screens, brain-storming sessions and post-its may all be helpful. Remote working and communication via e-mail may not be appropriate for everyone in the group. Ensure everyone feels safe to express how they wish to be communicated with and agree boundaries about this. Where possible, provide flexibility to allow different modes of engagement for different people. Ensure partnership working includes those with experience around communication and facilitation skills and experience in managing difficult discussions. Group facilitators should seek to ensure that all those in the group are heard and that the process for decision-making where differing views arise is fair. Where disagreements occur give significant time and space to understand these and be prepared to change direction as needed. Be flexible in your approach and provide opportunities for people to dip in and out of projects where they can. Some may wish to participate for a short time, others in the long-term. Offer a choice of in-person or remote participation where possible and give people the freedom to leave and rejoin the project based on changing circumstances.

Empowerment and choice Engagement in storytelling workshops as a group had a team-building element, which effectively supported the development of trust within the group. Participation in co-production activities can be empowering for all those involved. Project involvement can support the development of planning, organisational, communication and research skills and specific expertise. Choices were provided about training courses to develop skills. We participated in the story-telling/communications workshops to develop communication and public speaking skills. At times, some women in the group did not feel able to say 'no' to plans that were being developed. We changed our approach to providing training so that people didn't need to share personal experiences.	Consider engagement in team-building exercises and social activities to strengthen relationships. This might include sharing experiences as a group if people wish to do this, but consider carefully how people can choose not to share, rather than feeling pressured to share. Think about how to support individuals in the group who are seeking to develop specific skill sets in the context of the project. For example, some may wish to play a more active role in producing research output, for example, papers, or presenting, while others might value playing a role in logistics or administration. Provide choices about potentially relevant training for people in the co-production group and ensure this is costed into funding applications. Emphasise the freedom of individuals to disagree with the opinions of others, and to choose whether or not to share personal experiences. Provide opportunities for those in the group to feel safe to disagree with plans as they develop. Give opportunities for one-to-one discussions with trusted individuals to provide people the safety to say no. Ensure that it is made explicit from the start of the project that those with lived experience are under no obligation to share their difficult personal experiences, if they choose to share difficult personal experiences provide support and opportunities to pull out if needed.

Safety Check-ins at the start and check-outs at the end allowed us to discuss our own emotional safety and signpost if support was needed. Not everyone has access to a safe confidential space at home, or IT or Wi-Fi, to access online meetings. Meeting online made it difficult to ensure confidentiality and provide support to each other. It can be difficult to predict what conversations might be triggering. Some individuals might seem fine during the group but subsequently become more affected when on their own. These individuals were supported by the partner organisation. Differing approaches to safety and safeguarding need to be understood and strategies agreed upon between partners. Historical relationships/places may retrigger trauma and impact upon psychological safety.	Use check-ins and check-outs at all meetings to identify those in the group who may be struggling or need more support. Seek to provide a space for in-person meeting, where possible with flexibility for those who may wish to join remotely. Consider implications on confidentiality where meetings are being joined remotely and ways to maintain safety when meeting online. Ensure those leading the group have appropriate training to understand the impact of trauma, including symptoms of PTSD and complex PTSD, and strategies to support those who are experiencing these symptoms. Consider the need to cost in external clinical supervision for all those involved in the group and ensure the availability of support via partnership organisations between meetings. Ensure clear and transparent communication between group members around safety. Establish an agreed process at the start of the group about how safety concerns regarding group members should be managed and who should be involved in these situations. Preempt and explain who is likely to be at meetings so that people can discuss any issues arising and how to manage these. Be prepared for unexpected triggers and provide post-support wherever needed.

Our theoretical contribution is that we explicitly compare and contrast co-production and trauma-informed principles, highlighting differences in safety, how boundaries are managed and maintained and how and when the sharing of experiences may be healing and empowering, or potentially retriggering. This point has significance for the ‘deeper intellectual shift towards an epistemological position that values “knowledge as experience”’,[49] and we highlight the caution and care that is needed to ensure that the sharing of experiences is healing and integrative, rather than potentially triggering of past trauma. Whilst sharing of experiences can help to ‘work through emotional pain’,[50] this process needs to be carefully supported and tailored to the individual at that particular time.

Our project highlights how researchers and practitioners working within these fields can use their social connections and power to help people with lived experience to access funding, resources and knowledge to make changes to services.[51] Through the work there were moments of ‘transcendent unity’,[50] moving beyond difficulties to create new strength and stability. These insights link with bell hooks'[52] conceptualisation of love as bringing people together in solidarity, overcoming previous problems.[53] This power through love is not based on personal will, autonomy or sovereignty but on ‘the desire of well-being of another’, ‘a way of doing things individually or collaboratively for the wellbeing of others’,[53] love as ‘connected to the specific values of justice, honesty and generosity’.[53] With this in mind, we share one of the women's artwork with words of her experiences of Bridging Gaps:

You are loved
You are wise
You are a strong independent woman

You are brave

You are a beautiful lady

My experience of Bridging Gaps

STRENGTHS AND LIMITATIONS

Our study's strengths include that it uses both a data-led and reflective practice approach to identify recommendations and adaptations for those developing trauma-informed services using co-production. Despite the growing interest in trauma-informed services, there has been little attention given to date on the processes of partnership working between professionals, researchers and people with lived trauma experience as they develop services. Without careful consideration of these processes, there is a danger of partnership working being tokenistic at best, and even perpetuating existing power dynamics.[28] This is unlikely to lead to the transformational systems changes necessary to tackle existing inequalities. Future work could include further co-produced service improvement projects based on our recommendations, with further evaluation.

Our project took place over a number of years, which allowed time for reflections and lessons to be learnt. Interviews included a diverse range of perspectives including those from clinical, research and voluntary sector backgrounds and those with lived experience of trauma. Analyses were carried out jointly between those who were involved in group processes and those who were external, enabling triangulation between different viewpoints when analysing the data. Observational and reflective data were triangulated with interview data. Although the pandemic led to many difficulties in our group processes, it provided some valuable learning on the opportunities and difficulties of remote working for those with lived experience of trauma.

One limitation was the fact that changes in group membership meant that many women who were involved for certain periods of the project could not be interviewed about their experience. While those interviewed suggested that these women dropped out for reasons unrelated to the project, it would have been helpful to have their perspectives and reflect on whether any additional support may have enabled them to remain part of the process.

Looking forward

At present, the future has challenges and opportunities ahead for Bridging Gaps. Opportunities include some further Bridging Gaps funding to develop a website with our resources for general practices and to reach out to more general practices. Academic GP (L. P.) has received doctoral funding to develop a complex intervention to improve access to general practice for people with severe and multiple disadvantages.[54] Through these activities we are linking with others who have similar missions, to explore potential collaborations.

Challenges are that our partner charity One25 has experienced significant financial difficulties and has had to reduce its provision, closing its drop-in for women who are street sex working or at risk of street sex work, and support services for women who are further on in their recovery.[55] Ongoing challenges for securing funding in the context of a cost-of-living crisis where support services are in even higher demand is a situation that more and more charities are facing.[56–58] These issues highlight the ongoing challenges that can be faced with short-term, project-based funding when needs can be complex and long-term. The implications of this cut in service provision have been of great concern to Bridging Gaps. All lived experience members have received support and encouragement from this organisation and came to the Bridging Gaps project by way of it. That such opportunities will no longer be available to vulnerable women, as they were in the past, has been deeply frustrating and upsetting, not just for women with lived experience but also for the professionals as they will be dealing with the reality of these closures. Bridging Gaps has become more than just a ‘research project’ for members, it is a trusted place of safety, of nonjudgemental support and togetherness. However, this will be harder to manage in future as needs become greater because of the closure of their support network.

CONCLUSION

Our findings provide vital learning points for all those seeking to develop trauma-informed services and an opportunity for further evaluation of our recommendations for practice. The high prevalence of trauma in the general population also makes our findings even more broadly applicable and merits consideration for all those engaging in co-production work.

AUTHOR CONTRIBUTIONS

Lucy Potter started the Bridging Gaps group with support from Maria Carvalho (and Lesley Wye—see the Acknowledgements section) and was PI on three grants, coordinating the group's activities and facilitating their interactions with general practices. Helen McGeown joined Bridging Gaps as a GP trainee and Academic Clinical Fellow, observed sessions, analysed all data and wrote the first draft of this paper. Michelle Farr joined the group as a researcher and initially observed sessions. She then joined the group and became PI on two grants, coordinating the group, its work and its finances. She has supported Helen McGeown in the development of the writing of this article, including the comparison of co-production and trauma-informed principles. Tracey Stone conducted interviews with the group, analysed all interview data and contributed to the drafting of this paper and its theoretical analysis. Helen Cramer observed Bridging Gaps meetings, supported Helen McGeown in the the initial data analysis of observations, conducted an interview and contributed to the drafting of this paper and its theoretical analysis. Maria Carvalho was employed by Anon charity as a support manager and helped facilitate the group and provide support to women with lived experience. She contributed to conversations about the comparison of co-production and trauma-informed principles and the learning of the project. Florrie Connell is employed by Anon charity as a support worker and joined the group when Maria Carvalho left Anon charity, contributing to facilitating the group and providing ongoing support and input into meetings with general practices. Jeremy Horwood was an academic supervisor for Lucy Potter and Michelle Farr. Gene Feder was the main supervisor of Lucy Potter. Bridging Gaps group is a group of women who have experienced complex trauma and have faced numerous adverse circumstances such as addiction, mental health issues, homelessness, domestic or sexual violence, having children removed from their care and street sex work. All authors commented on and edited the draft of this paper and contributed to the final manuscript.

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CONFLICT OF INTEREST STATEMENT

Maria Carvalho and Florrie Connell worked for One25 at the time of this project. One25 received a fee to compensate the charity for the time that their staff committed to the project.

DATA AVAILABILITY STATEMENT

Original data are not available and research data are not shared due to the potential to compromise people's anonymity and the small number of interviews that were undertaken.

DETAILS

Subject:	Transparency; Exploitation; Collaboration; Domestic violence; Charities; Observational learning; Empowerment; Health care; Health problems; Trauma; Health disparities; Homeless people; Policy making; Sexual behavior; Honesty; Primary care; Social interest; COVID-19; Data analysis; Psychological trauma; Women; Learning; Decision making; Mental disorders; Power; Primary groups; Sexual violence; Sex crimes; Online instruction; Family physicians; Medical research; Mental health; Funding; Research; Mental health services; Poverty; Homelessness; Cooperation; Charity; Sex industry; Access; Flexibility; Safety; Psychological safety; Social justice; Decision makers; Interviews; Psychological distress; Power structure; Pandemics; Meetings; Addictions; Social services; Blurring; Principles; Sexual assault
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Patient engagement in health implementation research: A logic model

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ProQuest document link

ABSTRACT (ENGLISH)

Introduction

Growing evidence supports patient engagement (PE) in health implementation research to improve the quality, relevance and uptake of research. However, more guidance is needed to plan and operationalize PE before and throughout the research process. The aim of the study was to develop a logic model illustrating the causal links between context, resources, activities, outcomes and impact of PE in an implementation research programme.

Methods

The Patient Engagement in Health Implementation Research Logic Model (hereafter the Logic Model) was developed using a descriptive qualitative design with a participatory approach, in the context of the PriCARE programme. This programme aims to implement and evaluate case management for individuals who frequently use healthcare services in primary care clinics across five Canadian provinces. Participant observation of team meetings was performed by all team members involved in the programme and in-depth interviews were conducted by two external research assistants with team members ($n=22$). A deductive thematic analysis using components of logic models as coding categories was conducted. Data were pooled in the first version of the Logic Model, which was refined in research team meetings with patient partners. The final version was validated by all team members.

Results

The Logic Model highlights the importance of integrating PE into the project before its commencement, with appropriate support in terms of funding and time allocation. The governance structure and leadership of both principal investigators and patient partners have significant effects on PE activities and outcomes. As an empirical and standardized illustration that facilitates a shared understanding, the Logic Model provides guidance for maximizing the impact of patient partnership in various contexts for research, patients, providers and health care.

Conclusion

The Logic Model will help academic researchers, decision makers and patient partners plan, operationalize, and assess PE in implementation research for optimal outcomes.

Patient or Public Contribution

Patient partners from the PriCARE research programme contributed to developing the research objectives and designing, developing and validating data collection tools, producing data, developing and validating the Logic Model and reviewing the manuscript.

FULL TEXT

INTRODUCTION

Literature on patient engagement (PE) in research has increased exponentially in the last decade. The many benefits of having patients as partners in research (hereafter patient partners) are well documented. PE can improve the quality of research[1–4] by co-designing the study's protocols, choosing relevant outcomes,[5] improving processes and ethical practises,[2,4] as well as validating research instruments.[4] PE can also increase study enrolment.[5] Academic researchers who involve patients in research recognize patients' experience as expertise.[4] Based on patients' priority and holistic needs assessment,[6] this strategy can improve the relevance and uptake of research.[1,6,7] PE is more effective when patients with lived experience are meaningfully involved as research team members.[8] Involving patients in key aspects of implementation research can also facilitate and enhance implementation processes,[9] which can improve outcomes for both the research process and patient healthcare.[2] Patients' perspectives can produce innovative solutions that improve the health and well-being of the population.[7,10] PE has positive impacts on researchers and patient partners such as enhanced skills, and increased self-confidence, social support, learnings and satisfaction.[2,4,7]

Many tools and frameworks have been proposed to assess PE in implementation research.[11–13] In a systematic review that includes 65 frameworks, Greenhalgh et al.[14] classified them into five categories: power-focused; priority-setting; study-focused; report-focused and partnership-focused. In another systematic review that included 14 models and frameworks, Chudyk et al.[15] organised elements underlying PE in health service research into six categories: principles; foundational components; context; actions; levels and outcomes. For academic researchers and patient partners, these PE frameworks are useful to identify the essential components of their programme, but do not necessarily provide the 'recipe' linking, in operational terms, the principles, strategies, outcomes and impacts.[16] Logic models aim to provide a systematic way to visualize the interaction between the rationale of an intervention, planned activities, required resources and expected outcomes,[17] and offer an interesting means to advance our knowledge about this 'recipe'. Logic models can support the reporting and standardization of PE in research[18] by explaining the 'how' and 'what' of PE in implementation research.[19] For example, Merker et al.[20] proposed a logic model to articulate the activities being implemented to support PE and its anticipated outcomes in the specific context of veteran engagement. Developing a logic model about PE in a broader context of implementation research could be useful.

The objective of the study was to develop a logic model illustrating empirically the causal links between context, resources, activities and expected outcomes of PE in health implementation research.

METHODSSettings: PriCARE research programme

This study focused on the engagement of patient partners deployed in the PriCARE research programme, which is detailed elsewhere.[21,22] PriCARE implemented and evaluated a case management intervention for individuals that frequently use healthcare services in primary care clinics across five Canadian provinces: New Brunswick, Newfoundland, Labrador, Nova Scotia, Quebec, and Saskatchewan.

One to two patient partners were recruited in each participating province to work closely with the provincial research team. Each province circulated a posting to different networks where interested patient partners could apply and then meet with the local principal investigator and coordinator. In addition to taking an active part in the various steps of the research process, from the proposal stage to knowledge transfer activities, the patient partners participated in both the central decision-making committee as well as a 'community of practice' to foster their engagement in various stages of the research programme and ensure that their priorities were considered.

Design

A descriptive qualitative design[23] was conducted with a participatory approach[24] involving patient partners and academic researchers of the PriCARE programme. As some of the academic researchers were also healthcare providers, the perspective of this category of participant was included.

Sampling and participants

All the PriCARE team members were invited to participate in this study using purposeful sampling.[25] Twenty-two members agreed to participate including principal investigators (*n* = 5); co-investigators (*n* = 2); research coordinators and assistants (*n* = 8); one postdoctoral researcher; patient partners (*n* = 7) from four out of the five participating Canadian provinces. All participants discussed the aim of the current study during Steering Committee meetings and patient partners' Community of Practice meetings.

Data collection

Participant observation of team meetings was performed by the team members involved in the PriCARE research programme, from November 2018 to February 2021. The meetings observed were a monthly half-hour Community of Practice meeting including six patient partners and five research coordinators and assistants, and a monthly 1-h Steering Committee meeting including the same patient partners and research coordinators and assistants, as well as eight co-investigators and one postdoctoral researcher.

Individual semistructured interviews were conducted with team members who agreed to participate and who attended regular team meetings. Two research assistants external to the PriCARE research programme conducted the interviews to avoid social desirability bias and self-censorship. The interview guide was adapted to each category of participants (patients and research staff), and patient partners contributed to its design. Based on the categories of a classic logic model, questions were about resources allocated to support PE, types of research activities that participants were involved in or should have taken place to improve patients' contribution to the research, perceptions of the value that PE added to the research programme and expected outcomes of PE in the research programme. Other topics discussed included the role of team members who participated in the research programme; mechanisms put in place to support PE; opportunities for interaction and feedback amongst team members to support PE; team members' expectations of PE when they joined the research programme; potential activities, events or incidents related to PE and the contribution that team members would like to make in the future. Sociodemographic data (gender, age, location, first language, time of involvement in the PriCARE programme) were also collected so that the participants could be described. Since the 'context' component of the logic model was well described in the Canadian Institutes of Health Research SPOR UNITS document,[3] it was not explored during the interviews. ('SPOR' is the Canadian Institutes for Health Research Strategy for Patient-Oriented Research, which has formed funding partnerships with provinces and territories, philanthropic organisations, academic institutions and health charities. SPOR funds 10 SUPPORT Units across Canada to provide specialized services to researchers, patients, clinicians, policy makers and SPOR-funded entities to conduct patient-oriented research). Interviews with academic team members were digitally recorded and transcribed verbatim. To preserve the confidentiality of the patient partners, the two external assistants produced a deidentified summary of their interviews that was validated at a meeting in which the patient partners reviewed and approved the summary.

Analysis

Data were analyzed using a deductive thematic analysis approach[26] where the themes corresponded to the categories of a classic logic model (i.e., resources, activities, outputs, outcomes, impact). All data were categorized under these themes using NVivo 12 software by research coordinators and assistants involved in the PriCARE programme with expertise in qualitative research. Data about resources, activities, output, outcomes and impact were pooled[26,27] and included in a first version of the Logic Model. Team meetings with a principal investigator, a co-principal investigator, a coordinator, a research assistant and a patient partner helped to refine the Logic Model. It was then presented to all participants during Steering Committee meetings and patient partners' Community of Practice meetings where comments were incorporated. A new version of the Logic Model was then shared with everyone by email for review and final validation following an iterative and participative process.[28]

RESULTS

Table 1 presents sociodemographic characteristics of the participants. A total of 22 participants (72.7% female) completed individual or group interviews lasting 30–60 min. Seven patient partners and 15 academic research team members participated. Most patient partners were between 55 and 64 years old (57%), while most academic researchers were between 35 and 44 (47%). Most participants spoke English, had training in patient involvement in research, and had previous experience with patient involvement in research. Six academic researchers and two patient partners were involved as early as the grant submission stage.

Table 1 Sociodemographic characteristics of the participants (*N* = 22).

	Academic researchers (*n* = 15)	Patient partners (*n* = 7)
	n (%)	*n* (%)
Gender		
Female	11 (73.3)	5 (71.4)
Age (years)		
25–34	2 (13.3)	0 (0.0)
35–44	7 (46.7)	0 (0.0)

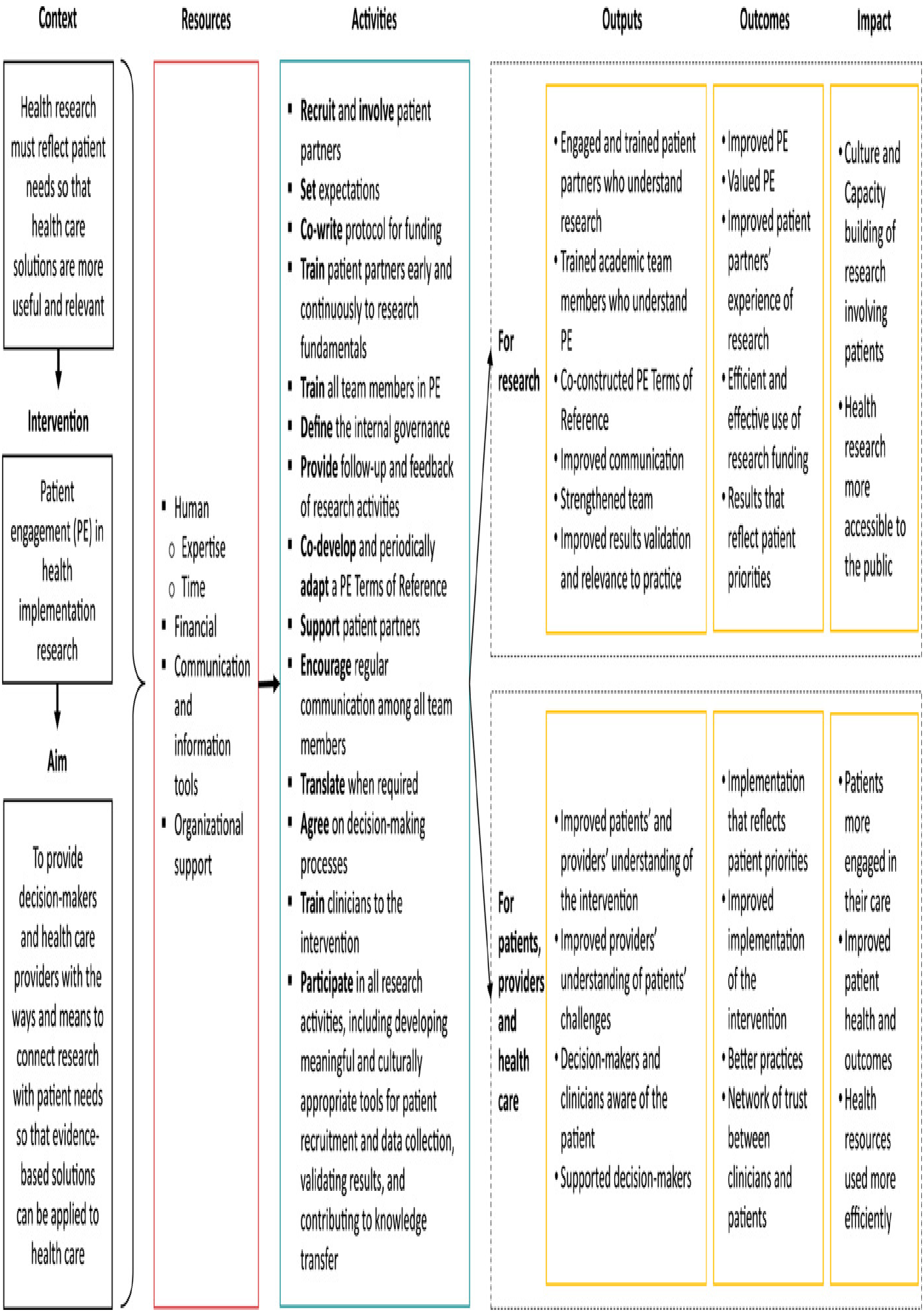
45–54	4 (26.7)	2 (28.6)
55–64	0 (0.0)	4 (57.1)
≥65	2 (13.3)	1 (14.3)
Location		
Newfoundland and Labrador	2 (13.3)	1 (14.3)
New Brunswick	4 (26.7)	2 (28.6)
Nova Scotia	3 (20.0)	2 (28.6)
Quebec	6 (40.0)	2 (28.6)
First language		
English	10 (66.7)	5 (71.4)
French	5 (33.3)	2 (28.6)
Time of involvement in PriCARE		
Since grant submission	6 (40.0)	2 (28.6)
Since initial implementation	5 (33.3)	0 (0)
Joined during the implementation	3 (20.0)	5 (71.4)
Joined recently (6 months)	1 (6.7)	0 (0.0)
Had PE in research training	8 (53.3)	4 (57.1)
Had previous PE in research experience	10 (66.7)	5 (71.4)
	Mean (SD)	Mean (SD)
Years of PE experience in researcha	5.8 (2.6)	10.5 (8.4)

Abbreviations: PE, patient engagement; SD, standard deviation.

a

Only for participants who had previous patient engagement experience in research (academic researcher *n* = 5; patient partner *n* = 4).

Figure 1 presents the linkages between context, resources, activities, outputs, outcomes and the impact of PE in research.



Health research must reflect patient needs so that health care solutions are more useful and relevant

Patient engagement (PE) in health implementation research

To provide decision-makers and health care providers with the ways and means to connect research with patient needs so that evidence-based solutions can be applied to health care

- Human
  - Expertise
  - Time
- Financial
- Communication and information tools
- Organizational support

- **Recruit and involve** patient partners
- **Set** expectations
- **Co-write** protocol for funding
- **Train** patient partners early and continuously to research fundamentals
- **Train** all team members in PE
- **Define** the internal governance
- **Provide** follow-up and feedback of research activities
- **Co-develop** and periodically **adapt** a PE Terms of Reference
- **Support** patient partners
- **Encourage** regular communication among all team members
- **Translate** when required
- **Agree** on decision-making processes
- **Train** clinicians to the intervention
- **Participate** in all research activities, including developing meaningful and culturally appropriate tools for patient recruitment and data collection, validating results, and contributing to knowledge transfer

For research

- Engaged and trained patient partners who understand research
- Trained academic team members who understand PE
- Co-constructed PE Terms of Reference
- Improved communication
- Strengthened team
- Improved results validation and relevance to practice

- Improved PE
- Valued PE
- Improved patient partners' experience of research
- Efficient and effective use of research funding
- Results that reflect patient priorities

- Culture and Capacity building of research involving patients
- Health research more accessible to the public

For patients, providers and health care

- Improved patients' and providers' understanding of the intervention
- Improved providers' understanding of patients' challenges
- Decision-makers and clinicians aware of the patient
- Supported decision-makers

- Implementation that reflects patient priorities
- Improved implementation of the intervention
- Better practices
- Network of trust between clinicians and patients

- Patients more engaged in their care
- Improved patient health and outcomes
- Health resources used more efficiently

Enlarge this image.

Resources

Both material and nonmaterial resources were mobilized in the PriCARE programme to support PE. ‘Human resources’ include all partners who contributed to supporting PE: principal investigators (some being healthcare providers); research coordinators and assistants and patient partners. Research assistants and coordinators were especially involved.

Patient partners identified human resources as resources allocated to ensure patient partners' engagement in the program. All research officers (research assistants, coordinators) are available to them to ensure that they do not feel like separate members, but rather full members of the research team. (Summary of patient partner interviews)

Team members had a range of experience with patient-oriented research within other research teams and projects, which fostered a common understanding of the goals and value of PE as well as how to work efficiently as a team. Patient partners brought their personal experiences to healthcare, which enriched academic team members' understanding of the issues. Moreover, some patient partners had considerable experience in research as well as skills to facilitate and coordinate activities (e.g., community of practice planning).

Patient partners who have experience analyzing data in other projects can really bring in ideas that we didn't have, angles that we didn't have, things that we didn't see, things that we might have tamped down but ultimately decided to keep. (Investigator #2)

Some patient partners had previous research experience and felt more comfortable with their knowledge of the research process. (Summary of patient partner interviews)

Lead members of the research team (e.g., a co-principal investigator) demonstrated support for PE, modelling what PE means in practice. Through the course of the research programme, which is in its third year in the spring of 2023, there have been many learnings and improvements that brought the experience and skills of the team members closer together.

A few patient partners mentioned that in several areas, significant progress has been made in having regular dialogue between patient partners and researchers. This included meaningful exchange of ideas and collaborative problem solving. […] Patient partners expressed that this was a learning experience for everyone on the research team. Though at first, they did not feel their voice was being heard or appreciated by all, they eventually worked through a process and co-designed a solution. (Summary of patient partner interviews)

PE support required a significant amount of time, especially for the lead coordinator and local coordinators who were in close contact with patient partners.

Like how do I manage the time so that it's optimal for everybody? So as a coordinator, that's the sort of stuff that I'm thinking through. (Staff #5)

It takes extra time to explain our thoughts, our rationale, our reasoning, and, you know, it makes us think twice about the decisions we're making. (Investigator #11)

A majority of patient partners stated that a lot of time is spent in meetings and/or reviewing emails with different Program documents. (Summary of patient partner interviews)

This time was spent completing various activities, as well as allowing trust and relationships to grow.

When we don't know each other, well, that takes time. There are patients who are partners, it's been a long time, and we don't know each other because we only see each other in the Communities of Practice, and we don't talk about our personal lives. (Staff #1)

In addition to ‘human resources’, ‘financial resources’ were allocated to recognize patient partners' valuable expertise and contributions, and the required funding had been planned in the initial budget of the grant proposal.

The PE was planned from the beginning, and it was budgeted. We believe in it, we think it is important, so we find ways to adjust and to be able to recognize PE in terms of time invested. (Investigator #6)

‘Communication resources’ in the Logic Model refer to technologies and tools used to share information and to ensure communication between patient partners and academic team members (email, telephone, online software or web applications to meet virtually).

Sometimes we have things to talk about, so instead of sending emails, we say to each other ‘Can we talk for 10 minutes online?’ So, we've used it a lot for our communication. (Staff #1)

‘Organizational resources’ refer to provincial SPOR SUPPORT units[3] (Newfoundland and Labrador, Maritime and Quebec) that helped with the training and recruitment of patient partners. The universities in each province also provided facilities and financial services (help in budget management, including patient partner payments), as well as information and technology services that supported the use and installation of software and communication tools.

Activities

Both patient partners and academic researchers were involved in all research activities from project inception to knowledge translation. Since PE was integrated into the governance structure of the research programme, ongoing activities related to PE support such as involving patient partners, defining roles, setting expectations, communicating between team members and participation in decision-making were not different from typical research activities.

I would say there's been a very highly participative group, as you know, functioning independently as well as together with the rest of us as well to really offer advice and support. And even independently, you know, not just providing feedback on stuff the researchers initiate, but also, I would say, initiating some ideas of their own and input of their own. (Investigator #15)

A co-development approach facilitated patient partners providing their feedback and support at any time, by email or telephone, during virtual team meetings, Community of Practice or ad hoc committee meetings. A PE Terms of Reference document aiming to describe patient partners' roles within the governance structure was co-developed and periodically adapted in collaboration with patient partners and academic researchers.

The PE Terms of Reference described how patient engagement worked within the team. So, whenever we recruited a new team member, we shared it with them. It was helpful because it gave a more global view of patient engagement in the project. (Investigator #2)

Patient partners' Community of Practice facilitated discussion of topics of particular interest or importance to them, or for which they have been mandated by the Steering Committee, and to later share some or all aspects of those discussions with the larger team. Patient partners' involvement in activities varied according to their availability and interests.

Patient partners have participated in different research activities based on their time involved in the work and the ways they would like to be involved in the work. Different patient partners want and expect different levels of engagement based on their interests, skills, availability, and lived experience. (Summary of patient partner interviews)

Some patient partners took on a leadership role such as the facilitation of meetings, communication between patient partners and members of the academic research team and contribution to clinicians' training to help them understand the experience of patients. As the research team was composed of both French and English speakers, translation of documents and discussions (oral or written) was an activity done by the academic researchers when necessary to achieve common understanding and to foster engagement of all research team members, particularly French-speaking patient partners.

Outputs, outcomes and impact

Participants reported outputs, outcomes and impacts of PE for both the research and for patients, providers and healthcare. Outputs for the research refer to significant patient partners' involvement; common understanding of both the research components and roles and benefits of PE in research; co-construction of PE Terms of Reference; communication amongst team members; a stronger team and improved validation of results and relevance to practice. For patients and providers, PE in research produces a better understanding of case management as an intervention, for example, an understanding of challenges faced by patients.

The voice of the patients, when you train professionals, has almost more weight than your own voice as a researcher, in the sense that I am the trainer, well, I know what case management is, I am a nurse, but when [name of a patient partner] spoke, it had even more weight, because she expressed it as the patients' experience. (Investigator #2)

PE enhances decision makers' and clinicians' awareness and understanding of the patient perspective and supports decision makers' role by giving relevant direction for the implementation of interventions.

Among the ways patient partners feel their group brings value or will bring value to the Program, there are […] support with decision makers […]. (Summary of patient partner interviews)

The outcomes mostly concern people who were directly involved in the research programme, including case management implementation, that is, research team members, decision makers, clinic managers, clinicians and patients. Regarding research outcomes, the PE activities enhanced the perceived value of PE, improved patient partners' experience of research, supported efficient and effective use of research funding and produced results that reflect patient priorities.

Helping researchers and implementers better understand patient-related considerations. For example, better understand what matters to patients, developing and delivering the questionnaire, patient recruitment approaches and communication material, bringing organizational skills to the Program, the Terms of Reference, committee organization, and local issues. (Summary of patient partner interviews)

Regarding outcomes for patients, providers and healthcare, PE activities contributed to an implemented intervention that has the potential to reflect patient priorities, an improved implementation of the intervention, better clinical practises (i.e., adapted to the needs of the patients) and a relationship of trust amongst researchers, clinicians, and their patients.

The involvement of patient partners has led us to discover and understand the importance of having the patient's voice in all our work of developing an intervention because, in the end, they are the ones who will receive the intervention. So, they tell us what they need. (Staff #3)

The project can provide better tools for clinicians and physicians, and good collaboration between clinicians and patients would also make it possible to create a network of trust. (Summary of patient partner interviews)

For the research, impacts included building culture and capacity for research involving patients and making health research more accessible to the public.

I think all the members of the research team will go away with a much fuller realization of roles that patient partners can play in these kinds of projects. And that's a huge contribution. That's a capacity building contribution well beyond the study itself, right. (Investigator #10)

We need to build a bridge with the population, create links and then put forward the experience of patients. I see this as a way to make research more accessible to everyone, more democratic. […] In the long run, I think it contributes to the development of a new culture in research. (Staff #4)

Overall, I think the Program has made all team members (PPs, researchers, coordinators) and hopefully Case Managers and clinical staff better at patient-oriented research and patient engagement. It has been a new approach to health research for most of us. We can all carry our experience to the remainder of the Program and on to our next research projects. (Summary of patient partner interviews - comments directly from individual patient partners)

Concerning impacts related to patients, providers and health care, PE in research facilitates patients being more engaged in their care, may improve patient health and related outcomes, and makes the use of health resources more efficient.

Ultimately, if the objectives of the research program are achieved, the engagement of patient partners will lead to better outcomes for patients with chronic conditions. It should ultimately improve their quality of life, highlight the importance of being involved in their care and lead to more efficient use of healthcare resources, i.e., people, infrastructures, and money. (Summary of patient partner interviews)

DISCUSSION

The Logic Model presented here illustrates the connexions between resources, activities, and outcomes of PE in health implementation research. As a roadmap, it provides guidance on which resources and activities are required to efficiently plan and operationalize PE in research. As a standardized evaluation tool, the Logic Model can inform which outcomes of PE the research team should focus on (or not), both for the research process and the implementation process of other complex interventions in various settings. Considering the broad context of primary care, the Logic Model may be transferable to other health implementation research contexts in industrialized countries.

Danish et al.'s[29] study on the description of the PriCARE 'program logic perspective' identified resources, processes and relationships (rather than context, resources, activities and outcomes). Their study supported the importance of a governance structure that integrates patient partnerships early in the programme to facilitate the evaluation and continuous improvement of PE. The authors argue that providing a framework for documenting, categorizing, monitoring and improving PE activities throughout the various phases of a research project strengthens PE evaluation capacity.[29] Boivin et al.[8,p.2] concur in an editorial on the importance of rigorous evaluation of the patient and public involvement in research, stating that there is a need to ensure that PE 'becomes an integral, robustly conducted, and well-resourced component of research, not a last minute add on'.

Logic models are often criticized for their inability to describe intangible factors such as relationships, collaboration and communication within a research team.[30] They also have limited capacity to evaluate a programme in a more comprehensive way.[11] However, Beland et al.'s[31] study, complementary to ours, mitigates these weaknesses by documenting relationships within the PriCARE team regarding PE from the perspective of both patient partners and academic researchers. 'Evolving relationships' described as 'how partnerships grew and improved over time with an acceptance of tensions and willingness to move beyond them'[31] can be considered as an outcome of the patient partners' support and regular communication amongst all team members, two activities identified in the Logic Model.

The Logic Model identifies expertise as a necessary human resource for significant PE. According to Danish et al.,[29] investigators have a major leadership role in supporting the integration of PE activities by modelling positive attitudes and behaviours towards PE, ensuring the availability and the expertise of dedicated personnel to facilitate the management of PE resources, processes and relationships, and ensuring a timely response to challenges. On their side, Beland et al.[31] identified that patient partners may also play an important leadership role by providing skills to facilitate meetings amongst patient partners.

The Logic Model corroborates other work, highlighting that PE increases the relevance of research by aligning the results and implementing interventions with patient needs and priorities.[3,6,31–33] PE connects research with patient needs so that evidence-based solutions can be applied in health care.[6] As mentioned by Duffet,[34] patient partners may increase transparency and trust in research, which may lead to research that has a greater impact on the ultimate care of patients. These remarks are consistent with the Logic Model, which identifies 'health research more accessible to the public' and 'improved patient and health system outcomes' as PE impacts.

Activities related to PE support take a significant amount of time, which remains an important element to consider in the planning of research projects that involve patients. Interestingly, a mixed methods study by Blackburn et al.[35] aiming to explore the extent, quality and impact of patient and public involvement in research, and a systematic review by Domecq et al.[5] on how to best conduct PE in healthcare research, and reported that the main challenge of PE for researchers is time. Funding needed for appropriate compensation for PE in research was also reported.[5] The Logic Model highlights time and funding as necessary resources for meaningful PE. Further research should be developed to better understand the dynamics between the time required to support PE, the funding required for this work and research team members' expertise, in relation to PE outcomes.

The data collection methods used in the current study (participant observation, in-depth interviews and dyadic approach) have also helped fill the gap concerning the need for more systematic data collection[30] and the need to assess PE from the perspective of both patient partners and academic researchers.[11]

Limitations

A limitation of this study is that patient partners and academic research team members acting as study participants and contributing to their own data analysis could potentially cause bias due to social desirability and the risk of self-censorship. However, external research assistants hired to collect data mitigate this limitation. The participatory approach and the active role of participants in data analysis and interpretation provide some strengths because of their familiarity with the research programme. Furthermore, the team members are also involved in many other projects involving PE and bring external perspectives as well. Lastly, the Logic Model does not include challenges in the PriCARE programme regarding PE, but they have been documented elsewhere by Danish et al.[29] and Beland et al.[31]

CONCLUSION

The Patient Engagement in Health Implementation Research Logic Model will help academic researchers, healthcare providers, decision makers and patient partners involved or interested in PE in implementation research to plan and operationalize the resources and activities to achieve desired outcomes.

AUTHOR CONTRIBUTIONS

Catherine Hudon, Maud-Christine Chouinard, Kris Aubrey-Bassler, Shelley Doucet and Vivian R. Ramsden contributed to the PriCARE research programme conception and design. Mathieu Bisson and Catherine Hudon led the different steps of the study. Mathieu Bisson drafted the interview guide with Jude Porter, Donna Rubenstein and Mike Warren. Mathieu Bisson analyzed the data. Mathieu Bisson, Catherine Hudon, Maud-Christine Chouinard, Mireille Lambert and André Gaudreau interpreted the data with Kris Aubrey-Bassler, Shelley Doucet, Vivian R. Ramsden, Olivier Dumont-Samson, Dana Howse, Charlotte Schwarz, Alison Luke, Norma Rabbitskin, Jude Porter, Donna Rubenstein, Jennifer Taylor and Mike Warren. The first draft of the manuscript was written by Mathieu Bisson, Olivier Dumont-Samson and Catherine Hudon, and all authors commented on subsequent versions of the manuscript. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions.

ETHICS STATEMENT

This study was approved by Ethics Review Boards in each of the four participating provinces in this study: Comité d'éthique du Centre intégré universitaire de santé et services sociaux (CIUSSS) de l'Estrie-CHUS; Research Ethics Boards Horizon Health Network; University of New Brunswick Research Ethics Board; Newfoundland and Labrador Health Research Ethics Board and Nova Scotia Health Research Ethics Board. All participants provided oral informed consent to participate in the study.

DETAILS

Subject:	Time allocation; Coding; Context; Health care; Meetings; Communities of practice; Time use; Provinces; Researchers; Health services; Empirical analysis; Teams; Primary care; Data collection; Leadership; Logic; Case management; Patients; Clinical outcomes; Clinical decision making; Decision makers; Optimization; Sociodemographics; Medical research; Implementation; Uptake; Qualitative research; Governance; Systematic review
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Is the early identification and referral of suspected head and neck cancers by community pharmacists feasible? A qualitative interview study exploring the views of patients in North East England

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ABSTRACT (ENGLISH)

Introduction

Head and neck cancer (HNC) is the eighth most common cancer in the United Kingdom. Survival rates improve when the cancer is diagnosed at an early stage, highlighting a key need to identify at-risk patients. This study aimed to explore opportunistic HNC identification and referral by community pharmacists (CPs) using a symptom-based risk assessment calculator, from the perspective of patients with a diagnosis of HNC.

Methods

Purposive sampling was used to recruit patients from the HNC pathway in three large teaching hospitals in Northern England. Qualitative methodology was used to collect data through an iterative series of semistructured telephone interviews. Framework analysis was utilised to identify key themes.

Results

Four main themes were constructed through the analytic process: (1) HNC presentation and seeking help; (2) the role of the CP; (3) public perception of HNC and (4) the role of a symptom-based risk calculator. Participants agreed that CPs could play a role in the identification and referral of suspected HNCs, but there were concerns about access as patients frequently only encounter the medicine counter assistant when they visit the pharmacy. HNC symptoms are frequently attributed to common or minor conditions initially and therefore considered not urgent, leading to delays in seeking help. While there is public promotion for some cancers, there is little known about HNC. Early presentation of HNC can be quite variable, therefore raising awareness would help. The use of a symptom-based risk calculator was considered beneficial if it enabled earlier referral and diagnosis. Participants suggested that it would also be useful if the public were made aware of it and could self-assess their symptoms.

Conclusion

In principle, CPs could play a role in the identification and referral of HNC, but there was uncertainty as to how the intervention would work. Future research is needed to develop an intervention that would facilitate earlier identification and referral of HNC while not disrupting CP work and that would promote HNC and the risk calculator more widely.

Patient or Public Contribution

Patient and public involvement and engagement (PPIE) was integrated throughout the project. Initially, the proposal was discussed during a Cancer Head and Neck Group Experience (CHANGE) PPIE meeting. CHANGE was set up to support HNC research in 2018. The group is composed of seven members (four female, three male) with an age range of 50–71 years, who were diagnosed at Sunderland Royal Hospital. A patient representative from the University of Sunderland PPIE group and a trustee of the Northern HNC Charity were recruited as co-applicants. They attended project management group meetings and reviewed patient-facing documentation.

FULL TEXT

INTRODUCTION

Head and neck cancer (HNC) is the eighth most common cancer in the United Kingdom and incidence rates are continuing to rise. HNC includes cancers of the oral cavity, larynx, pharynx, nose, throat, tonsils and salivary glands. HNC accounts for 3% of all new cancers diagnosed in the United Kingdom.[1] The North East of England has been identified as the region with the highest incidence of HNC,[2] with evidence supporting both increased incidence and mortality rates in areas of high deprivation.[3] Avoidable premature mortality amongst cancer patients is higher in the United Kingdom compared with the mean survival in Europe, and earlier detection could eradicate the gap.[4,5] A key ambition of the 2019 NHS Long Term Plan is to improve early-stage cancer diagnosis, with a target of 75% of patients diagnosed early by 2028.[6] However, it is recognised that at the point of diagnosis, many patients with HNC have progressed to advanced disease status[7,8]; whereas survival rates improve when the cancer is diagnosed at an early stage, highlighting a key need to identify at-risk patients.[9]

HNC is mostly diagnosed upon symptomatic presentation, which varies amongst patients. While oral cancers are frequently preceded by potentially malignant oral disorders (e.g., leukoplakia, erythroplakia, oral lichen planus etc.), other HNCs may initially present with ear pain, a sore throat or a neck obstruction. This means that patients may present their symptoms in a variety of healthcare settings.[10] Community pharmacies are easily accessible, with 90% of the UK population living within 20 minutes of their local pharmacy.[11] The 2022 Pharmacy Advice Audit report confirmed that UK pharmacies are saving 32 million general practitioner (GP) appointments per year. These data are being used to advocate for walk-in pharmacy advice services.[12] In June 2022, NHS England announced that pilot schemes would be created to allow community pharmacists (CPs) to refer potential cancer cases directly to hospitals.[13] In addition to the routine provision of over-the-counter treatments and advice for conditions that may be the result of an undetected HNC (e.g., persistent oral ulceration), CPs participate in healthy living promotion campaigns each year (e.g., smoking cessation counselling).[14] Research conducted alongside this study explored the views of CPs regarding their involvement in the early identification and referral of HNCs and found that while they would support such an intervention, further work was needed to develop a sustainable and cost-effective intervention that would include CP training for optimum patient care.[15]

Clinical decision-making tools and risk calculators are available for a number of common cancers and are routinely used to aid prompt referral of high-risk individuals to specialist clinics for further assessment.[16–18] A validated HNC symptom-based risk assessment (www.ORLhealth.com) has been produced, which provides a straightforward web-based tool, that could potentially be used in a pharmacy setting.[19] Accordingly, our study aim was to explore opportunistic HNC identification and referral in a community pharmacy setting through the perspectives of patients with a diagnosis and lived experience of HNC.

METHODS

To enhance the reporting of this study, the COnsolidated criteria for REporting Qualitative studies checklist[20] was used (see Supporting Information: File 1).

Study design

Data were collected through an iterative series of semistructured interviews with patients who had a diagnosis of HNC. An initial topic guide was developed by the lead investigators (S. M. B. and A. S.) based around the following criteria: awareness of HNC symptoms; use of risk prediction tools and perceptions of potential future roles for CPs in HNC identification/referral. The semistructured style of interview provided flexibility to explore other topics that arose.

Identification, invitation and recruitment of participants

Purposive sampling was used with the patients being invited to be contacted by the researchers via their HNC care team and hospital consultants working in three large teaching hospitals in Newcastle upon Tyne and Sunderland, United Kingdom. Patients were contacted by telephone, informed about the study and invited to participate by the lead investigator (S. M. B.), who also conducted the interviews. The overall objectives of the study, information about the funding source and key points relating to participation, confidentiality and anonymisation of data transcripts were explained to the participants and informed consent was obtained before commencing the interviews.

Data collection and analysis

Individual semistructured interviews lasting up to 60 minutes were undertaken by telephone with the participant at home, sometimes alone and other times accompanied by a relative. Field notes were collated during the interview. Interviews were audio-recorded and transcribed verbatim to facilitate analysis. A conversational style of interviewing was used to encourage a comfortable and fluent dialogue. An iterative cycle of data collection and analysis facilitated the adaption of the topic guide to enable further exploration of new lines of enquiry in subsequent interviews. In the absence of a priori theory, framework analysis was utilised to identify key themes.[21] Initial analysis allowed familiarisation with the data, and this was followed by a process of revisiting data via the transcripts alongside audio-recording with manual coding of concepts to develop a thematic framework. There were no repeat interviews. Themes were reviewed by the lead investigators (S. M. B. and A.S.) and discussed with the wider research and patient, public, involvement and engagement team to establish definitive concepts.

Reflexivity statement

The research team included experts in oral medicine, HNC, pharmacy, periodontology and general medicine. S. M. B. obtained informed consent and interviewed the participants. S. M. B. is a female researcher with a background in dental hygiene and experience in oral and dental research using qualitative and mixed methods. S. M. B. had not met the participants before, but they were informed that she worked at the Dental School.

RESULTSPARTICIPANTS' CHARACTERISTICS

Nineteen patients were approached: and 6 were lost to follow up or did not want to take part, whereas 13 participants signed consent and completed an interview (see Table 1). They were eight males and five females, aged between 42 and 79 years old. They were recruited from HNC pathways in three large hospitals in North East England: six from the Department of Oral and Maxillofacial Surgery, Sunderland Royal Hospital, four from Ear, Nose and Throat Department, Newcastle Freeman Hospital and three from Oral Medicine Department, Newcastle Dental Hospital. All participants received a referral for their symptoms from their primary care GP or general dental practitioner (GDP). Eight participants were ex-smokers and three had never smoked. Ten reported drinking alcohol within the current government guidelines and three admitted to drinking more than the recommended limits. One participant received a positive human papillomavirus diagnosis following his HNC diagnosis. Seven were ‘problem-orientated dental attenders’ or irregular attenders at a dentist, only seeking care when having dental pain and problems, rather than attending for regular preventative care; and six were reluctant to go to the doctor, only going if they had to. Seven said they had previously attended their pharmacy for advice, while six said they went for prescription dispensing only.

Table 1 Participants' characteristics.

ID	Completed Interview	Gender	Age	Hospital	Employment	Smoking history	Alcohol history	Dental care attendance	Medical care attendance	Pharmacy attendance
SR01	Yes	M	53	SRCDC	Unemployed	Nonsmoker	<government guidelines	POA	POA	PO
FH01	Yes	F	42	NFHENT	Charity work as a coach	Ex-smoker	<government guidelines	RA	POA	PAS
FH02	Yes	M	64	NFHENT	Retired	Ex-smoker	>government guidelines	POA	POA	PAS
DH01	Yes	M	73	NDHOS	Retired	Nonsmoker	<government guidelines	RA	POA	PAS
DH03	Yes	M	79	NDHOS	Retired	Nonsmoker	<government guidelines	POA	POA	PO
DH02	Yes	F	56	NDHOS	Pharmacy (at counter)	Ex-smoker	<government guidelines	RA	RA	PAS
SR03	Yes	F	55	SRCDC	Accountant	Nonsmoker	<government guidelines	RA	RA	PAS
FH05	Yes	M	74	NFHENT	Retired	Ex-smoker	>government guidelines	POA	POA	PAS
SR04	Yes	M	60	SRCDC	Public transport	Nonsmoker	<government guidelines	RA	RA	PO
SR05	Yes	M	60	SRCDC	Window supplier	Ex-smoker	<government guidelines	RA	RA	PO
FH06	Yes	F	61	NFHENT	Care assistant	Ex-smoker	<government guidelines	RA	RA	PAS

SR09	Yes	M	59	SRCDC	Engineer	Ex-smoker	>government guidelines	POA	RA	PO
SR08	Yes	F	61	SRCDC	Retired	Ex-smoker	<government guidelines	POA	RA	PO

Abbreviations: F, female; M, male; NDHOS, Newcastle Dental Hospital Oral Surgery department; NFHENT, Newcastle Freeman Hospital Ear, Nose and Throat department; PAS, prescription, advice, screening; PO, prescription only; POA, problem-orientated attendance; RA, regular attendance; SRCDC, Sunderland Royal Cancer Diagnostic Centre; <, less than; >, more than.

Findings

The thematic analysis methodology revealed four main themes that were identified through the analytic process.

HNC presentation and seeking help

The participants had diagnoses of HNC that included cancers of the lip, tonsils, tongue, vocal cords and throat. The initial sign or symptom was often innocuous and included a persistent ulcer or sore, a lump or swelling, earache or hoarseness of the voice; and there was frequently no pain. Participants described initially attributing the signs and symptoms to a minor ailment like a cold sore; or an abrasion resulting from a broken tooth, or a side-effect of medication being taken for another chronic condition or a vitamin deficiency. Some participants used a variety of ways to self-treat their symptoms, but as time passed and symptoms persisted or worsened, participants would start to consider seeking help, although sometimes it took a family member or friend to persuade them to seek advice. Where there was inertia, this was attributed to living alone (easier to ignore), not wanting to waste anyone's time, a phobia or not considering it an emergency.

Well, it started about, just after Christmas a couple of years back when my, my voice started getting very croaky. And I let it go for a couple of months, and when a friend of mine actually said, you know, I should get this, get it checked out really. And, because it wasn't getting any better, and my voice was getting increasingly croaky. So that's the reason I went to the doctors, it was to get it, you know, to see why my voice was croaky.… And there was no pain at any time. [patient with throat cancer, FH05]

Once participants had made the decision to get help, some participants found it straightforward to access care and get an immediate referral, whereas others described difficulty in being seen and delays in getting a diagnosis. Some experiences were exacerbated by the COVID-19 pandemic, either due to not having access to face-to-face appointments or having to cope on their own due to ‘attend-alone’ protocols.

I noticed, well my husband noticed a lump in my neck in April 2020 and so it was the very start of lockdown. And then I rang the GP who said ‘well, Mrs [name], you're at far greater risk of COVID than you are of cancer’. So, I rang them back in a few weeks and I said it's still here and I'm worried, I'm having pains down my arm, and he said ‘well, what are you worried about?’ and I said ‘well, I'm worried that I might have cancer or I'm going to have a heart attack’ and they laughed. They said ‘no, Mrs [name], that's not going to happen. If you're still concerned in a few more weeks let me know because under the current circumstances, it wouldn't be wise to make any referrals’. It took until August of me ringing and they, they eventually sent me for a scan on my neck and within three days it came back, and they still didn't see me. They rang me and said, ‘I can't tell you that it's cancer over the phone, but we need you to go to the hospital’, and that's when it was all explained to me. [patient with cancer of the tonsil, FH01]

Role of the CP

All participants agreed that CPs were highly qualified and could play a role in the early referral of HNC, particularly with additional training. The pandemic had shown that CPs could undertake extended roles, such as in delivering COVID-19 and influenza vaccinations. CPs were often attached to a medical centre or on the ‘high street' with extended opening hours and no appointment was necessary. There were consultation spaces created in many pharmacies, that provided an option for privacy; and, furthermore, as a face-to-face appointment with a GP/GDP was often difficult to obtain following the COVID-19 pandemic, CPs were considered much more accessible than GPs.

…if there'd been a pharmacist and I'd went there, they might have turned round and said, ‘That isn't off tablets, tablets don't do that’. But I didn't know any different, you know… With training I think they would, yes, they would be the right people. You know a pharmacist's role at the minute is a different thing, isn't it? We've seen it with the pandemic, I mean they're giving flu injections, they were doing the virus, you know inoculations… Well, being honest I think there's more pharmacists than what there is doctors… So you know, surely they can come up and go, ‘Mr [name] like we'd better refer you back to the doctors’. [patient with cancer of the vocal chords, FH02]

Notwithstanding, there was a perception that CPs' main occupation was dispensing medicines. If they were to offer advice, it was in relation to a specific pharmaceutical regimen; or they discussed potential side effects or suggested over the counter, possibly cheaper alternatives to the prescribed medicine. CPs were also regarded as being incredibly busy, frequently observed with a queue of people waiting. Often, the CP would spend much of their time ‘hidden around the back’ with possibly very little time to spare for consultations. In addition, the counter space was not considered an appropriate place for engaging in confidential and potentially highly personal forms of health-related discourse. Even with a consultation room, it was considered off-putting that to access the CP, there may still have to be a conversation with the medicine counter assistant first. Finally, consideration was given to the seriousness of the potential diagnosis and prognosis. Would the consultation be managed appropriately, and would the CP be able to offer support and compassion if the person became distressed?

A pharmacist could definitely offer that service, I would've said. But I don't know if it would be a port of call that I would consider, if I'm honest with you. I wouldn't consider walking into the pharmacist down here. I live in XXX [a village in a large county of North East England]. I wouldn't consider walking into that Centre, that girl behind the counter, chap behind the counter. Would you mind having a look at this? I don't know if that's a good thing or a bad thing, but that's truth of it…[I] was spitting blood…I was in a pretty dark place at the time.…and, and that's something you don't want to hear in the pharmacist, as well. It surely doesn't look quite good. [patient with throat cancer, SR05]

Public perception of HNC—what does HNC look like?

HNC is a category of cancer that manifests in a diverse way due to the anatomy of the head and neck. Participants described being unaware of HNC and not knowing what to look out for. Notwithstanding the lack of awareness or ‘silence’ surrounding HNC, even a small tumour that is caught early, can have a hugely distressing impact on the person's life and rehabilitation. This quote is from a patient who considered their cancer to be a ‘minor’ cancer, as they didn't realise how serious it was.

And I just think to myself, I see the advertisements on television. And you see people with breast cancer, lung cancer, and I think I've got nothing and then the nurses [told me] it's cancer, [and] cancer is something. But I find it hard to think that it's serious you know…this is probably one of the problems when I've seen the picture on the internet. I certainly thought, oh, I've got that. But I still didn't do nothing about it because I didn't think it was that serious… But like I said, I also didn't know, which I know now, that I'm under super…, like under consultation now for the next five years. So I mean, that's a big thing in your life. They said the first two years it can come back. And I said, oh comes back on me lips? He says no it can comeback anywhere. I says, well, I never knew that, nobody taught me that. [patient with cancer of the lip, SR01]

Some of the participants questioned why some cancers receive more healthcare promotion than others. Breast cancer, for example, was mentioned frequently, being publicised in campaigns that were advertised ‘everywhere’, with self-examination recommended, and it was clear what to look out for. While raising awareness about HNC was felt to be a good idea, the fact that HNC presents in multiple ways made it more complex. Nevertheless, using posters, adverts via multiple sources of media and personal testimonials was felt to be important. In the next quote, a participant describes how their cancer was found and how their cancer journey was featured on the Macmillan website.

Like I say…I'm only telling you what's happened to me. Mine was basically like I said; it wasn't something I was having trouble with. I didn't have a sore throat; I got two teeth taken out [which was unrelated but led to the diagnosis]. And, touch wood, from that, like I say, I wouldn't say it was a ‘run of the mill, I'm suffering from a sore throat, I had a hoarse voice’, or anything like that. Mine was totally different [no symptoms], but anybody who's had teeth taken out, found a lump anywhere, go to the doctor straight away you know, get it checked out. Yeah, I did a story on the Macmillan website…March 2020; you'll see my story and me wife's story. [patient with cancer of the tonsil, SR04]

Role of a symptom-based risk calculator

During the interviews the use of the online symptom-based risk calculator for HNC, http://orlhealth.com/ was discussed. The participants were told that the calculator consists of 14 questions related to symptoms of HNC such as dysphagia, hoarseness, ulcer, neck mass, persistent skin lesion, sensation of a lump in the throat, otalgia and odynophagia. Participants were in agreement that anything that would enable a faster referral would be good. CPs were known to be highly qualified professionals, but also very busy, and as the calculator was a simple tool, it was suggested that medicine counter assistants in the pharmacy could use it. Furthermore, some thought it would be good if it was accessible to the public.

Absolutely, couldn't agree more. Had I had something like that, I'm sure we could have got that diagnosis a little bit quicker. You know, maybe a couple of months quicker, which makes the world of difference when you've got something like that. And I absolutely think had there been a tool like that, even if it was online or whatever, I would've used that without a shadow of a doubt. Absolutely, one hundred percent, one hundred percent. [patient with cancer of the tonsil, SR05]

In addition to questioning the practicalities of completing an HNC risk consultation by a CP, such as time constraints and the need for privacy, some participants wondered how the conversation would be initiated. As medicine counter assistants and CPs are frequently giving advice, would they know when to suggest a risk calculator? Would it be up to the customer to ask for a risk assessment?

If the pharmacist asked me a few questions would I have waited about for them to do it? Probably not. I would have tended to go to my GP late at night, after work and that. Is it a good idea? Yes, I definitely think it is because there will be some people that are not like me who would be happy to wait. But who would ask all those questions because when I go to the pharmacy it tends to be effectively shop assistants that help me with my prescription. Would they have the sense to say, ‘Oh, [name] has been in three times and had Difflam or had Bonjella’.…Would it rely on me saying, ‘I've had this ulcer for three weeks, is there anything I can use on it?’ At that point they'd say to the pharmacist, ‘This lady…’ or would they just turn round and say, ‘Try Bonjella, or rinse it with salt water’.…I think for me I would want to see a poster in the pharmacy saying, ‘Have you had a sore mouth for more than three weeks? Have you had a sore throat for more than three weeks? If so, talk to your pharmacist and they may be able to suggest something’. Or ‘If so, look up this [the symptom based risk calculator]’. [patient with tongue cancer, SR03]

DISCUSSION

This qualitative semistructured interview study explored the views of patients regarding the feasibility of CPs providing a role in the early identification and referral of suspected HNC. The participants shared a diagnosis of HNC, but they were in different stages of their HNC pathway with some having had surgery recently and others being some way into remission. They all agreed that anything that reduces the length of time it takes to diagnose HNC is valued as it will improve outcomes. During the interviews, an intervention to evaluate risk and facilitate early referral was unpacked in practical terms.

Regarding the role of the CP, patients perceived that while CPs were highly trained in medicines and no appointment was needed to see them, there were barriers to access as CPs were incredibly busy and medicine counter assistants were the first person, and sometimes the only person, the patients spoke to. This raised the question of whether the medicine counter assistant could have a role in the early identification of suspected HNC. This idea was further strengthened if the consultation included the use of the symptom-based risk calculator, as this was designed to be quick and simple to complete and didn't require any expertise. Furthermore, as CPs tend to rely on indirect referrals,[15] or signposting, it would not make a difference who delivered the intervention if the ultimate advice was for the patient to go to their GP or GDP. The Northern Cancer Alliance has a website with an urgent referral form, but it is currently only available for GPs or GDPs to complete.[22] Future research would be needed to explore the role of a medicine counter assistant in delivering this intervention, in addition to investigating the possibilities for adapting the urgent referral form for nondentists/medics to complete.

Awareness of HNC was poor and this was considered to have an impact on health seeking behaviour. Patients described the varied and sometimes innocuous symptoms of HNC and how the initial presentation of, for example, an ulcer or a croaky voice did not seem to indicate an emergency or something life threatening. Research has found that those cancers that present with vague, ‘non-urgent’ symptoms can take a median of 34 days longer to diagnose.[23] There was uncertainty as to why certain cancers and not others were the subject of healthcare promotion. If people were given access to information in adverts, campaigns or in the media, participants felt it would alert them to the fact that an ulcer or croaky voice, for example, could be HNC. Raising awareness seemed to be important as the location of HNC tumours often resulted in treatment that was highly invasive and traumatic. Indeed, HNC survivors often suffer with ongoing alteration of daily functions, psychological distress and ongoing issues with speech and swallowing.[24–26] It was considered that perhaps a pharmacy could be less formal and therefore a preferred environment to ask for advice regarding these symptoms; but there were also concerns about the lack of privacy and whether the CP would recognise the potential risk of HNC when the early symptoms can be so common and minor.

The data suggested that the idea of using a symptom-based risk calculator was good if it would help earlier identification or referral, although research is yet to identify if clinical decision-making tools are disruptive to consultation times, increasing them to an inappropriate degree.[27] Furthermore, the calculator does not include premalignant oral conditions such as leukoplakia, erythroplakia and oral lichen planus. Notwithstanding, for cancer symptoms such as an ulcer or a croaky voice, the calculator would result in the recommendation of an urgent referral if the symptoms were persistent and unexplained, even with an absence of a history of smoking or excess alcohol consumption. It was suggested that if CPs were trained in the risk assessment tool and the symptoms and concept of ‘persistence’, this could improve the chances of earlier referral or signposting. Persistence is difficult to define for some symptoms of HNC, such as sore throat, but Tikka et al. suggest over 3 weeks for oral ulcer or swelling, dysphagia and under 3 weeks for a recent unexplained neck lump.[28] Furthermore, there was some suggestion that if the risk calculator was more publicly advertised and available, it may help people to contact a healthcare professional earlier. The calculator also has functionality for printing the results, which the patient could then take to their GP/GDP appointment.

The promotion of HNC was considered important by all participants, who had poor awareness, indicating a need for more publicity. The United Kingdom has nominated 23rd September as HNC Awareness Day. In addition to the Northern Head and Neck Cancer Charity, which has supported this research, there are other cancer charities offering a range of resources.[29] The Macmillan cancer support charity has information on all cancers, including HNC, and a function to chat to a specialist online; the Northern Cancer Alliance has information on HNC and a GP/GDP urgent referral function and the Mouth Cancer Foundation has an oral cancer self-check video and testimonials.[22,30–33] Furthermore, in January 2023, *The Times* published an article by the Scottish Health Correspondent, Helen Puttick, on the merits of the symptom-based risk calculator.[34] The participants in this study appeared to be largely unaware of these resources.

A strength of this study is that it is the first that we are aware of that explores the views of patients regarding a CP's role in the early detection and referral of HNC. Furthermore, it includes a variety of subsites and patients at different stages of the HNC pathway. A limitation is the potential for selection bias. Potential participants were identified and initially approached by their consultant. All participants had received a diagnosis of HNC as we wished to explore the views of those who had lived experience, and we recruited from three hospitals in the region to find a range of perspectives. Notwithstanding, our selection strategy may have influenced the findings, and this may limit their transferability to other areas of the country or to those presenting in emergency settings.

While the data support the concept of CPs delivering an intervention that could lead to earlier identification and referral of HNCs in principle, there was uncertainty as to how this would work in practice. Research conducted alongside this study explored the views of CPs regarding their involvement in such an intervention and although it was felt to be possible to support HNC awareness initiatives, early identification and referral, the findings suggested that further work was needed to develop a sustainable and cost-effective intervention.[15] This study found that regarding accessibility, there were concerns about waiting times, privacy, CP training and support, which would suggest the need to raise public awareness about the clinical role of a CP. CP capacity to deliver the intervention would also need to be assessed and reviewed locally to consider staff time and strategies to mitigate disruption. Furthermore, if a CP could make a 2-week urgent referral via the Northern Cancer Alliance website, this could improve and add value to the intervention.

CONCLUSION

The findings of this study suggest that the principle of utilising CPs in the early identification and referral of suspected HNC was accepted by all participants, with the agreement that it may encourage some people to make an appointment with their GP/GDP. However, there was uncertainty as to how the intervention would work. Future research will need to look at intervention development and implementation that includes CP and the wider community pharmacy team training and capacity building; and the design and delivery of an effective HNC public health campaign.

AUTHOR CONTRIBUTIONS

All authors contributed to the study conception, design, analysis and interpretation of data, and reviewed/revised the submission. Marco Carozzo, Michael Nugent and James O'Hara identified the patient participants. Susan M. Bissett took consent, acquired the data and drafted/reviewed the final article.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

The study was reviewed and approved by North-West Preston Research Ethics Committee (reference: 21/NW/0126) on 26.05.2021; and the HRA and Health and Care Research Wales, on 27.05.2021.

DETAILS

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‘Creating a culturally competent pharmacy profession’: A qualitative exploration of pharmacy staff perspectives of cultural competence and its training in community pharmacy settings

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ABSTRACT (ENGLISH)

Introduction

Cultural competence is an important attribute underpinning interactions between healthcare professionals, such as pharmacists, and patients from ethnic minority communities. Health- and medicines-related inequalities affecting people from underrepresented ethnic groups, such as poorer access to healthcare services and poorer overall treatment outcomes in comparison to their White counterparts, have been widely discussed in the literature. Community pharmacies are the first port of call for healthcare services accessed by diverse patient populations; yet, limited research exists which explores the perceptions of culturally competent care within the profession, or the delivery of cultural competence training to community pharmacy staff. This research seeks to gather perspectives of community pharmacy teams relating to cultural competence and identify possible approaches for the adoption of cultural competence training.

Methods

Semistructured interviews were conducted in-person, over the telephone or via video call, between October and December 2022. Perspectives on cultural competence and training were discussed. Interviews were audio-recorded and transcribed verbatim. The reflexive thematic analysis enabled the development of themes. QSR NVivo (Version 12) facilitated data management. Ethical approval was obtained from the Newcastle University Ethics Committee (reference: 25680/2022).

Results

Fourteen participants working in community pharmacies were interviewed, including eight qualified pharmacists, one foundation trainee pharmacist, three pharmacy technicians/dispensers and two counter assistants. Three themes were developed from the data which centred on (1) defining and appreciating cultural competency within pharmacy services; (2) identifying pharmacies as 'cultural hubs' for members of the diverse, local community and (3) delivering cultural competence training for the pharmacy profession.

Conclusion

The results of this study offer new insights and suggestions on the delivery of cultural competence training to community pharmacy staff, students and trainees entering the profession. Collaborative co-design approaches between patients and pharmacy staff could enable improved design, implementation and delivery of culturally competent pharmacy services.

Patient or Public Contribution

The Patient and Public Involvement and Engagement group at Newcastle University had input in the study design and conceptualisation. Two patient champions inputted to ensure that the study was conducted, and the findings were reported, with cultural sensitivity.

FULL TEXT

INTRODUCTION

Cultural competence can be defined as an individual's ability to possess the skills and knowledge to effectively interact with people from different cultural backgrounds.[1] It involves the acknowledgement, understanding and appreciation of an individual's cultural identity such as their religion, ethnicity, nationality, gender and sexual orientation.[2,3] Evidence has demonstrated that being culturally competent promotes communication between individuals,[4] respect for other cultures, individual self-awareness[1] and support shared decision-making between individuals.[5] Therefore, it can be considered a key attribute to those working within the healthcare system.[6]

The General Pharmaceutical Council Standards for Pharmacy Professionals report demonstrates the responsibility of pharmacy professionals to 'treat people as equals, with dignity and respect, and meet their own legal responsibilities under equality and human rights legislation, while respecting diversity and cultural differences… (and) assess and respond to the person's particular health risks, taking account of individuals' protected characteristics and background'.[7] Similar statements are acknowledged in the General Medical Council Equality, Diversity and Inclusion Policy, which ensures that the organisation and all medical professionals 'treat anyone who [we] interact with fairly, without bias or discrimination',[8] and in the principles of good practice for community pharmacy teams, to address health inequalities (point 1.2.6) in the National Institute of Health and Care Excellence Guidance.[9] Despite referring to cultural competence within the guidance from professional bodies, there remains evidence of healthcare and medical inequalities affecting patients belonging to ethnic minority communities.[5,10,11]

Recent studies have identified several factors that may contribute to these health inequalities, including poorer health outcomes, lower reported health literacy levels, lower socioeconomic status and feelings of disempowerment and distrust within the healthcare system for those from underrepresented ethnic communities, compared to their White counterparts.[12,13] Evidence suggests that one approach to tackling the aforementioned health inequalities could relate to the education and training of healthcare professionals, particularly developing skills to become culturally competent.[11,14–16] Govere et al. demonstrated that cultural competence training had a positive impact on cultural awareness and overall competence of healthcare professional consultations, hence improving rates of patient satisfaction.[14]

Most knowledge around the training of cultural competency within healthcare settings currently focuses on the fields of nursing, medicine and dentistry. There have been variations in proposed strategies and frameworks for teaching cultural competence to these healthcare professionals[17]; for example, including the provision of online, self-directed learning sessions for trainees,[18] as well as face-to-face workshops and seminars, delivered by trainers.[19–22] One setting within healthcare that encounters a wide range of culturally diverse patients is a community pharmacy.

Community pharmacy is regarded as a vital and easily accessible healthcare setting to any patient who requires health advice and treatment.[23] A recent study proposed that cultural competence training should be implemented into the training curriculum of all staff working within community pharmacies[10]; however, limited research exists on the optimal delivery methods of cultural competence training to meet this need.[24,25]

By exploring the perspectives of community pharmacy staff members, this qualitative study aims to: (i) provide new insights that showcase beliefs and attitudes towards cultural competence within the pharmacy profession and (ii) identify strategies to implement and deliver training for community pharmacy staff to use within their culturally diverse places of work.

METHODSRecruitment and sampling

The consolidated criteria for reporting qualitative research checklist was followed for this work (see Supporting Information: File).[26] Given the capabilities of digital strategies to support qualitative research, a blended strategy was applied to perform participant recruitment and data collection with pragmatism. Recruitment was facilitated by community pharmacies, community charities and professional networks based in the North East of England, as well as on the social media profiles of two members of the research team (J. McC and A. R.-B.). All interested participants who contacted the research team were emailed an information sheet and consent form detailing the purpose and aim of the research. Those who expressed an interest and gave their written consent were enroled in the study. There was no relationship established between the researcher and participants before study commencement or recruitment. Inclusion criteria comprised: participants over 18 years of age who held a role within a community pharmacy team working in the United Kingdom (including, but not limited, to: pharmacists, foundation trainee pharmacists, pharmacy technicians, dispensers/dispensing staff and counter assistants). Purposive sampling was used to recruit participants and ensure representation from a variety of typical job roles within community pharmacy teams; participants were also of mixed age ranges, had been qualified in their job roles for varying lengths of time and were from varying ethnic backgrounds.

Semistructured interviews

In-depth, semistructured interviews were conducted by one researcher (J. McC, a female pharmacy student researcher with experience in qualitative research) between October and December 2022. Interviews were conducted either remotely, via Zoom® or telephone calls, or in-person (face-to-face); all participants were offered the choice of which format they would prefer. The semistructured interview topic guide (see Supporting Information: File) was developed based on three pilot interviews and covered key issues identified in the existing literature,[5,10,11] including participants' knowledge of cultural competence within the pharmacy and wider healthcare settings; participants' perspectives and experiences of interacting with patients from ethnic minority communities and their views and suggestions on cultural competence training. In addition, the topic guide was informed by findings from a previous qualitative study conducted by the research team[5] and the lived experiences of patient champions involved as co-authors in this study (L. S. and A. K. D.).

Data analysis

All semistructured interviews were audio-recorded to enable data analysis. The audio files were encrypted and transcribed verbatim by J. McC; immediately following transcription, the audio files were deleted. All interview data were anonymised at the point of transcription and all transcripts were checked for accuracy and correctness by A. R.-B. Participants did not provide comment on the transcripts nor feedback on results.

Following reflexive thematic analysis processes, as defined by Braun and Clarke,[27,28] the principle of constant comparison guided an iterative process of data collection and analysis. Reflexive thematic analysis was performed by two researchers (J. McC and A. R.-B.) to analyse the interview data. A close and detailed reading of the transcripts allowed the two researchers to familiarise themselves with the data. Initial descriptive codes were identified in a systematic manner across the data sets; these were then sorted into common coding patterns, which enabled the development of analytic themes from the data. The themes were reviewed, refined and named once coherent and distinctive. Two authors (J. McC and A. R.-B.) performed the data analysis through discussion and, if the agreement was not reached, by consensus with the wider research team (L. S., A. K. D., W. M. L., A. K. H. and

A. T.). Postinterview field notes enhanced this reflective process and enabled the researchers to work iteratively and inductively between interviewing and data analysis. NVivo (version 12) software was used to facilitate data management. The research team was in agreement that data sufficiency and information power occurred after conducting 12 semistructured interviews and thus, study recruitment stopped following interview number 14.[29,30] To ensure confidentiality when using direct patient quotes within this research, nonidentifiable pseudonyms are used throughout, for example, participant 1 and participant 2, and so forth.

Considerations when reporting participant demographics

The researchers wished to consider whether there were any connections or associations between perspectives shared by participants and their ethnicity. Collecting data on a person's ethnic group is complex since ethnicity in itself is a multifaceted and changing phenomenon.[31] Various ways of measuring ethnicity exist and could include a person's country of birth, nationality, religion, culture, language, physical appearance or a combination of all of these aspects.[3,32] Efforts have been taken in this study to report a multitude of these aspects, to demonstrate the multi-faceted layers that accompany discussions about ethnicity. The UK Office of National Statistics ‘Ethnic group, national identity and religion’,[3] the UK Census Reporting Classification[33] and the National Institutes of Health (NIH) ‘Racial and Ethnic Categories and Definitions for NIH Diversity Programs and Other Reporting Purposes’[32] guides were used to inform the reporting of participant ethnicity for this study (as demonstrated in Table 1). Table 1 also includes a column for self-identified ethnicity and is reported verbatim from each participant's interview.

Table 1 Participant demographics.

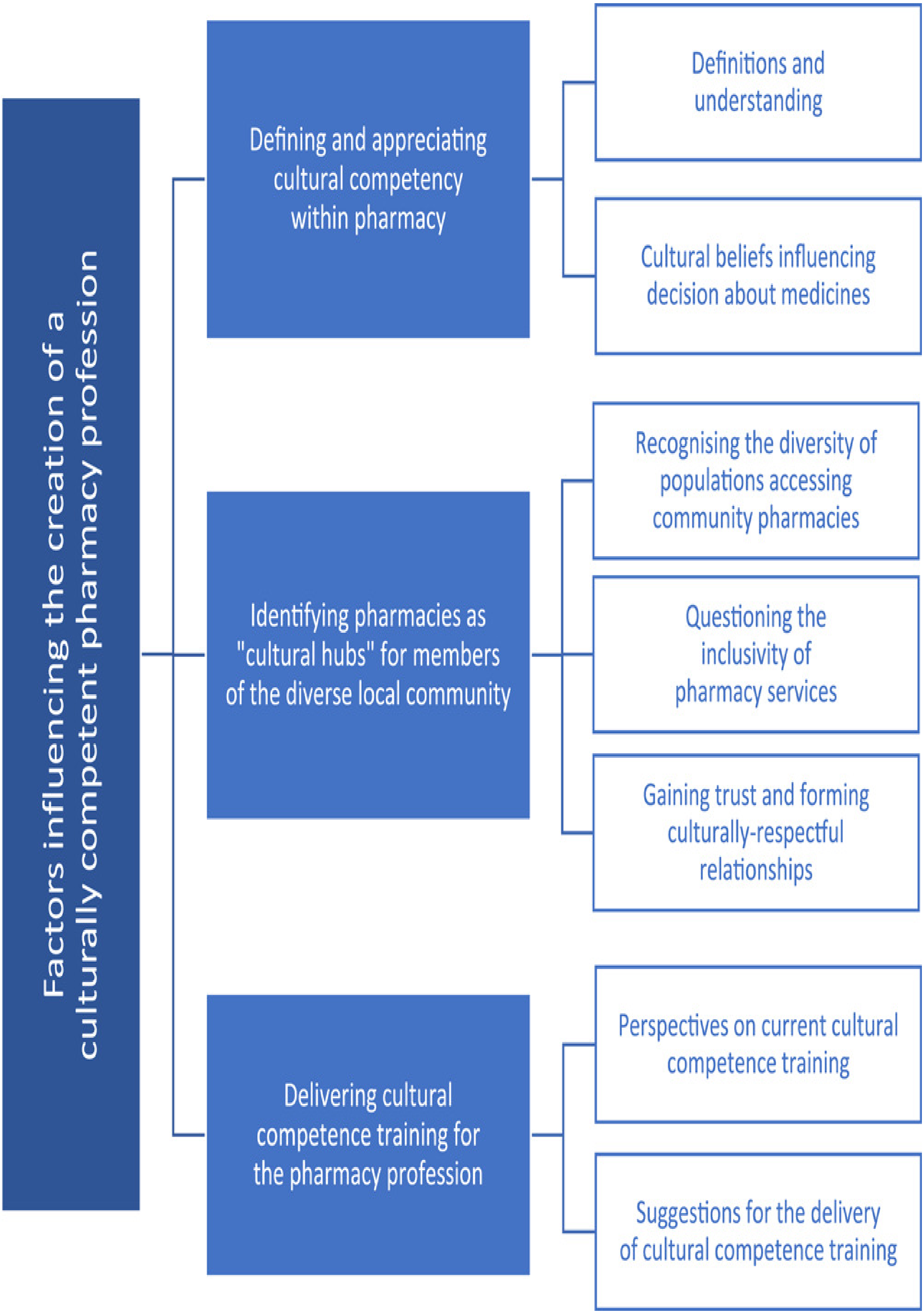
Participant number	Reported sex	Age range (years)	Staff role within community pharmacy	Self-reported ethnicity	Interview format	Region of practice within the United Kingdom
1	Female	20–29	Pharmacist	White, British	Video-call (Zoom)	North East England
2	Female	20–29	Dispenser	White, British	In-person	South Yorkshire
3	Female	40–49	Counter assistant	Mixed-race, British	Telephone	North East England
4	Female	30–39	Pharmacist	White, Scottish	Telephone	Scotland
5	Female	40–49	Pharmacist	White, British	Video-call (Zoom)	North East England
6	Male	20–29	Pharmacist	White, British	Video-call (Zoom)	North East England
7	Female	30–39	Pharmacist	White, British	Video-call (Zoom)	North East England
8	Female	40–49	Pharmacy technician	White, British	Video-call (Teams)	South East England

9	Female	30–39	Pharmacist	Chinese	Video-call (Teams)	North East England
10	Male	40–49	Pharmacist	Pakistani	Video-call (Zoom)	South Yorkshire
11	Male	30–39	Pharmacist	Chinese	Video-call (Zoom)	South East England
12	Female	20–29	Counter assistant	White, British	Telephone	North East England
13	Male	20–29	Dispenser	White, British	Telephone	North East England
14	Female	20–29	Foundation trainee pharmacist	White, British	Video-call (Zoom)	North East England

RESULTSParticipant demographics

Fourteen participants in total were recruited and interviewed for this study (participant characteristics are described in Table 1). Of the 14 participants interviewed; 8 described their job roles within community pharmacy as pharmacists (57%), 1 interviewee was a foundation trainee pharmacist (8%), 3 were dispensers/pharmacy technicians (21%) and 2 were counter assistants (14%). Ten participants self-reported their ethnicity to be White, with nine stating they were British and one stating they were Scottish; one participant identified as mixed-race British; two participants identified as Chinese, and one identified as Pakistani. The average age of the participants was 30 years (SD ±8.06). Participants worked within community pharmacy settings across the United Kingdom; specifically, nine participants worked across the regions of Northumberland, Tyne and Wear (England), three participants worked across Yorkshire (England), two participants stated they worked in London (England) and one participant worked in Glasgow (Scotland). Nine interviews were conducted over video call-based software (64%), four interviews were conducted over the telephone (28%) and one interview was carried out in person (8%). There were no refusals to partake, participant dropouts or repeat interviews.

Three overarching themes were developed to reflect the perceptions of community pharmacy staff on cultural competence and the delivery of cultural competence training within community pharmacy. These focused on (1) defining and appreciating cultural competency within pharmacy services; (2) identifying pharmacies as ‘cultural hubs’ for members of the diverse, local community and (3) delivering cultural competence training for the pharmacy profession (Figure 1). The three themes, and their subthemes, are discussed in turn.



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Theme 1: Defining and appreciating cultural competency within pharmacyDefinitions and understanding

Cultural competence was believed by most participants to relate to the awareness and appreciation of another person's culture, with one explaining that being culturally competent is ‘about understanding and appreciating people from a lot of diverse backgrounds –that are different to yours. So that's whatever ethnicity you are, it's understanding about cultures and upbringing and all the things that make you, you’ (Participant 8). In this sense, cultural competence was interpreted, in a wider social context, as a skill that an individual can develop through interactions with people from different cultures. Other participants described cultural competence as a concept relative to health, and drew on their medicine expertise to address this; they described cultural competence as being ‘inclusive in your treatment of those patients and being able to build that into the way we approach patient care and healthcare decisions’ (Participant 6).

You've got to be aware of issues such as religion, race or cultural differences that may require a different approach to treating that patient… you know what they can and can't eat for example, you can offer them alternative medication with products that wouldn't be offensive or unacceptable to them. (Participant 5)

Cultural beliefs influencing decisions about medicines

Participants provided examples where it was important to be aware of formulation considerations and excipients within medications. Specifically, the suitability of capsules containing pork products for someone practicing religions including Islam or Judaism was discussed, with one participant stating ‘somebody who's Muslim wouldn't be happy with pork products, like gelatine, in their capsules’ (Participant 4). Others also recalled examples of investigating alternative medications to suit a patient's cultural needs. A pharmacist explained, ‘it took me probably a couple of hours to source the medication in liquid form… I had to ring manufacturers and contact lots of different companies to try and find an alternative and (pause) it took a lot of time’ but they ‘knew it was super important to them [the patient] and if it was me in their shoes, I wouldn't have taken that medication because it's not acceptable’ (Participant 5). It was acknowledged by many participants that although it may take additional time to source suitable medications for patients, it was important for delivering high-quality care, and there was an underpinning belief that these additional considerations would lead to a more individualised approach to patient care.

Other participants reflected that the beliefs of certain cultures may impact an individual's ability to engage with healthcare access or medicine-taking. It was suggested that certain cultural beliefs could pose barriers to individuals accessing the care that they need, as there may be a cultural stigma surrounding certain health conditions. A pharmacist recalled an example where a Muslim patient, who was receiving methadone treatment, said he would be ‘mortified if a person from their community had seen them’ (Participant 4). The pharmacist contemplated that ‘some people perceive that Muslims don't drink and therefore it's unusual for a Muslim to end up on methadone or a dependent substance’ (Participant 4). They hinted that patients should not be labelled under common stereotypes and that health professionals should know to provide equal treatment to patients, regardless of their cultural background.

I think it's about being concerned that they [patients] may be stigmatised within their community… or if it's perhaps not something that's seen as appropriate in their religion. It's a little bit about shame, and personal shame and er, feeling like they're going against the cultural norm for them. I think that stigma could potentially prevent them seeking help for their conditions. (Participant 4)

Two participants reflected on experiences of barriers that prevented a person from seeking healthcare or medication advice, because they were ‘a female (pharmacy professional) and their (the patient) religion means they can't, or shouldn't, interact with females’ (Participant 5). Suggestions were given around possible ways to overcome such barriers, even ‘how pharmacy regulators could engage with key members of those communities to try and explain how we can work together to overcome that’ (Participant 5).

I think that one of the hardest challenges is where maybe the gender of the person who delivering the care, is not seen as being appropriate to speak to a male member of the public and say, ‘It's ok to engage with a female member of staff at the pharmacy. You're not going to get in trouble if you do that’. (Participant 5)

Theme 2: Identifying pharmacies as ‘cultural hubs’ for members of the diverse local communityRecognising the diversity of populations accessing community pharmacies

Participants discussed that community pharmacies are unique healthcare settings; they are an accessible ‘source of health advice and health care, where you can speak to a qualified professional, all without requiring an appointment' (Participant 3). One participant reflected that being a community pharmacist meant 'you are often the first point of contact like in the community for any patient' (Participant 1) and one counter assistant recognised the diversity of patients that attend community pharmacies, stating 'it's not always the same ethnicity (within the patients we are treating) and you're rarely going to get a pharmacy that only has one ethnicity (in its population)' (Participant 12). Participant views across all job roles within the community pharmacy described the potential for interactions with members of a diverse population accessing the pharmacy. One participant viewed the potential for community pharmacies to be regarded as 'cultural hubs' that local communities can access, knowing they will 'be recognised and spoken to in way that accounts for them and their culture' (Participant 11).

Most of the participants had experience working within various pharmacies across the United Kingdom and were able to recall differences in the level of diversity between the pharmacies on a national level, as well as on a local level. One participant discussed their experience of working as a locum pharmacist across a number of cities across the North East of England, where diversity differences were even noticed 'only 2-miles down the road you've got an entirely different community living there and they'll most likely need different approaches to people living 2-miles the other direction' (Participant 6). Another pharmacist acknowledged diversity differences comparing inner-city pharmacies; they described 'particularly in the North East, like in [name of major city], you can cross the bridge and find communities that are highly populated with Jewish people, or you can cross another bridge and find areas even more diverse again, like housing for refugees or asylum seekers from War torn countries' (Participant 6). There was also a suggestion that pharmacies located in areas of higher deprivation contained a greater population of ethnic minority patients. One pharmacist discussed noticing diversity variations between two pharmacies they worked at with 'different sort of socio-economic areas between [names of two villages]' (Participant 7). As well, a participant who worked in Scotland suggested 'where I work, [name of city], it's like an affluent rural area… so I would say predominantly the community is Caucasian, middle class people' (Participant 4).

Questioning the inclusivity of pharmacy services

There was variation between participant perspectives on whether their pharmacy services demonstrated inclusivity towards patients from ethnic minority groups. Most participants believed their pharmacy services could better appreciate a person's culture when providing care. One pharmacy technician stated 'I think people are polite (pause), generally. But I don't think there's anything in place to first recognise a patient's cultural needs and then go from there' (Participant 8).

Approaches that could improve the inclusivity of pharmacy services were discussed, with many relating to language and the need for translators or interpreters to support conversations about medicines. Translation and interpreter services were recognised as a potentially beneficial pharmacy service for patients who do not speak English as 'a lot of information that we give across to patients i.e., patient information leaflets, which are inside and the boxes and everything, well the majority are just in English' (Participant 7). Another participant, who worked in an area with a higher level of deprivation, discussed strategies employed in their pharmacy which were managed by a pharmacist from an ethnic minority background. They described how steps towards being more culturally inclusive included 'translated medicine instructions on the wall… sometimes posters are in different languages… I don't know it just feels different working in that pharmacy compared to your average pharmacy, in that they're more inclusive' (Participant 9). It was also acknowledged by several participants that community pharmacy records 'may not have someone's ethnicity in the notes that you can see' (Participant 8) and the benefit of making this information readily accessible was suggested, to inform decisions made by pharmacy professionals about the best course of treatment for a patient.

I'd say we could probably do more, and that's probably all community pharmacies in general. And it's even things like having leaflets in a different language available –I mean we can print them off, but do we?… I'm aware of a company that's er that does prescription transcribing in hundreds of different languages and it's more accurate that Google Translate. But it's only a very small number of pharmacies that are using it. But I think the ones that are, it is just so helpful to the patients. (Participant 10)

Gaining trust and forming culturally-respectful relationships

Participants reflected on factors that might negatively impact on building culturally-respectful relationships; for example, the effect of language barriers if a person has limited or low English language proficiency, or use of colloquialisms when conversing with someone that does not speak English as a first language. A counter assistant reflected ‘where I work you sort of know a lot of the people that come in –they're like locals so you can have that like joke or bit of a chat with them. And with someone of a different background, you don't always have that. And er, it can be a bit tricky’ (Participant 3). In fact, using cultural colloquialisms to build a better rapport with patients was highlighted by a pharmacist. They stated that within Asian cultures ‘they call like “Auntie” and “Uncle”, they use that language and it's friendly language instead of “Mr or Mrs.” Er, yeah, very friendly terms used to create more of that rapport within the community’ (Participant 9).

Building trust and establishing culturally-respectful relationships was deemed by one participant to be potentially more challenging to achieve between a pharmacist and a patient from a different ethnicity or culture. The employment of staff members from ethnic minority backgrounds was recognised as a strategy to overcome this. Many participants reflected on examples they had witnessed where staff members who spoke languages other than English were asked to speak to certain patients. One pharmacist stated that their pharmacy had ‘quite a few Romanian customers who come in because they know that they can speak to someone in their language. Er, and I think they tell their friends, “If you go to this pharmacy, they'll speak Romanian”’ (Participant 1). It was speculated that this approach could help overcome communication barriers between pharmacy staff and patients, by enabling inclusive conversations about medicines in a person's native language. Further, it was considered that diversity within pharmacy staff may lead to greater patient satisfaction rates specifically focused on medicines; one participant stated ‘so, I know it's important to build a rapport up with someone, but then to be able to have a proper focused conversation understand it from a certain cultural perspective… that's like, that's achieving a proper goal for us’ (Participant 9). A dispensing assistant echoed this thinking, describing ‘when a patient who comes in who's a Sikh, for example, our pharmacist is a Sikh so he can focus on their background and kind of knows where they're coming from when they're asking about if it (their medication) is suitable’ (Participant 2).

Theme 3: Educating and training cultural competence within the pharmacy professionPerspectives on current cultural competence training

There was a consensus amongst participants involved in this study that their education and training were lacking in topics encompassing cultural competence and its place within the pharmacy profession. Some pharmacist participants stated that they remembered receiving some cultural competence training once they had qualified, but this was included as part of a ‘bigger topic such as Equality &Diversity or Protected Characteristics’ within the workplace environment (Participant 7). These perspectives around the paucity of cultural competence training were shared with other community pharmacy staff, where one counter assistant stated that ‘you just sort of have to deal with it yourself, you don't really get any training on that’ (Participant 3). In fact, there was a common opinion that due to the lack of cultural competence training within professional teaching, it was necessary for individuals to educate themselves on cultural competence. One pharmacist reported ‘this thinking wasn't built into our teaching really. It wasn't er something we were taught; it was just a good thing for you to look up in your spare time’ (Participant 1).

All interviewees regarded cultural competence as a necessary and important skill and all were in agreement that some form of education should be built into pharmacy staff training. One pharmacy technician stated ‘I think whoever you are, if you are talking to members of the public who come into the pharmacy or are someone who speaks to patients, you should have gone through a minimum level of training on cultural competence’ (Participant 8). However, across the different job roles within community pharmacy, there was a mixed consensus on who should receive cultural competence training and to what level/depth. Almost all participants felt that cultural competence training should be provided for counter assistants, with one participant stating ‘a person walks in and the first people they'll speak to is the counter staff’ (Participant 5). It was acknowledged that if counter assistants were not trained on cultural competence, ‘it may affect the treatment of a patient and could potentially impact how much a patient will use the pharmacy or whether they come back or feel comfortable even coming in(to the pharmacy)' (Participant 1). When discussing their perspectives, a pharmacy dispenser expressed that pharmacists ' are the main people who are giving advice out so if they're not competent in what they're saying (pause), then it's not going to help the situation' (Participant 2).

Despite acknowledging the importance and place of cultural competence training, a number of participants suggested that the profession of pharmacy, as a whole, has unmet needs around the training and delivery of culturally competent patient care. One participant mentioned that, following the Black Lives Matter movement, they have requested additional training on cultural competence from their employer to improve their knowledge. Another reflected on the growing discussion of equality and inclusivity in wider society, stating that 'the (COVID-19) pandemic was what brought the whole issue about inequalities to light in my mind, and since then I've been thinking about what it means for these patients from other communities' (Participant 13).

… I don't think, personally, as a profession, we're prepared really. And we don't have that awareness –I certainly don't feel like I'm optimally prepared for dealing with situations where I have a lack of knowledge about someone's ethnic background. It's actually something that I've requested at work is some training around it. (Participant 5)

Suggestions for the delivery of cultural competence training

Participants gave suggestions on how cultural competence could be incorporated into formalised training for each professional group. The training for counter assistants was described involving 'booklets at the start… which you had to complete, and you had so long to complete them. And if you pass them, you're classed as a counter assistant' (Participant 3). The same participant went on to mention that 'it [cultural competence training] should be in the booklet when you initially start, and that should definitely be covered in the booklet' (Participant 3). Another counter assistant held a different opinion and suggested that 'if it was in a training handbook like where you watch videos and answer quizzes, then people maybe wouldn't take it seriously. Er, like people might do the quiz and not actually care or take it in as actually being important' (Participant 12). They reflected on the potential for variation in the population of each pharmacy, dependent on geographic location, as well as postulating a constant, dynamic change in 'people living nearby, "cos those trends of communities choosing to live in a certain area might change"' (Participant 12). When asked about what should be taught within this training, it was proposed that a basic understanding and awareness of different cultures should be taught 'I think just explaining what it (cultural competence) is and maybe an idea on how different backgrounds, you know, different people –their views on sort of… pharmacy and medicines and things like that' (Participant 3).

There was a suggestion made that it may be beneficial to teach cultural competence training separately within the different professions and tailoring the training towards each professions' specific roles within the pharmacy. A dispenser proposed that 'if everyone's taught separately but on the same kind of guidelines, so it (cultural competence training) kind of factors in their different job roles… then it's helpful if it's got some examples of what we can do, personally, relevant to us' (Participant 2).

Every pharmacist interviewed agreed that cultural competence training should be taught within the undergraduate Masters of Pharmacy (MPharm) degree; however, there were differing perspectives on the value it holds within the degree's curriculum. One pharmacist remarked 'I think it should be taught, I think it's core, it's just as important as learning about pregnancy and drugs in pregnancy… it needs to be included in the curriculum' (Participant 5). As well, participants discussed the need for cultural competence to underpin the entirety of their learning, rather than only featuring in one part of the degree. There was a particular emphasis on introducing 'this way of thinking' from the first year of the degree, with one foundation trainee pharmacist discussing the value in having 'these types of discussions or training from like an earlier stage, and from a younger age at university… that would be good as opposed to leaving it until you're in the workplace like I am now' (Participant 14). While other pharmacists recognised its importance, they considered the logistics of integrating cultural competence training within the greater context of the MPharm degree curriculum and acknowledged that there may be limited room to include this training. One pharmacist stated that cultural competence training should be 'definitely part of it [the MPharm]. I don't know if I'd say a big part. Er (pause) not because it's not important –just thinking more in terms of how you'd fit it all in' (Participant 6).

Pharmacists offered suggestions on how cultural competence training could be delivered within the MPharm degree. The most frequently mentioned methods considered adopting an integrated approach to teaching, for example, through the inclusion of ethnic minority patients within workshops, patient-case examples and observed structured clinical examination stations, as well as exposing students to working with people from ethnic minority communities on placements.

In case studies when you're doing seminars, you should ensure there's varied names and ethnicities used in patient examples. Perhaps trying to encompass it more into placements as well, where you are actually in real-life examples, so you've got real-life patients and are seeing varied cross-sections of the population in placements. You could potentially look at patient sessions where you bring patients in and getting different backgrounds to talk about their experiences. (Participant 7)

Two participants contemplated that, rather than training students on cultural competence, the aim of the MPharm teaching should be to instill an open-minded and inquisitive attitude in students for whenever they engage with people from ethnic minority groups. These participants argued that giving cultural training would not be appropriate, with one stating ‘to sit down and have a lesson and say, “This is how you speak to someone who's Muslim” or “This is how you speak to someone who is from this ethnicity” –I think that's patronising’ (Participant 1).

I think it's really important that students don't become stereotypical and judge people and assume based on the way that someone looks, that they have a certain belief. I think it's more about students being open-minded (pause) and having the ability to ask these questions… I just feel that's a skill we need to get rather than understanding all the nuances of different cultures cos you can't teach that –it's not possible. It's more about giving them the skills and then once they work in practice, they deal with the communities that they encounter. (Participant 4)

DISCUSSION

This study builds on the limited evidence that focuses on the perspectives of community pharmacy staff surrounding cultural competence training. By exploring the perspectives of members of staff across the entire skill mix of community pharmacy, this study (i) sheds new light on staff perspectives on cultural competence training and (ii) offers unique suggestions on how cultural competence training should be taught and delivered to all members of the community pharmacy team. This study collected the perspectives from representatives of all community pharmacy staff members: pharmacists, technicians, dispensers and counter assistant staff; an approach that is unique to this study with these views previously being under-reported within healthcare research.

A consistent finding across all interviews reported an increase in the ethnic diversity of people accessing community pharmacies, hence recognising the greater need for community pharmacy staff to adopt an inclusive approach towards meeting the needs of their ethnic minority patient groups. This echoes the findings from previous work[11,23] and has been highlighted even more following the COVID-19 pandemic.[34–36] Ethnicity-related health inequalities are a well-researched area, with numerous studies reporting a lack of patient engagement with services and variable treatment outcomes in patients from ethnic minority groups, compared to their White counterparts. Multifactorial reasons for this have been recognised, including perceived distrust in the healthcare system, lower health literacy, limited access to timely care and language barriers[12,37–39]; initial strategies to overcome such challenges, specifically within community pharmacy, have been identified in this study.

Echoing previous studies,[40,41] communication difficulties and language barriers between patients and healthcare professionals were perceived as a key challenge in achieving inclusive patient care within community pharmacy settings. Interestingly, encounters with non-English speaking patients were also a major concern amongst other healthcare professional groups.[42] Previous work revealed that computer-based translational resources were perceived as easily accessible and helpful within American community pharmacy, but were infrequently used.[43–45] ‘The Written Medicine,’ is a new UK web-based software that has been developed to tackle this issue through bilingual prescription labels, including English alongside the person's native language.[46] Future research should explore the uptake and utilisation of such software within community pharmacies.

The use of interpreters was also a recognised approach to overcoming communication difficulties between patients with Low-English Proficiency and members of the pharmacy team. Interpreters were also important for providing high-quality care to these patients. Although the use of professional interpreters has been acknowledged as beneficial to facilitate healthcare consultations within outpatient clinical settings,[47–50] there has been a longstanding historical challenge to accessing interpreters within community pharmacies.[51–53] Research on facilitating access to interpreters and exploring pharmacy team experiences with interpreters could result in the sharing of best practices, to improve culturally competent and medicines-focused communication.

While participants recognised the significance of cultural competence training, they reported very little to no experience of having cultural competence training within their professional education. Results from this study echo the wider literature,[54,55] which recognises the importance of integrating cultural competency into the training of pharmacy staff. In 2021, the Center for Pharmacy Postgraduate Education launched a learning campaign on ‘Culturally competent person-centred care’, designed for pharmacy professionals.[56] At present, research has yet to be done to evaluate the impact or uptake of this amongst postgraduate, qualified pharmacists. Further, limited work exists to explore the perspectives of student and trainee pharmacists on cultural competence within their initial education and training; future studies should seek to address this to close the gap between training at undergraduate and postgraduate levels.

A key relationship was identified between participant ethnicity and their views on the importance of cultural competency, with its training being deemed important by all White participants who were interviewed. However, two participants who self-reported as being from an ethnic minority group themselves (from Chinese and Pakistani backgrounds), hinted that cultural competence training does not necessarily need to be a key part of professional training. Several White participants stressed the importance of this training as, within their practice, they often worry about unintentionally using the incorrect language/terminology.[57,58] This study offers a new finding that White healthcare professionals may regard cultural competence training as more important than those from ethnic minority backgrounds; further research is needed to explore whether this is the case and identify reasons why this may exist.

The researcher acknowledges that there were some limitations to this study. While efforts were taken to ensure an equal split in job roles amongst the participants, the majority were pharmacists (n = 8). Future studies should seek to further explore the perspectives of the wider roles within community pharmacy teams. The most common ethnicity amongst the participants was White, British; to make this study more representative, the perspectives of staff members from underrepresented ethnic communities need further investigation. In doing so, this may help to determine if culture plays a part in how cultural competence and training are perceived.

Perspectives of community pharmacy staff have been reported within this study. Future studies could investigate the perspectives of underrepresented ethnic patient groups on how they believe cultural competence training should be delivered to community pharmacy staff, to allow a cooperative approach to re-evaluating the training strategies.[59] Previous studies have reviewed co-production and co-design approaches to tailor health services to the needs of its users.[60,61] Therefore, including the perspectives of people from underrepresented ethnic groups would allow their lived experiences and suggestions to be considered when formulating and reviewing cultural competence training for community pharmacy staff. Furthermore, research could be widened even more, by exploring perspectives on how cultural competence teaching can be promoted to address the needs of other seldom-heard communities.

Researcher positionality and reflexivity statement

When conducting research on cultural competence and its wider connection to ethnicity, it is important to acknowledge the positionality and reflexivity of the research team. Authors J. McC (an undergraduate student pharmacist), A. H. (a professor of clinical pharmacy practice), A. T. (a professor of pharmaceutical public health) and A. R.-B. (a doctoral researcher, with a specialist interest in medicines-related inequalities) recognised their privilege as nonethnic minority UK citizens and act as allies in addressing inequalities within pharmacy practice and wider health care delivery. Authors W. M. L. and S. V., and patient champions L. S. and A. K. D., self-reported as being from an ethnic minority community; they ensured cultural appropriateness and sensitivity throughout the entire research process.

CONCLUSION

Cultural competence is important for community pharmacy staff to develop, due to the increasing patient diversity they encounter. As pharmacists and counter assistants are primarily patient-facing roles, cultural competence training should be an essential part of their professional training. Interactive, informal teaching to encourage an open-minded attitude towards cultural differences, was preferred over structured, information-based sessions. Future research may seek to further explore the integration of cultural competence training with undergraduate pharmacist initial education and training, as well as postgraduate learning programmes. Research opportunities into co-production and co-design strategies between trainees and training organisations could improve the design of cultural competence training. Additionally, the perspectives of patients from ethnic minority communities could provide valuable insight and offer recommendations on the cultural competence training delivered to pharmacy professionals, and wider.

AUTHOR CONTRIBUTIONS

Jessica McCann led on the day-to-day running of the project, data collection and writing of this manuscript. Anna Robinson-Barella and Wing Man Lau oversaw the running of this project as principal investigators and provided project management expertise. Anna Robinson-Barella, Andy Husband and Adam Todd provided qualitative methodological input and expertise. Anna Robinson-Barella and Andy Husband supported the recruitment of participants. Laura Sile, Sneha Varia and Amandeep Kaur Doll contributed to their appointment as ethnicity champions and ensured cultural appropriateness and sensitivity throughout the entire research process. All authors read, provided comments on and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

Ethical approval was obtained from the Newcastle University Research and Ethics Committee (reference: 25680/2022) and research governance was followed in accordance to Newcastle University research policies. There were no patients involved in this study; it was conducted to gather the perspectives of healthcare professionals (and signed consent was gained at study enrolment).

DETAILS

Subject:	Health disparities; Minority &ethnic groups; Technicians; Health care; Cultural competence; Health care access; Training; Profession; Community pharmacists; Pharmacists; Pharmacies; Ethics; Data management; Public involvement; Design improvements; Pharmacy services; Cultural sensitivity; Ethnic factors; Patients; Pharmacy; Trainees; Ethnic groups; Health services; Teams; Citizen participation; Co-design; Clinical outcomes; Minority groups; Drugs; Professional training; Interviews; Medical personnel; Multiculturalism &pluralism; Qualitative research
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Document 27 of 30

#TreatmentResistantDepression: A qualitative content analysis of Tweets about difficult-to-treat depression

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ProQuest document link

ABSTRACT (ENGLISH)

Introduction

Treatment-resistant depression (TRD) is depression unresponsive to antidepressants and affects 55% of British primary care users with depression. Current evidence is from secondary care, but long referral times mean general practitioners (GPs) manage TRD. Studies show that people with depression use Twitter to form community and document symptoms. However, Twitter remains a largely unexplored space of documented patient experience. Twitter data could provide valuable insights into learning about primary care experiences of TRD. In this study, we explored Twitter comments and conversations about TRD and produced patient-driven recommendations.

Methods

Tweets from UK-based users were collected manually and using a browser extension in June 2021. Conventional content analysis was used to provide an overview of the Tweets, followed by interpretation to understand why Twitter may be important to people with TRD.

Results

A total of 415 Tweets were organised into five clusters: self-diagnosis, symptoms, support, small wins and condition experts. These Tweets were interpreted as showing Twitter as a community for people with TRD. People had a collective sense of illness identity and were united in their experiences of TRD. However, users in the community also highlighted the absence of effective GP care, leading users to position themselves as condition experts. Users shared advice from a place of lived experience with the community but also shared potentially harmful information, including recommendations about nonevidence-based medications.

Conclusions

Findings illuminate the benefits of the TRD Twitter community and also highlight that the perception of a lack of knowledge and support from GPs may lead community members to advise nonevidenced-based medications.

Patient and Public Contribution

This study was led by a person with lived experience of TRD and bipolar. Two public contributors with mental health conditions gave feedback on our study protocol and results.

FULL TEXT

INTRODUCTION

A recent study showed that at least half of adult Internet users find and share health information on social media.[1] This information offers insight into how people understand and conceptualise their illness and communicate with others about their experiences.[2] Social media enables access to information that may not be easily collected with other methods.[3] For example, people with mental health conditions may not want to participate in interviews or focus groups because it can surface traumatic experiences.[4] However, people often do share their mental health publicly on social media.[1]

Twitter is one of the most popular social media sites, with a global reach of ~19.05 million users as of October 2021.[5] Twitter is a microblogging social media site where users can send 280-character messages or ‘Tweets’. Twitter profiles are public, except for users who have set privacy settings. This is compared to Facebook, where users tend to have private profiles and mostly interact with friends and family.[6]

Evidence shows that mental health can improve by talking to friends and family.[7] Therefore, it is reasonable to assume that Facebook would be an appropriate social media for mental health discussions. In qualitative studies, however, people have said they prefer Twitter. For example, in Berry et al.'s study,[8] participants perceived people on Twitter to be more authentic and less judgemental about mental health. This suggests that there would be more discussion on Twitter about treatment-resistant depression (TRD) than on other social media.

Studies have focused on the potential associations between depression and increased Twitter use. For example, a recent quantitative study found that excessive Twitter use was associated with depression among university students.[9] A regression analysis also found associations between mental health crises and the consumption of Twitter mental health content.[10] However, in qualitative studies, people with mental health conditions have reported using Twitter to form a community, document symptoms, and safely express themselves.[8] These findings illustrate our limited understanding of the relationship between Twitter and mental health. Twitter could be a valuable resource for learning about this relationship. Users often Tweet complex, in-the-moment experiences they might not recall in interviews.[11]

Mental health Twitter studies have focused on hashtags like #MyDepressionLooksLike,[12] #WhyWeTweetMH,[8] #DearMentalHealthProfessionals[13] and #Schizophrenia.[14] In these studies, people Tweeted about medication, crisis planning and service provision. However, it is unclear if these Tweets transfer to TRD. TRD is depression that does not respond to antidepressants[15] and is consistently linked to high economic burdens due to the increased use of health services, increased cost of care, poor quality of life and loss of productivity.[16–18] Approximately 55% of UK primary care users have TRD.[19] People with TRD should be referred to secondary care, but long wait times prevent this from happening.[20,21]

There is limited guidance for general practitioners (GPs) on managing TRD,[21] and people with TRD have described dissatisfaction with GP care.[22] Therefore, it might be important to investigate how to improve health experiences and how GPs can be supported in caring for these people. Much research on TRD has focused on secondary care, despite the long wait times mentioned above.[22] This may mean that a large cohort of people with TRD is not reflected in the research. This study addresses this research and service gap. Tweets could provide feedback about how people experience primary care mental health services.

Twitter is increasingly used in clinical training and continuing professional development. For example, a qualitative study found that GPs sometimes read #TipsForNewDocs to improve their knowledge of the patient experience.[23] A systematic review also found that health-related Tweets were described as useful when incorporated into undergraduate education and continuing professional development.[24]

This study presents a qualitative content analysis[25] of Tweets about TRD. We aimed to identify *what comments and conversations are posted on Twitter about TRD*. Understanding the content people with TRD share on Twitter could support GPs and researchers in understanding people's experiences.

METHODS

A patient-led methodology[26] was used, meaning it was led by A. T., who has lived experience with TRD and bipolar.

Data collection

A. T. (a female, young adult, PhD student and qualitative researcher) developed a search strategy using synonyms for TRD found in Brown et al.'s systematic review.[27] Synonyms included: ‘chronic’, ‘complex’, ‘difficult to treat’, ‘enduring’, ‘life-long’, ‘long-term’, ‘major’, ‘multiple episodes’, ‘persistent’, ‘recurrent’, ‘relapse’ and ‘treatment-resistant’. The strategy was discussed via email with two public and patient contributors (PPI) with mental health conditions. PPI additionally suggested including terms with and without hashtags.

A. T. entered search terms into NCapture,[28] a web browser extension that gathers web content for direct importation into NVivo.[29] NCapture[28] was not gathering sufficient Tweets, collected mostly research and retweets and could not capture replies. Therefore, A. T. stopped using NCapture and supplemented data with a manual method of collecting Tweets, which she called ‘Tweet-Chasing’. This involved looking at the original users' feeds (identified through NCapture) and then collecting relevant data from (a) their interactions with others, (b) those other users' feeds and (c) those other users' interactions. A. T. uploaded relevant Tweets identified through Tweet-Chasing into NVivo.[29] A. T. collected replies to Tweets where the user had reported in the Tweet or their biography (bio) that they had TRD.

A. T. collected Tweets using NCapture[28] on 30 June 2021, with 6431 Tweets collected. A total of 6384 of these Tweets were excluded (see next section for inclusion criteria and results for reasons for exclusion), leaving 47 eligible for analysis. A. T. collected an additional 368 Tweets via Tweet-Chasing between 20 July and 2 August 2021. The final sample was 415 Tweets, comparable to the amount used in similar studies.[8,30–32]

A. T. followed a pragmatic approach to sampling,[33] stopping during analysis when she interpreted there to be adequate data to support findings within the practicalities of the research. A. T. did not use saturation because she believes researcher subjectivity means that new interpretations can always be made.[33]

Exclusion criteria

A. T. excluded Tweets manually against the following criteria:

- 1. Advertisements (including for research).
- 2. One word or hashtags. It would be difficult to extract meaning from these Tweets.
- 3. Private profile.
- 4. Published outside of the United Kingdom (and non-English language). We focused on the United Kingdom because of the different cultural contexts pertaining to healthcare (e.g., private healthcare in America). Users can report locations in bios; an approximate location is reported on NCapture.[28]
- 5. User is a health, governmental or charitable organisation.

- 6. User is suspected to be <18 (e.g., mentions Child and Adolescent Mental Health Services).

Search terms were excluded during Tweet-Chasing, where users reported living with TRD in their bio or prior Tweet. This ensured that contextually relevant Tweets were collected. Demographics were not collected as they were not reported in bios. Likes and retweets were ignored as our question was not about Tweet popularity. Replies were collected as part of Tweet-Chasing if the user had reported living with TRD in their bio or previous Tweet. There was no date limit on Tweets. We made this decision because we were likely to find Tweets from the past few years, as Twitter limits how far you can go into the archives. The full search strategy can be found in the registered report.[34]

Analysis

A. T. coded the Tweets qualitatively using Hsieh and Shannon's[25] conventional content analysis. This inductive method involved developing ‘descriptive clusters’ to provide condensed descriptions of the contents of Tweets.[25] The process involved: (i) reading the Tweets and noting down initial ideas/codes; (ii) coding each Tweet in NVivo[29] descriptively, with some Tweets coded twice if they contained multiple meanings; (iii) checking that each Tweet was coded appropriately; (iv) merging similar codes into clusters; (v) calculating how many Tweets were coded for each cluster and (vi) writing up these clusters. Consistent with conventional content analysis,[25] we did not contextualise the clusters with existing literature until the discussion.

A. T. interpreted the descriptive clusters using the One Sheet of Paper (OSOP) method.[35] The OSOP[35] involved mind mapping all codes and their relationships on OSOP to identify the line of argument across clusters. Deviant cases were included in the OSOP. A. T. created one latent (interpretative) cluster from the OSOP method that described why Twitter might be important to people with TRD. Coding was developed iteratively with feedback from all authors and PPI. All authors agreed with the final clusters.

Our ontological approach was grounded in critical realism,[33] following a view that there is one social reality, but subjectivity limits our understanding of it.[36] The team followed Ahuvia's[37] conception of content analysis, which states that content analysis is interpretive, not simply descriptive, as the researcher's subjectivity makes pure description impossible. This means that our resulting descriptive clusters are not ‘counts of content’, but ‘counts of our interpretations’ of the Tweets.[37]

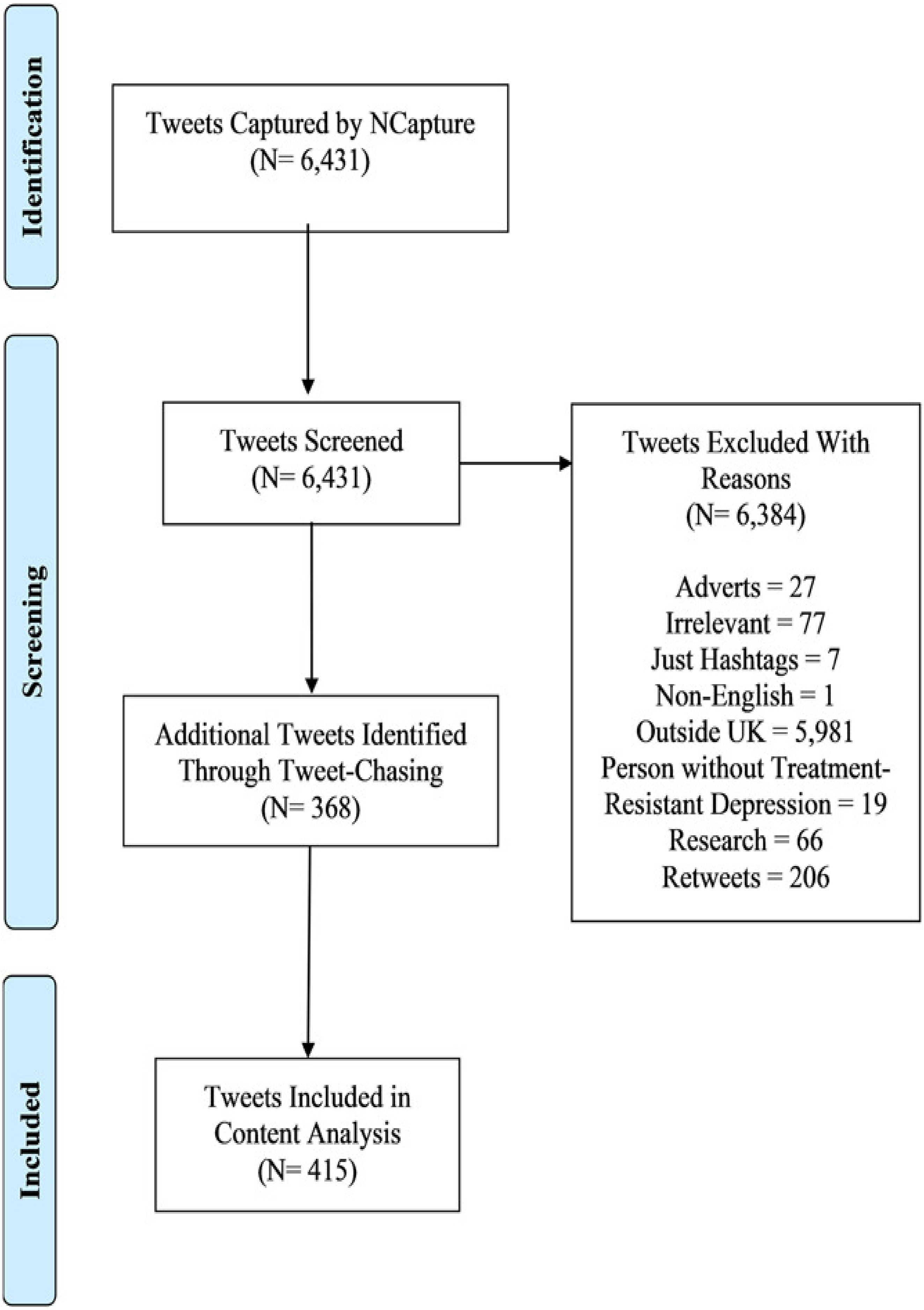
Ethical considerations

The University of Oxford approved this study (reference: R76585/RE001). The British Psychological Society[38] considers Twitter part of the public domain, where users can expect to be used in research without consent. We decided that because Tweets are public, does not mean users give up their privacy. We developed a careful plan with PPI to safeguard users. The plan included removing identifiers and paraphrasing Tweets in a way that retained their original meaning. A. T. re-entered paraphrased Tweets into Twitter to ensure they could not be traced back to users. This approach is congruent with similar studies.[8,30,31]

The team also planned how to safeguard any users expressing suicidal ideation. We reported these to Twitter so that users could receive crisis resources. Evidence shows that 14% of suicide-related Tweets require intervention.[39]

RESULTSDescription of tweets

Of the 6431 Tweets found by NCapture, we excluded 6384. The reasons for exclusion are shown in Figure 1. We Tweet-Chased 368 Tweets, totalling 415.



Enlarge this image.

Tweets were posted between December 2017 and August 2021 by 152 users. Tweets were posted between

December 2017 and August 2021 by 152 users. The longest Tweet was 240 characters, and the shortest was 20 characters (range = 220, mean = 182). Frequent words included depression (*N* = 389, 94%), treatment (*N* = 118, 28%) and resistant (*N* = 111, 27%). The most common synonyms for treatment resistance (*N* = 115, 27%) were life-long (*N* = 52, 13%) and chronic (*N* = 46, 11%).

Descriptive clusters

We developed five clusters to describe the Tweets: (1) self-diagnosis: I think I have TRD; (2) symptoms: I experience helplessness, exhaustion and suicide ideation; (3) peer support: I offer advice to others with TRD; (4) small wins: This is what I can do despite my TRD and (5) condition expert: I know my TRD best. Clusters are introduced with a number and percentage to demonstrate how many Tweets were coded for each cluster. Consistent with other conventional content analyses, we do not use numbers/percentages elsewhere.[8] The number of users who Tweet something does not show how insightful or important it is for answering our research question. Every Tweet in this section comes from a different user.

Cluster One: Self-diagnosis

We interpreted 26 (6%) of Tweets to relate to users self-diagnosing with TRD. Some users said that even if they had a ‘well-documented’ history of not responding to antidepressants, their doctors had not considered treatment resistance:

My doctor did not diagnose me [with TRD]. He was reviewing my antidepressant medication, and I was recounting my depression symptoms to him, with many years of well-documented history of depression treatment …Nobody has ever diagnosed me, but I understand my depression as persistent and treatment-resistant

Some users Tweeted that they were diagnosed with TRD. However, these users said that they knew they had TRD before being diagnosed:

Have just been diagnosed with TRD, which I already knew

A few users may have self-diagnosed TRD because of Twitter interactions:

Someone on Twitter suggested that my condition could be TRD. I got help and learned a lot about myself…

Users' reactions to self-diagnosis varied. Two users described the thought as ‘scary’ and ‘frightening’. Four users said it was a relief to have an explanation for why antidepressants were not working. A self-diagnosis helped these users reconcile with their symptoms and understand that their lack of response was not their fault:

TRD sucks, but when I learned about it, I felt relieved. Because when you do not respond to treatment, you start to think it is your fault for not trying hard enough

One user said it saved their lives to have an explanation for why antidepressants did not work:

It saved my life when I self-diagnosed myself with TRD. Knowing I may never respond to treatment, you may think it would make me feel worse, but actually, it was a relief

Cluster Two: Symptoms

We interpreted 148 (36%) Tweets as describing symptoms of TRD. Symptoms included exhaustion (*n* = 19), helplessness (*n* = 37), sadness (*n* = 31), self-harm (*n* = 40) and suicide ideation (*n* = 21). We describe each of these below. Many users described feeling helpless and, like their depression, would never improve:

Because of my depression, I feel like things will never change; I have lost hope about the situation; it's hard to look after myself

Some of these users mourned for a life without depression. The following user said that it hurt to imagine what their life would have been like had they not had depression and their other conditions:

I have fibro issues, chronic pain, and TRD. I think about the loss of what could have been, the little and big things… it hurts

Many users Tweeted about self-harm and suicide ideation. Several users described their self-harm methods, and others expressed their identity as a ‘suicide survivor’:

I am a suicide survivor. TRD is painful

Many users described feeling exhausted. Some of them wished their depression would end:

I am absolutely exhausted from my TRD; I wish it would stop; I wish it were not like this

A couple of users wished that people without depression would understand how much energy is required to do simple things (e.g., making a bed, brushing their teeth):

I have TRD. I wish normies [people without depression] would understand how exhausting it is and how much it takes to do simple things

Cluster Three: Peer support

We coded 81 Tweets (20%) as peer support. Most users shared how they managed their own TRD when providing peer support. Self-management included practising resilience and not watching potentially triggering movies:

TRD is dreadful, especially when you have those deep patches. It nearly claimed me too, but it will not and will not claim you either

Many users said that they had found a way to manage their TRD and told readers with the condition to ‘not give up’:

I have been living with TRD and anxiety since 2004. I finally feel stable with the right medication. I am getting better, do not give up

Direct messages were interpreted as an additional channel of support:

There are support groups that have helped me. Not sure where you are located, but here is the group I use [link]. DM me if you need help

Cluster Four: Small wins

We coded 62 (15%) Tweets as ‘small wins’—accomplishments that might seem easy, but they are significant when considered in the context of cluster Two (symptoms). Indeed, users appeared to experience severe, debilitating symptoms. Yet, they were still able to achieve ‘small wins’ like getting out of bed, going outside, or doing something that made them anxious:

I have TRD, and it gets worse without human contact. But I am doing well, considering. I have a lot of hobbies, and I tidied most of my house today

Many users appeared to feel proud of their progress with their TRD. They described working for a long-time to become well-managed. This success was illustrated with words like ‘proud’ and ‘I did it’:

I have had TRD for years. I have worked very hard on my mental health. Proud to say my mental health is the best it has been in some time

Users decided to complement their antidepressants with self-reflection, counselling or mindfulness. It was unclear whether health professionals offered these alternatives:

I got my TRD well-managed with antidepressants, counselling, lifestyle change, and mindfulness

Another small win was accepting depression as a potentially long-term condition. One user said their support network helped them achieve acceptance:

I have had TRD for most of my life. In the last couple of years, I have come to a place of acceptance and peace that I did not think possible. I have an excellent support network who have helped me

Cluster Five: Condition expert

We perceived 40 users (10%) as viewing themselves as experts on self-diagnosing and coping with TRD. We interpreted the lack of perceived quality GP care as why users established themselves as condition experts. For example, referring back to Cluster One (self-diagnosis), users mentioned wanting an explanation for why antidepressants did not work. When GPs (and other health professionals) did not explain and continued with recurrent antidepressant prescribing, users took on the role of diagnosis and self-diagnosed TRD:

I was told by my therapist that my doctors finally recognise TRD, even though this is how I have understood my depression for some time

The condition expert role also manifested in regards to treatment. For example, some users said they decided to stop taking antidepressants after trying ‘every single antidepressant the NHS can give’. One user perceived themselves to no longer be treatment-resistant after stopping antidepressants. It was unclear whether this user spoke to their GP about this decision, and we do not know if their recovery was linked to stopping antidepressants:

I decided to stop taking my antidepressants and am cured of my TRD

This establishment of being a conditioning expert resulted in many users sharing their expertise with other users. Some of these Tweets relate to Cluster Three (peer support), where users shared what they did to manage their TRD. A couple of users, for example, shared how their symptoms reduced with St John's Wort (herbal medication). Although there are risks to self-prescribing,[40,41] it was evident that a lack of support from GPs led users to take these medications and give and receive medical advice:

How about St John's Wort? I tried it, and it really has helped my depression. I found it all by myself. Not sure my GP knows it exists…

Indeed, many users described not having any choice but to become condition experts and manage their treatment on their own when their GPs offered no support beyond antidepressants:

I have come to realise that many GPs are dumb; you really have to advocate for your own body and needs

There were benefits from users sharing their experiential expertise, including reflections on TRD improving over time (Cluster Three). However, most users described wanting to combine their experiential expertise with the clinical expertise of a GP. These users described rejecting the advice from GPs who told them to ‘get over’ their depression and searching for GPs who understood appropriate treatment pathways for TRD:

I changed my GP several times. They kept saying I should ‘get over it’ and ‘pull myself together’. I cannot be treated by someone who doesn't understand the situation

Latent cluster

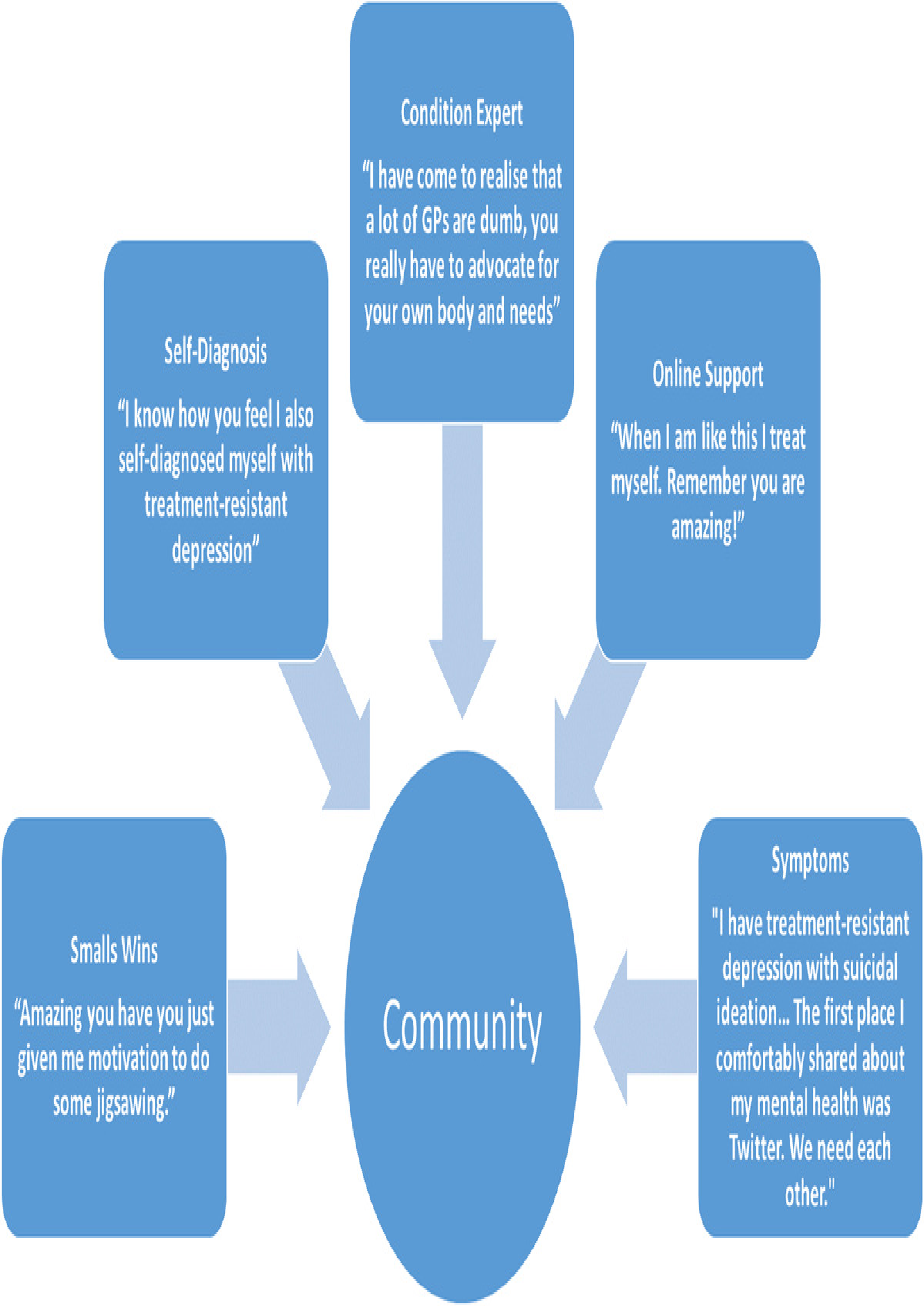
Our interpretation of descriptive clusters showed that Twitter could be a community for people with TRD. Users could connect, form new friendships, ask and receive advice and share experiences with GPs and other health professionals. This interpretation is captured in the latent cluster ‘supportive community’. The majority of Tweets in this section contain ‘@username’. The @ sign indicates a response to a user/Tweet. We interpreted these @s as a sign of mutuality and engagement with the community.

Latent cluster: Supportive community

Analysis of the descriptive clusters highlighted Twitter as a positive and supportive community for users with TRD (Figure 2). There are many online communities where users promote harmful content and misinformation.[42–45] However, we interpreted the users in this community as friendly, empathetic, and helpful. These community users are described as valuable in the absence of GP care, saying, for example, ‘This community is incredible’ and ‘I love this community’. Some evidence was latent within the text. For example, several users used the word ‘we’, which we interpreted as signifying reciprocity with other users. Several Tweeted, ‘We need each other’, ‘We've been there’, and ‘We're here for you’. Users foregrounded how Twitter enabled them to connect with a wider community of people with TRD and access support:

@username. Thank you for Tweeting this when you are so feeling low. If you want to talk, just DM me. I am feeling very depressed too. We are here to listen

@username. I also have TRD. I have tried every antidepressant. I find it hard to talk about, but I just want to send you love



Condition Expert

"I have come to realise that a lot of GPs are dumb, you really have to advocate for your own body and needs"

Self-Diagnosis

"I know how you feel I also self-diagnosed myself with treatment-resistant depression"

Online Support

"When I am like this I treat myself. Remember you are amazing!"

Smalls Wins

"Amazing you have you just given me motivation to do some jigsawing."

Community

Symptoms

"I have treatment-resistant depression with suicidal ideation... The first place I comfortably shared about my mental health was Twitter. We need each other."

Enlarge this image.

Twitter was described as a place for users to share their experiences, ask for help, gain and offer support. Indeed, many users described using Twitter to connect with like-minded people and access support they might not have had access to elsewhere. Several of these users used words like ‘thank you’, which we interpreted as users being grateful for the supportive community that Twitter can provide:

Thank you to everyone who responded to my previous Tweet about my depression. I was nervous to Tweet about something so personal, but Twitter is supportive, and this community is incredible. Thank you, it means the world to me

Users described feeling comfortable engaging and receiving support from the Twitter community. They said that Twitter was the only place they felt comfortable talking about their TRD:

I have TRD with suicidal ideation, anxiety, panic disorder, ADHD, and alcoholism. The first place I openly and comfortably shared about my mental health was Twitter. We need each other

Users also appeared to be comfortable sharing their experiences with GPs for TRD on Twitter. For example, one user said their GP refused to refer them for their self-diagnosed TRD. Among the responses: ‘What?!’, ‘Report that’ and ‘I experienced the same thing!’ This perception of poor quality GP care led to users positioning themselves as condition experts responsible for diagnosing and treating TRD, as discussed in Cluster Five (Condition Expert). Users' role as condition experts seemed to make them comfortable with sharing and receiving advice, including groups, hotlines and crisis resources:

@username. Have you tried the Samaritans? They are great at snapping you out of suicide ideation

@username. When I am like this, I treat myself. Remember, you are amazing

These self-management tools are evidence-based and recommended by the UK National Institute for Health Care Excellence guidance.[46] However, users also sometimes shared and encouraged other users in the community to take potentially unsafe, nonevidenced-based medications (e.g., St Johns Wort; Cluster Two), abruptly stop taking antidepressants (Cluster Five) and incorrectly diagnose themselves with TRD (Cluster One). This means that while users in the community were kind and supportive, some Tweets contained harmful content and could expose users to potentially dangerous information.

Reflexive statement

The Tweets in our analysis come from users with TRD. A. T., who is part of the Twitter TRD community, suggest that users could also be exposed to harmful information from noncommunity members. Indeed, A. T. has received Tweets about nonevidence-based pseudoscientific diets and medications in response to some of her Tweets about TRD. A. T. usually ignores these Tweets and blocks the user, but it is unlikely that every user with TRD will do the same. Indeed, you may be willing to try anything when you live a severe, life-limiting condition like TRD (Cluster Two). A. T.'s experiences are supported by an interview study by Morris et al.,[47] who found that social networks influence perceived support needs and attitudes to self-management.

CONCLUSIONS

Our qualitative study shows that people with TRD experience the Twitter community as positive and supportive. Twitter can help people connect with others and access support anytime and when they do not receive care from GPs. These findings are consistent with studies on mental health generally[8] and non-TRD.[12] People asserted themselves as ‘condition experts’ expressing dissatisfaction with care from their GPs. In asserting this expert role, members of the TRD community suggested medications to each other that were untested, unsafe and nonevidenced based. This included information regarding St John's Wort, which has mixed evidence for its effectiveness and safety for major depression.[48]

This role of the condition expert seemed to result from perceived low quality and lack of GP care. Indeed, most users described taking responsibility for diagnosis and treatment when GPs ignored their nonresponse to antidepressants. This absence of GP care resulted in some users self-diagnosing and encouraging others to self-diagnose TRD (Cluster One). Giles and Newbold[49] found that self-diagnosis after interacting with social media is common among people with mental health conditions. Self-diagnosis was described as helping some users reconcile with their nonresponse—supporting Lewis's[50] interview study on self-diagnosed autism. However, self-diagnosis can also be dangerous because of the associations between self-diagnosis and medical misinformation, health anxiety and misdiagnoses.[51] This self-diagnosis, if accepted by clinicians, could escalate into more serious, incorrect and intensive treatments like ketamine which can be costly to the NHS and cause side effects like headaches, fatigue and increased suicide ideation.[52]

The lack of GP support beyond recurrent antidepressants might result from the term TRD not being commonly used in primary care and may be thought to describe those in secondary care.[15] Yet, as the authors have said in a previous paper[22] and have been told by others working on TRD,[15,53] many people in primary care continue having inadequate responses to antidepressants and describe the feeling that the term usefully describes their symptoms. Without GP care, people may turn to the Twitter community for support which could expose them to both supportive and harmful information. GP training and continuing professional development may support GP awareness of TRD and help them become familiar with appropriate treatment pathways beyond recurrent antidepressants. More active management of people with TRD may also improve outcomes for this group.[15]

We interpret Twitter as both advantageous and disadvantageous to people with TRD. Users can find support and community anytime while exposed to a potentially inaccurate self-diagnosis and encouragement to withdraw antidepressants and try nonevidence-based medications. These interpretations align with Susi et al.'s[54] systematic reviews that found viewing self-harm images online can have harmful (encouragement to self-harm) and protective effects (access to peer support). Susi et al.'s[54] study and ours show the importance of GPs assessing an individual's access to images and information related to TRD, self-harm and suicide.

Users clearly valued the community aspect of Twitter, reflecting people's experiences with offline mental health communities.[55] These communities value and allow people to share their experiential expertise, but the information shared is usually moderated to address potentially distressing and nonevidence-based information.[55] GPs may wish to encourage people to join local support groups to be involved with a moderated, supportive community.

Our study was exploratory, so we did not use theory. However, our results may show that an advantage of using Twitter is that users with TRD can increase their social capital. Social capital posits personal relationships as resources that increase human functioning.[56] Social capital can be lower among people with depression, resulting in fewer social connections and fewer opportunities for support.[57] Our study showed how users could form new social connections with people with TRD on Twitter. Many users described their relationships with community members as supportive and reassuring. This kind of support, some users said, was not available elsewhere. Our interpretations are supported by a quantitative content analysis of online depression forums by Pan et al.[58] Again, offline community groups may contribute to the growth of social capital in a safe and moderated environment.[59]

Strengths and limitations

We have contributed to the small qualitative literature base on TRD and primary care.[22] NCapture did not identify relevant tweets, so we developed the 'Tweet-Chasing' method. We perceive this method as useful for future Internet-mediated research. We used conventional and latent content analysis. This method allowed us to summarise and develop depth and meaning from the Tweets rather than operating at just the surface level. This study was led by A. T., a person with TRD and bipolar who has experienced Tweeting about mental health. A. T.

perceived her experiences as a useful tool for interpretation.

On limitations, Twitter has a 280-character limit, so Tweets lack context and may have been misinterpreted. Tweets were posted between December 2017 and August 2021, but some relevant Tweets will have been missed. Researchers have suggested that negative experiences can be more heavily weighted in Twitter studies.[30] The cluster ‘small wins’ shows that users Tweet positively about their TRD, so this limitation does not necessarily apply. There may have been recall and social desirability bias. Tweets were from active users, so we cannot learn from or understand the reasons why some people may have left Twitter. It is unknown whether users' self-diagnoses of TRD align with clinical definitions. This research was conducted before Elon Musk bought Twitter (October 2022). It is unknown whether Musk's purchase of Twitter has affected the community reported here. However, Twitter's monthly active users are growing.[60]

Conclusions

Our qualitative study of Tweets about TRD found that Twitter provides a positive, supportive community where people with similar illness experiences ask for and receive advice. Twitter can help people reconcile with symptoms and find community, supporting self-management in the absence of GP care. However, the advice shared was not always underpinned by evidence, and users sometimes recommended nonevidence-based medications. Our findings illuminate the benefits of the TRD Twitter community and also highlight that the perception of a lack of knowledge and support from GPs may lead community members to try and advise untested medications.

AUTHOR CONTRIBUTIONS

Amelia Talbot: Conceptualisation; data collection; formal analysis; funding acquisition; methodology; project administration; software; original draft; writing; review; editing. **Tori Ford**: External audit; review; editing. **Sara Ryan**: Funding acquisition; methodology; supervision; review; editing. **Kamal R. Mahtani**: Supervision; review; editing. **Charlotte Albury**: Funding acquisition; methodology; supervision; review; editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared due to using Tweets that could make individuals identifiable.

ETHICS STATEMENT

The study was ethically approved by the University of Oxford Medical Sciences Interdivisional Research Ethics Committee (Reference: R76584/RE001).

DETAILS

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Developing a Women's Thought Collective methodology for health research: The roles and responsibilities of researchers in the reflexive co-production of knowledge

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ABSTRACT (ENGLISH)

Background
Co-produced research holds enormous value within the health sciences. Yet, there can be a heavy focus on what research participants think, do and know; while the researcher's responsibility to explore and re/work their own knowledge or praxis tends to escape from view. This is reflected in the limited use of co-production to explore broad structural distributions of health and risk(s). We argue this missed opportunity has the potential to unfold as what Berlant calls a ‘cruel optimism’, where something desirable becomes an obstacle to flourishing and/or produces harm. We explore challenges to involving lay populations meaningfully in health research amidst a neoliberal cultural landscape that tends to responsibilise people with problems they cannot solve.

Methods and Findings
Drawing together principles from hermeneutic and feminist philosophy, we develop a novel methodology for co-producing research about determinants of health and health risk (using a case study of alcohol consumption as an example) that centres on what researchers do, know and think during research: *Women's Thought Collectives*.

Discussion
Keeping the constructed nature of social systems—because they shape ideas of value, expertise and

knowledge—in view during co-produced research illuminates the potential for cruel optimisms within it. Such reflexive awareness carves out starting points for researchers to engage with how social hierarchies might (tacitly) operate during the co-production of knowledge. Our work has broad utility for diverse population groups and provides important considerations around the roles and responsibilities for reflexive co-production of knowledge at all levels of health systems.

Patient or Public Contribution

The development of these ideas was sparked by working with lay participants during the Women's Thought Collectives for Kristen Foley's doctoral research 2021–2023, but undertaken without their direct involvement—in accordance with the responsibilities of researchers in the reflexive co-production of knowledge. Forthcoming publications will address the outcomes and processes of this work.

FULL TEXT

INTRODUCTION

It is clear that co-produced research should happen on topics about health[1–3] and it has become an expected feature of many health-related research grant applications and funding awards. The benefits of co-produced research are thought to have value across three axes[4]: (1) it builds relationships with people that live with the issues being researched; (2) develops more robust knowledge to inform interventions that will in turn be more effective or acceptable and (3) upholds an ethical mandate to broaden research participation and knowledge development. Much is written about how variations of co-production can achieve these values in practice.[2,5,6] Yet, there remains more focus in this research on what lay populations think and do, rather than consequences for health researchers such as how their values or relationship to the social order must be problematised and changed through these encounters.[7]

Co-produced research is desirable because it aims to explicate how power and health are unevenly spread across society (according to social hierarchies). Yet, researchers and the systems they work in (including various knowledge ‘economies’) are directly embedded in this unevenness. When the focus of co-production then is exclusively on what lay populations do (or do not do), it unfolds the potential for cruel optimsm—where something that is desirable because it will promote flourishing, instead, paradoxically prohibits or dissolves it.[8] When lay populations are only invited to participate in research in ways that fit research/er expectations and environments, it can risk situating them as problematic and dismiss their knowledge (ironically, the very potential for transformation)—while responsibilising them with the burden of solving complex multilevel research issues that require their insight in the first place. Reflexive awareness of the social systems in which health researchers are embedded, including the knowledges which shape perceptions of value,[9,10] is critical to guard against the unfolding of cruel optimism[8] during the co-production of knowledge in health research.

This manuscript discusses a novel methodology that aimed to enhance opportunities for lay women from different walks of life to co-produce research about health risks, without burdening them with problems they cannot solve: *Women's Thought Collectives*. This methodology was inspired by journalist Ariel Gore's[11] project to critique happiness through assembling a ‘council of experts’ who informed and reviewed her thinking about western cultural obsessions with happiness. She invited women to think alongside her about how happiness works (or not), when, how, and for whom—akin to Ahmed's[12] exploration of how happiness gets stuck to different objects and economies to various ends. The council helped collect data and shared their ideas (via keeping a journal), then were invited to contest, extend and corroborate her ideas about happiness over a period of 2 years. This type of co-production methodology could expand investigator knowledge over time while also giving participants space and time to adjust and inflect interpretations. Her book included limited methodological details, so rather than following her approach, we attempted to develop our own, although loosely based on her council of experts.

The flipped positioning of this approach places the researcher's learning, thinking and reflections in view and open to exploration by research participants. We explored how these ideas sat with key principles from hermeneutic and feminist philosophy, then developed a novel methodology for Kristen's doctoral research, which focused on illuminating the commercial determinants of alcohol consumption for Australian women in midlife. The purpose of our paper is fourfold.

- 1.
  Reflect on the flipped positioning of a council of experts methodology, which brings into view what researchers think, do and know (reflexivity) when co-producing research in health settings
- 2.
  Explore how contemporary feminist and hermeneutic philosophical thought might add to, or refine, methodologies for co-producing health research
- 3.
  Outline the *Women's Thought Collective* methodology which will be of use and interest to researchers in diverse health settings
- 4.
  Discuss how to pursue co-production research that *does* elevate the role of lay populations in research but *does not* reconstitute a cruel optimism by eliding roles and responsibilities for researchers during the co-production of knowledge.

We, therefore, distill key ideas from hermeneutic and feminist philosophy, then reflect on critical ethical considerations for health researchers to keep in mind when co-producing research in neoliberal settings—a cultural landscape that tends to reconstitute the problem and responsibility for solution[8] within groups and individuals already experiencing oppression. We hope that this structure will showcase the flow of ideas from the macro context of philosophy (presented in the methods) into the specific methodology developed (outlined in the findings) and residual questions (raised in the discussion) for co-produced research about upstream distributions of health resources and health risks.

We weigh co-produced research against its potential to enable different groups to exert control over knowledge as a resource and determinant of their lives and living conditions.[13] This focus on power and social structure illustrates the democratic and politically-motivated nature of co-produced research and demarcates it from 'cobiquity' where broad and diffuse research partnerships might constitute co-production.[14] Aligned with the 'values and principles' typology of co-produced research, differences between researchers and lay experts are democratised, and the co-production process is treated as evolving rather than a rigid or fixed concept.[2] We recognise there are diverse histories and disciplines which inform the words used to describe involved participants in co-produced research, and that rather than these terms (i.e. lay, expert, research participant) having objective meanings we argue they are made meaningful through their contextual relationship to the researcher/s and research process/es. In the co-production sphere, a key feature of this contextuality can include whether participants are paid and how (much), as well as what is possible in the cramped spaces of academia.[15]

While these terms matter, we use several within this manuscript but do not see this to contradict our central argument: that keeping the contextuality in view enables exploration of how health researchers, lay knowledges and co-production initiatives can be situated around socio-political structures including historical trajectories and the distribution of power and resources[16]—the key undercurrent of co-production research. Our research context is a useful area for this, in exploring *alcohol* consumption (a health risk in a healthiest society that carries sociomoral dangers[17]) by *women* (who have historically been scrutinised, surveilled and muted) during the multilayered transitions of *midlife* (culturally constructed in the west around erasure and invisibility[18]). In Australia, alcohol is complexly interwoven with social life and empirical evidence shows it has significant use-values for women in midlife; including managing uncertainty,[19] happiness,[20,21] and wellness[22] as well as smoothing difficulties at home.[23]

Co-production research in health: All about what participants do?

Early arguments for involving lay populations in health research responded to the recognition that they hold expertise that will enhance understanding of health and its social genesis.[1,24] The distinct, plural and free-form ideas from lived experience are now seen as critical to realising epistemic justice within democratic methods,[25] yet this sits in tension with ingrained logics of natural science which pursues the exclusion of participants and their subjectivities.[26] It may also irritate tightly wound socialisation(s) around the authority and expertise of health professionals and systems, to the extent that both lay experts and health researchers tend to misinterpret and downplay what and how to lay populations can contribute to health research.[9] These knowledge contests are scaled up during power-focused co-production methods,[5] because they explicitly seek to elevate the power participants have in research processes and even help to reimagine[27] and reorganise[28] power dynamics. This radical politic likely underpins why turbulence will unfold if co-production is done ‘properly’.[29]

Researchers are directly embedded in these dynamics, which is why reflexive practices are so central to[30,31] and entangled within knowledge systems, prompting our focus on epistemic[9] and ontoepistemological reflexivity.[32] The perceived value of knowledge moulds subjectivities,[10] and then influences what research participants think to disclose and what health researchers think to ask during research encounters.[9] Unasked questions and undisclosed knowledge are key examples of the need for reflexivity and showcase its relationality with epistemic privilege.[33] This is crucial within co-produced health research, where despite its political ambitions, lay participants are less commonly involved in healthcare planning, design, delivery and improvement[34] or the review of systems innovation.[35] Instead, they are more typically represented in technical aspects[36] of research more acceptable in neoliberal settings but still branded as co-production, such as activities like usability testing that can be more passive and defined because they have a preset agenda.[37] Concomitantly, theoretical guidance about how to involve lay populations in co-analysis of data has been obscure[38] with some suggestions that these processes need ‘downgrading’[39] or risk being ‘dirtied’ and ‘stretched’ during co-production.[6] Lurking doubts about the capabilities of citizens to engage in co-produced research[40] alludes to lingering conflicts about whose knowledge is legitimate and in what settings. How knowledge is valued further influences what is viewed as a valuable output from analytical or interpretive processes—further showcasing why the histories that give rise to contemporary configurations of knowledge are manifestations of power that enfold co-produced research.[16]

Broadly, the potential role—and value—of involving lay populations at macrostructural levels of in/equality remains undertheorised and underachieved.[16] We suggest that there are two layers to this problem. First, the value of lay expertise might be misunderstood (*a reasoning error*) and therefore efforts are not invested in developing researcher critical consciousness towards epistemic and political contests. The fact that much of what citizen scientists produce is ignored by scientists[41] is likely symptomatic of this, in addition to unwritten rules about whose expertise matters and whose does not.[42] Second, the short-term and scarce nature of health-related funding and implementation cycles contracts the scope for such work (*an execution error*) because it does not afford the time and care needed for collaboration[43] that is sustained, open-ended, and able to transform civic arenas.[44] Both of these co-production ‘errors’ engender layers of cruel optimism.

The *reasoning error* continues to situate lay participants as the *problem*, in a position of deficiency where they *lack knowledge* (per Foucault,[45] docile bodies that are positioned as vacuous vessels that need filling with new information)—rather than the knowledge they bring being examined by researchers to break cycles of ‘circulating reference’.[46] It then follows that they cannot bring air into closed political systems[15] nor disrupt the quest for monophonic patient voice in health settings[47] because the ways in which the knowledge they bring can be valued is already prescribed by dominant cultural systems that privileges some knowledge above others.[10] The *execution error* occurs when the value of lay participants is understood (at least to some level) but the expectations, needs and practices of co-production research spill over what health researchers can fulfil—resulting in disengagement (and/or moral injury on behalf of the researcher and participants)—as well as cramping of what can be achieved during the process,[15] which turns the gaze again to what lay participants do, think and know that can be made available for critique in a short-term window.

Considering that epistemic precarity frequently coincides with material precarity,[48] the cruel optimism of co-production can be twofold—rhetorically and materially engaging with lay populations who experience disadvantage *because* of this perceived vulnerability while dissolving potential benefit from their involvement, because their insight is not viewed as 'knowledge' nor enabled to challenge the 'status quo' of knowledge production systems.

METHODSResearch context and prelude to women's thought collectives

In thinking about how to transition the snippets of Ariel Gore's council of experts method detailed in her book (as we were unable to connect with her in-person), she talks about travelling to meet different women she knew or contacted because they had expertise in exploring the question of happiness, drawn either from lay or professional experience. We liken her approach to purposive sampling in an emergent research design,[49,50] where she included people at unstructured points throughout her project in response to what she learned. Gore[11],[p.9] states wanting to 'ask women and femmes of all genders –groups who'd been extensively studied when it came to depression and completely ignored when it came to positive psychology –what made them happy'. After interviewing hundreds of women (p. 22), she then 'convened a council of experts –artists, mothers, service workers, scholars, psychologists, and women's health-care providers… to keep their own journals for several weeks and then join me for a liberation psychology forum' (p. 22, number of women within the council unstated).

The value of this open-ended approach was identified as an innovative way of centring the researchers' growth and reflection (in contrast to lay participants) during Kristen Foley's doctoral research exploring the commercial determinants of alcohol consumption in the context of rising consumption levels for Australian women aged 45–64 and associated increases to population breast cancer risk.[51] A linked study was already running within the public health department in which Kristen's PhD would be located, to explore how social class shapes alcohol consumption for women in midlife using interview methods[52]. To complement these insights, she designed and received funding for a companion study to explore the social context of alcohol consumption and experiences of marketing to women to increase profit margins and market share. Given that so much of targeted marketing is specifically tailored and delivered to particular groups and individuals to increase purchasing and consumption, involving the lay population seemed unavoidable and completely necessary.

The timely and evocative reading of Gore's[11] book, however, sparked creativity about how research participants could be involved in co-analysing and co-interpreting research findings about them—co-producing knowledge about issues that concern them while also placing them in a position to refine the evolving meanings and interpretations made from the research. There were few details, however, about the liberation psychology forum she held and it was unclear how her ideas were refined by the presence of her council of experts (hence our reason for contacting her). This move from what was said to her, her reflecting over what it meant and then pulling into a narrative—makes stark what is done to knowledge between its 'provision' by research participants and subsequent 'development' by researcher(s) during analysis and interpretation, typically without recourse to participants (member-checking being an exception, although still subject to the researcher terms of conduct). Something Gore captures well is her wrestling with these ideas, both in granular detail and how it changes her ideas about what happiness is. She journals about trying to live differently according to the knowledge she adopts. In using her work to spark intellectual creativity,[53] we set out to explore how a council of experts might resonate with ideas in the social science literature about co-producing research regarding structural distributions of consumption, health, risk and resources.

Developing insights from contemporary feminist and hermeneutic philosophy

We summarise here the learning from (1) hermeneutic and (2) feminist philosophy, which were read in response to Gore's[11] method to ground it in the contemporary thinking about knowledge, truth and method—and infused a co-production methodology to create space for researcher reflexivity under the guidance of co-analysis and co-interpretation of lay participants.

Hermeneutic philosophy

Philosophical hermeneutics explores in-depth what it means to ‘know’, ‘understand’ and ‘interpret’.[54] Centrally, hermeneutic thinkers are convinced that our being and essence as humans is to *interpret* (following Heidegger[55]) and that we *are* what we know, which comes from understanding[56] and feeds back into new knowledge.[57] In this conceptualisation, knowledge is not something special cordoned off in the realms of science or literature. Rather, we live it in everyday life through what we do,[54] whether this be conscious or not and this is how humans transmit the effects of history.[58] Given how knowledge is shaped by early learning, there can be no ‘absolute zero’ to knowledge[59] ; rather through our lives, we embody different facts which come from both private and professional spheres.[60] Because some of this happens unconsciously, hermeneutic thinkers argue that we can never ‘bracket out’ bias from the research process (as assumed in positivism) because we do not know what effect it has.[54] Instead, hermeneutic methods aim to build a positive relationship with prejudice[54]—by turning inwards, to the self, uncovering how what we think and do is driven by particular ideas and beliefs, and exploring what angles are opened up through this as a field of learning.[61] This is akin to the practice of reflexivity, although it takes a particular focus on the ontological (nature of being) and epistemological (nature of knowledge) level.[32]

The researcher and their reflexive posturing is therefore as much the object of study in hermeneutics as is the research topic or population of interest. This focus is brought to life by the use of a knowledge horizon as imagery to picture hermeneutic methods. When looking at a horizon, the objects in the foreground shape what is seen on the horizon. As the position of the researcher shifts—they get a different view of the foreground objects and also the horizon[61]—this metaphor emphasises that where the researcher ‘stands’ influences what they ‘see’. Recognising the positioning of the self in generating knowledge is therefore quintessential to working with hermeneutics[32,62–64] and a hermeneutic situation can only be said to have been achieved if there has been a change in the researcher's way of understanding the world.[65] In terms of thinking about how hermeneutic ideas might be useful in co-production research, because there is no possibility of complete knowledge[66] the research project is attuned to the context(s) in which these views arise. Methods would be thought less about as processes for data gathering and more about ways of becoming entangled with how things work (or not) for different people in the world.[67]

Feminist philosophy

Feminist philosophy is centrally concerned with exploring how gendered power moves in and through everyday life. The concept of gender was constructed to enable women to be considered outside of the relationship to their reproductive body alone,[68] and contemporary feminist methods seek to understand how aspects of gender intersect complexly[69] with other identities/experiences of exclusion or subordination.[70] Feminist historians in Australia have traced how exclusion from commanding economies has been linked with madness,[71] the ways in which social demography furthered control of class and family politics in Australian colonies,[72] and also the invisible power and privilege of whiteness within Australian feminism.[73] Feminist philosophy is strongly linked with activism, where a diverse range of theoretical positions[74] explores whose knowledge has counted[75] through diverse methods that loosely cohere around centring lived experiences[76]—particularly those excluded from dominant societal narratives. [12,33] Feminist theory and research can therefore be thought of as a disruptive knowledge practice[77] that aims to unsettle traditional power differentials around knowledge production, in which researcher reflexivity[78] and positionality are key.[79]

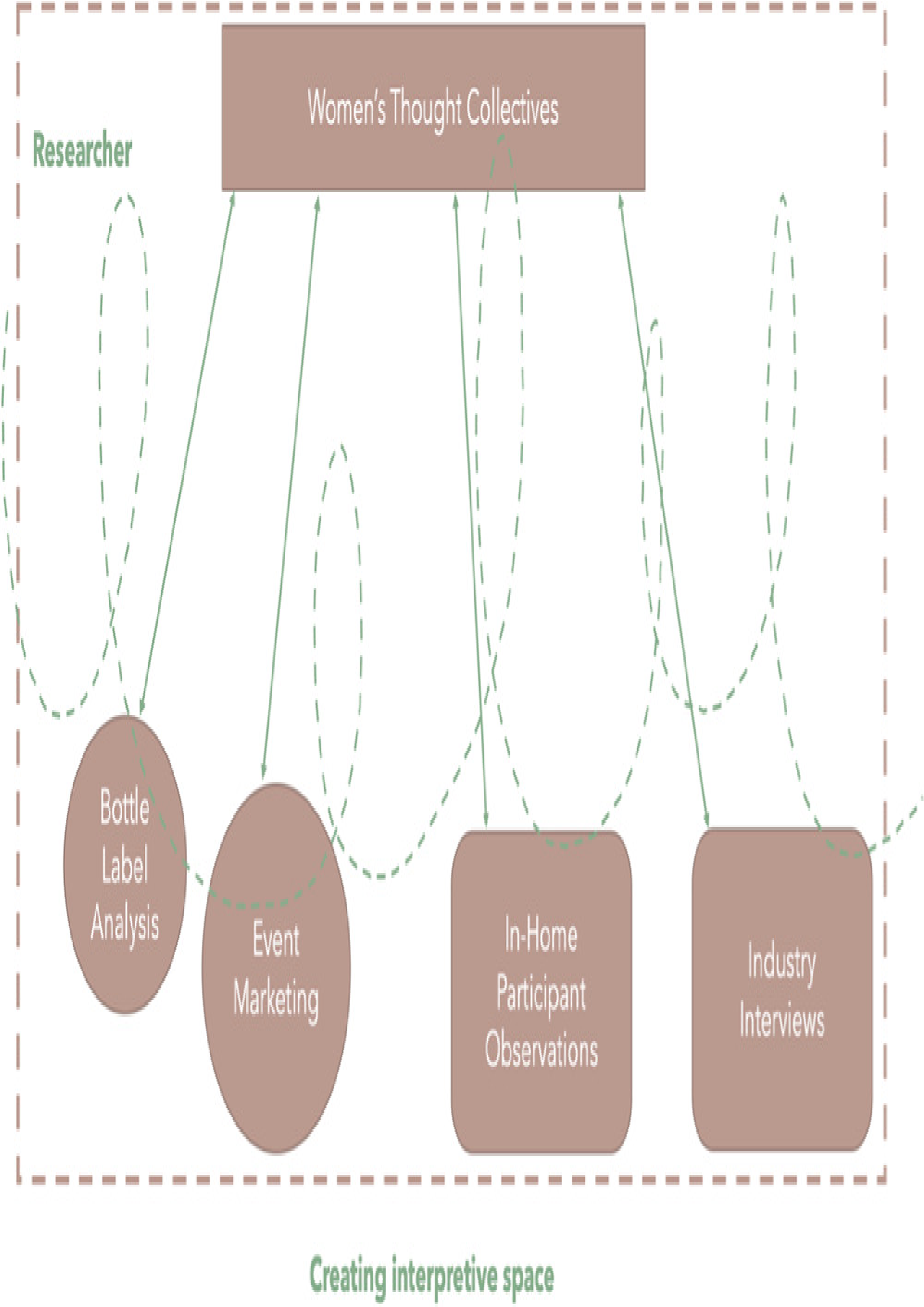
Health systems and sciences have often used an extractive or possessive logic for knowledge acquisition,[80] which tends to erase the sociopolitical context from which knowledge is developed[81] while shedding the relationships which gave rise to it.[80] By contrast, feminist methodologies aim to centre relational methods of knowledge production and theorise the social world (and degrees of epistemic privilege) in relational ways.[33] Considering the historical positioning of the female body as deficient in much of medical and health discourse/practice,[82] the health system is an important landscape in which giving voice to women's experiences and how women understand themselves[83] takes on political and ethical significance.

FINDINGS: *WOMEN'S THOUGHT COLLECTIVES* AS METHODOLOGY

The methodology involved two different groups of women being recruited to oversee Kristen's doctoral research over a 2-year period, with the invitation to co-collect research data and contribute to thinking through research data and findings with the researcher. The term ‘oversee’ was used specifically to signpost the elevated role of women within the research methodology, beyond what is typically conjured when thinking about a ‘research participant’ (contributing data only) –as well as illuminate the gaze on the researcher. The key principles of the methodology were:

- 1. Elevating the role of lay researchers in developing knowledge that concerns them, without responsibilising them with problems they cannot solve.
- 2. Opening as many opportunities for researcher reflexivity and accountability through data co-collection, co-analysis and co-interpretation—and recognising this is where the legwork and insight should emerge.
- 3. Being explicit with participants about research is one way of knowing amongst many, including that gained from everyday (and a lifetime of) living, thinking and doing.
- 4. Adopting a flexible research approach that enables change to methods based on input from involved participants.

These principles are represented in Figure 1, where the spiral line shows how the Women's Thought Collective could inform, influence and reflect on the studies designed to comprise the doctoral research before recruiting them as a Thought Collective (due to funding cycles running so far ahead of the work starting). The novelty of the methodology is that the Collective was engaged throughout the research process to inform decision-making and reflection, but the gaze is focused on what the researcher is doing and how their knowledge (and research progress) shifted in relation to reflections contributed by the Collective. We decided to use the term Women in the Thought Collective title (as an attempt to deter women from participating in the case it was named ‘expert’, etc.).



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Methods

Two Collectives were assembled; one with midlife women from South Australia and another with midlife women nationally. The state-based Collective was where the researcher was located and also where the parallel study had run about the reasons as to why women in midlife drink[20,52,84] which could be explored in relation to broader structures, the focus of this study. The national Collective was assembled to help elucidate differences between states and create a further reflection on the experiences and perspectives of women living in different locations. Group meetings and individual conversations were combined in a flexible, semistructured process, on the logic that both contributed to creating entry points for reflexivity for the researcher. Three group meetings were held with each group (*n* = 6) at the beginning of the doctoral work to discuss ideas for exploration which had emerged from gaps in (1) the parallel sister study; (2) the multidisciplinary literature review regarding commercial determinants of alcohol consumption and (3) the extent to which the proposed design would achieve an understanding of these gaps. Research participants were provided with journals and asked to record any instances of alcohol advertising or commercial activity they saw, thoughts about how expectations or practices around alcohol had changed across their lives, views on alcohol companies, and reflections on work, play and rest generally as they had grown and transitioned through the life course. They were encouraged to email any photos or reflections in real time to the researcher. The researcher, in turn, also kept a regular reflexive research journal that documented reflections about input from collective members, the research process and emerging thoughts drawn from engagement with academic literature.

Recruiting (and describing the research)

Significant thought was put into how to convey the value of lay expertise within the research to participants, with recruitment material outlining what participation would involve:

- 1.
  Recording in a journal observations and reflections about alcohol consumption and relevant advertising/marketing in your own life.

- 2.
  Attending 4–5 meetings with ~15 women throughout 2021–2022 (scheduled on demand in relation to what is coming out of the research) to discuss your reflections as well as data analysis and interpretation in the wider study, which will be audio-recorded (for purposes of note-taking and background analysis only).

- 3.
  Providing input and guidance to Kristen during the development and progression of ideas surrounding alcohol consumption for Australian women in midlife.

Interested women were encouraged to contact the researcher. The following script was used to convey to them why participating for such a long period of time was useful, per Box 1:

1**Box**

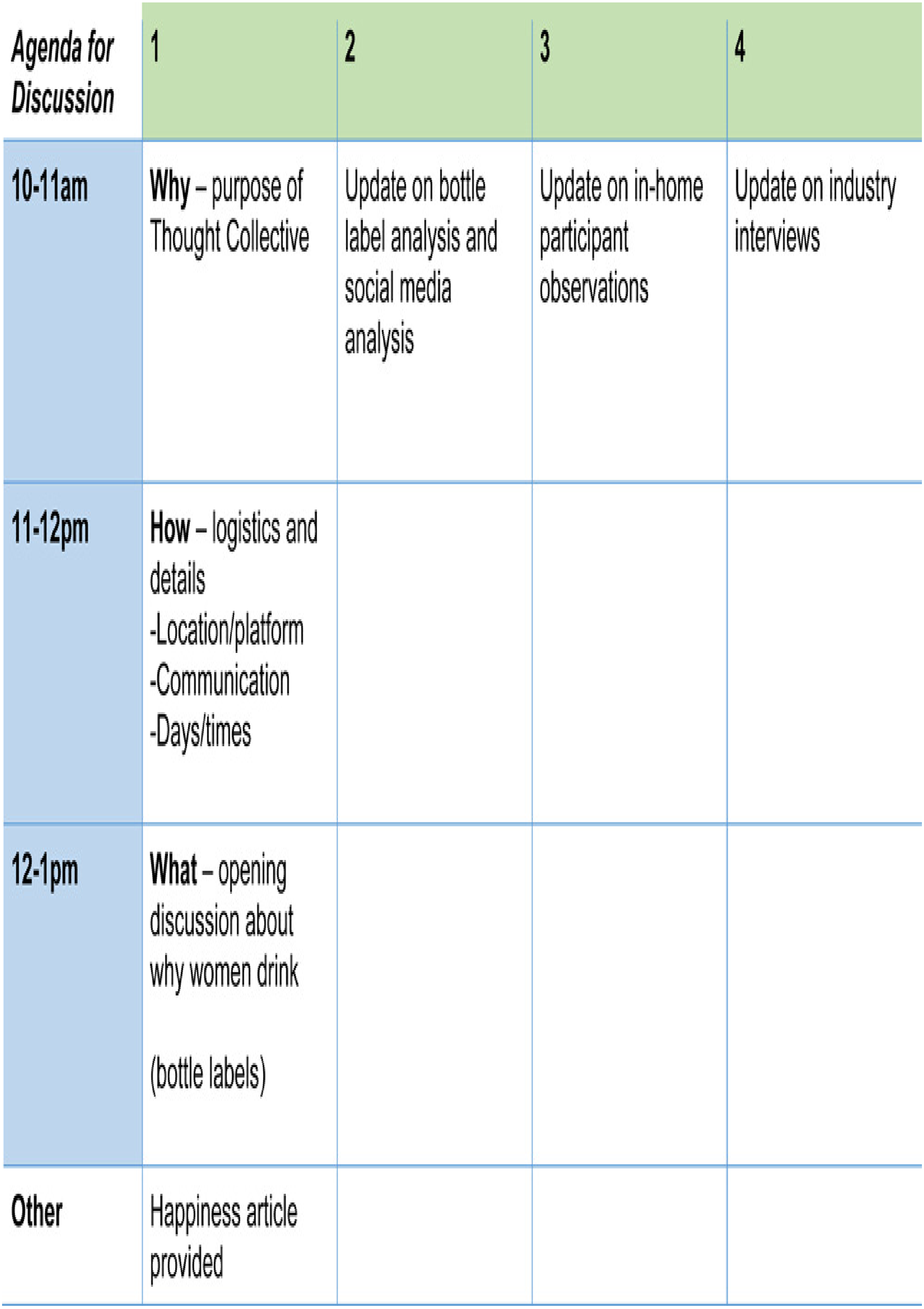
The idea for holding a Thought Collective came about because while many people participate in research, they do not have a role in influencing the analysis, outcomes or interpretation of that research. We hope the Thought Collective will engage women directly in developing knowledge that concerns them.

We distributed this material around university networks (i.e., flyers) and relevant community groups (i.e., notice boards and by contacting specific groups). Snowball sampling was also used, where motivated participants contacted others to suggest participation. Those who participated were provided reimbursement for their time and participation. We aimed for as much heterogeneity in the sample as possible, including in living circumstances (i.e., single/married/divorced, having had children or not, having elderly parents, living alone or with others, in metropolitan or regional areas) and social class (a mixture of economic, social and cultural capitals as measured by a validated tool[85]; drinking level (light, medium or heavy as measured by the AUDIT-C tool) and age range between 45 and 64.

We did not target participation from any Aboriginal or Torres Strait Islander communities, recognising that Australia's colonial legacy shapes alcohol practices in ways that differ for Caucasian women in midlife.[86] No women communicated identifying as Aboriginal or Torres Strait Islander. We recognise the paradoxical nature of arguing that disadvantage accumulates at layers of intersections and the knowledge they bring is critical to unsettle entrenched hierarchies and power dynamics[27] but not specifically targeting groups likely to have diverse ontoepistemological positionings.[33] Following our logic of widening participation in knowledge development, draft outputs will be circulated to a wide range of audiences, that accounts for groups (i.e., organisations or champions) that may not have been represented in the Collective and could be used to develop future partnerships if desired by these groups. This will create further entry points to co-producing (or contesting) knowledge, and aligns with Erikainen et al.[79] support for widening the way in which ‘research engagements’ are conceptualised and the structural conditions under which they occur.

Undertaking the research

The Collectives were shown Figure 2 at the first meeting to try and offset any feelings their knowledge was not valuable and might not influence the trajectory of the project—by way of blank spaces being included in the plan, contingent on forthcoming discussions. We also asserted that the purpose of the Collective was not to come to a consensus about an issue, because such a task was unlikely and intractable—rather, to unearth a range of different perspectives and how these all might help to understand the commercial determinants of alcohol consumption for Australian women in midlife. This openness to dissent and difference is important for co-produced research so that perspectives are not marginalised nor recast through hegemonic values needed to present uniformity or ‘one voice’, [87] ideas contested by democratic methods which highlight the problematic nature of conflict-free consensus such as agonistic pluralism.[88] We provided examples of the breadth and depth of information that might have been relevant—a bottle label, in-store motivators for purchase, etc.—to make what we were hoping for seem approachable and clearly tied to their expertise of what happens to them in everyday life.



Agenda for Discussion	1	2	3	4
10-11am	**Why** – purpose of Thought Collective	Update on bottle label analysis and social media analysis	Update on in-home participant observations	Update on industry interviews
11-12pm	**How** – logistics and details -Location/platform -Communication -Days/times			
12-1pm	**What** – opening discussion about why women drink (bottle labels)			
Other	Happiness article provided			

Enlarge this image.

The vision of the methodology was designed to prioritise lay participant input for analysing and interpreting research findings and outcomes, while the legwork for doing so forces the researcher's decision-making to remain in view throughout the study. Accordingly, 1–2 page summaries were developed for each research activity undertaken and sent to members of the Thought Collective to act as feedback windows into the development and circulation of ideas throughout the project. This also kept them engaged with the research and maintained a relational or reciprocal element. The researcher maintained a progress sheet of contacts to ensure that each participant member was checked in with at regular intervals, and sent a snippet of something that might spark conversation or for them to see something in their lives differently. Regular and ad hoc communication was typically by email, with frontloading that a nonresponse would be interpreted as them being too busy at the time, and would be re-contacted again in a few weeks—but that they could cease their participation if they asked via return email. Participant preferences were followed regarding communication, and recognising that some preferred phone contact, emergent thoughts and ideas were discussed with participants via phone rather than in addition to email.

Field notes were taken throughout the project. This resulted in reflections about different ontologies and epistemologies held by the participants in the Thought Collective, which helped to understand the research topic (commercial determinants of alcohol consumption), spark reflection for the researcher about their own ontoepistemological positionings, and create space for problem-solving any ideas raised by participants. An example is included below in Box 2:

2**Box**

One of the Collective members suggested we explore with police what data they have available about women in midlife being fined for drink-driving because she had a few friends who drove only because their partner was too drunk to drive (male in her examples). I did this twice in 2021 via the general inquiry line through police, but received no input. I've been thinking about it again, as to whether I should pursue it, but was just thinking today how I don't think I viewed it as important as other lines of exploration because it's not as clearly linked to commercial determinants of health—although of course, lay participants do not see their lives in such terms, and lines of gendered power are a key way in which structures (which in our modern life are significantly influenced by actions within the commercial sector) are lived by people. So—it is highly relevant, and I'm embarrassed I didn't follow it up more aggressively earlier on. I'm going to try and pursue a different line of inquiry, to get in touch with an academic that has published a few pieces in partnership with the police, to see if they can help with pursuing this line of inquiry further, even though I'm not sure where it will go.

In this excerpt, it is the researcher who changes over time evident in the reflexivity here about ontologies (as influenced by consumption and commercial activity) and epistemologies (where ways of knowing are highly specialised for researchers and can variously inform the question of relevance, which are linked differently for lay participants). The change came about in response to the ideas of a Collective member and the consideration of philosophical concepts. Another reflection in Box 3 surrounds the tendency towards missing bodies in descriptions and discussions about alcohol:

3**Box**

It is curious to me that often I can have a whole conversation with someone about alcohol (work-related or not), or read a whole article about alcohol, and what the body does can be absent from them… it makes me think about Elizabeth Grosz's ‘volatile bodies’ argument, where bodies were overlooked as orienting or disrupting forces in the philosophical ideas prominently circulated in the west… and bridges to some of the reflections from Collective members that talked about midlife as being a time where they had to (or were able to) pay attention to their bodies in ways they hadn't earlier in their lives or for some period of time. I wonder if alcohol has a role in facilitating this awareness?

Time passing was important to being able to have these discussions with participants and a key source of benefit to the novel insights which can emerge when what the researcher does, thinks and knows is brought into view during co-produced research. The attention to this space for reflexivity also means that questions of method are clearly in view and considered for discussion throughout the research, and has led to the researcher reading in ways that support ongoing ontoepistemological reflexivity (i.e., privileging reading texts from authors with life experiences and worldviews different to the researcher).

CRITICAL CONSIDERATIONS FOR HEALTH RESEARCHERS DURING THE CO-PRODUCTION OF RESEARCH IN NEOLIBERAL SETTINGS

Clear synergies exist between hermeneutic and feminist praxis: in both, the researcher is embedded and entangled in knowledge production, to the extent that they cannot be separated from it.[33,78] Health researchers become subjects of inquiry, rather than objects/objective parties in inquiry, messying the power dynamics of traditional research[89] because it becomes the researcher's reflexive ability to recognise, make available for comment—to lay participants and research audiences—how they will consider the knowledge that is objective, subjective or emergent in local worlds.[5] This flipped expectation is evident in our *Women's Thought Collective* methodology, where the researcher must reflexively work between their own values and the knowledge or value systems these are fostered by[10] to co-produce knowledge about health. The view that knowledge is a social commodity developed out of science, health *and* lived experience must become part of expected literacy and discussion for health researchers working in co-production. It could be embedded into training and education with health professionals but also publishing expectations; perhaps the mandated inclusion of a section within manuscripts where researchers reflect on what they will do, think or know differently as a result of research that involved lay participation (broadly defined). Ensuring that researchers are held responsible for attention to scientific quality[90]—where this involves a working knowledge of the philosophy of co-production methodologies as well as the research methods they might use, will be critical during editorial and peer-review processes.

We agree that co-production requires agreement on principles and values rather than definitions,[2] and suggest that when principles that illuminate the democratic and political undercurrents necessary for productive co-production research are outlined,[14] reasoning and execution errors may be lessened. The value of genuinely involving lay participants in research must be coupled with a wariness of co-production as a new buzzword of neoliberalism[34,91] that can engender complicity in structural inequalities[92] during co-produced research that apparates the researcher and the knowledge systems in which they work within out of the picture. Centring the difficulty of this work may help to further guard against these errors in co-produced research and glossing over the dislocation and disorientation during forms of public deliberation.[93] Our work adds to crucial reflection about co-produced research which can scapegoat lay participants during ‘inefficient’ co-production research[89] and risk a twofold cruel optimism, which not only impedes flourishing but also diminishes it.[8] By contrast, we present a methodology that situates the researcher as responsible for cohering co-production methods that take form around socio-political structures and the distribution of power and resources,[16] by attending to the contested value/s of knowledges. The philosophical view of entangled knowledge production—drawn from feminist and hermeneutic domains, and enacted through reflexivity—illuminates the potential for cruel optimisms within co-produced research while also outlining pathways to guard against them. Attending and responding to these entanglements are critical roles and responsibilities of health researchers during the reflexive co-production of knowledge because they stem from the epistemic origins of entrenched inequalities in health research that necessitates the participation of lay populations in the first place.

AUTHOR CONTRIBUTIONS

Kristen Foley designed and undertook the Thought Collectives, including securing grant funding, organising ethics approvals and recruiting participants. She conceived and wrote the manuscript. Belinda Lunnay substantially contributed to the design and facilitation of the Thought Collectives as well as adjusting the design, ethics requirements and possibilities for interpretation in live circumstances. She critically reviewed the manuscript for important intellectual content. Catherine Kevin substantially contributed to the design of the Thought Collectives as well as an approach to data collection, analysis and interpretation. She critically reviewed the manuscript for important intellectual content. Paul R. Ward substantially contributed to the design and facilitation of the Thought Collectives, including support of grant and ethics applications. He reviewed the manuscript iteratively for important intellectual content.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data involved in developing this manuscript can be made available from the authors upon reasonable request.

ETHICS STATEMENT

Data cited in this paper are drawn from field notes from Kristen Foley's doctoral research, which has ethical approval from Torrens University Australia.

DETAILS

Subject:	Feminism; Health sciences; Happiness; Middle age; Alcohol use; Health risks; Epistemology; Councils; Reflexivity; Values; Neoliberalism; Social systems; Optimism; Knowledge; Women; Health risk assessment; Medical research; Researchers; Health professional-Patient communication; Alcohol; Philosophy; Hierarchies
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Issue:	5
Pages:	1954-1964
Publication year:	2023
Publication date:	Oct 2023
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Place of publication:	Oxford
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Conceptualization of patient-centered care in Latin America: A scoping review

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ProQuest document link

ABSTRACT (ENGLISH)

Introduction

Patient-centered care (PCC) has been declared as a desirable goal for health care in Latin American countries, but a coherent definition of what exactly PCC entails for clinical practice is missing. This article's aim was to identify how PCC is conceptualized in Latin American countries.

Methods

Scientific databases (MEDLINE, EMBASE, PsycINFO, CINAHL, Scielo, Scopus, Web of Science) and webpages of the ministries of health were searched, and experts were contacted for suggestions of literature. References were included if they contained one of a range of a priori defined keywords related to PCC in the title, were published between 2006 and 2021, and were carried out in or concerned Latin America. Definitions of PCC were extracted from the included articles and analyzed using deductive and inductive coding. Deductive coding was based on the integrative model of patient-centeredness, which unites the definitions of PCC in the international literature (mainly North America and Europe) and proposes 16 dimensions describing PCC.

Results

Thirty-two articles were included in the analysis and about half of them were from Brazil. Numerous similarities were found between the integrative model of patient-centeredness and the definitions of PCC given in the selected literature. The dimensions of the integrative model of patient-centeredness that were least and most prominent in the literature were physical support and patient information, respectively. A differentiation between PCC and family-centered care (FCC) was observed. Definitions of PCC and FCC as well as their cited references were diverse.

Conclusion

A considerable overlap between the conceptualization of PCC in Latin America and the integrative model of patient-centeredness has been identified. However, there are substantial differences between countries in Latin America regarding the emphasis of research on PCC versus FCC and diverse conceptualizations of PCC and FCC exist.

Patient Contribution

This scoping review takes the patient's perspective based on the integrative model of patient-centeredness. Due to the study being a review, no patients, neither caregivers, nor members of the public, were involved.

FULL TEXT

INTRODUCTION

In an effort to improve population health, the global community has worked towards the development and advancement of health care systems around the world.[1] Health outcomes have globally improved, leading to an aging population over the past decades. An aging population brings about novel challenges to health care systems, for example, increasing prevalence of chronic noncommunicable diseases.[2] These developments were complemented by a retraction from the paternalistic approach to health care and the emergence of alternative concepts as patient-centered care (PCC). In a paternalistic health care setting, the health care professional (HCP) is an authority who applies objective criteria to determine the treatment plan and informs the patient about the chosen intervention.[3] PCC proposes a shift towards balanced power in the relationship between HCP and patient, towards patient empowerment, active participation of the patient in the health care process, as well as a focus on individual patient needs, values, and preferences.[4,5]

Arguments in favor of PCC are of ethical, moral, and scientific nature. To treat all patients equally, respectfully, and recognize their autonomy are standards of medical ethics[6] and promoted by PCC.[5] It is emphasized that essentials to health care are, among others, cultural appropriateness, provision of information, recognition of individual circumstances and needs, and access to care without discrimination.[7] These standards are supposed to decrease inequalities in access to health care. Research suggests an association between aspects of PCC and positive patient outcomes, for example, health status,[8] treatment adherence,[9] costs,[10] health behavior,[11] social support, quality of medical decisions,[12] and self-rated health.[13] Thus, diverse lines of argumentation suggest PCC to be a desirable process and outcome in health care.

The increasing number of scientific publications on PCC has brought about diverse definitions of PCC in the international literature. Scholl et al.[5] saw a need for a coherent conceptualization of PCC which would provide common ground for future scientific and health policy work on PCC. To address this need, Scholl et al.[5] developed the integrative model of patient-centeredness (henceforth “integrative model”) by a systematic synthesis of diverse definitions of PCC described in the international literature, mainly from North America and Europe, but none from Latin America. The model proposes 15 dimensions of PCC (Supporting Information: Appendix S1) and has since been used in research on PCC, for example, in the development of a patient-reported experience measure of PCC[14] and came to close a gap in the international conceptualization of PCC.[15–17]

Research on and implementation of PCC have not been uniform around the world. PCC has been widely described and investigated in the global north.[18] In contrast, in regions where accessibility to health care and social inequalities remain an issue, as in Latin America,[19] there has been comparably little research on PCC. The socioeconomic, political, and economic structures of Latin American countries are diverse.[20] After the end of colonialization, military dictatorships undermining human rights were implemented in many countries, which lead to socioeconomic and health inequalities in Latin America.[20] Social movements achieved the restatement of civilian rule in some countries. These political changes as well as economic growth were precursors for health system reforms that have been implemented in Latin American countries to achieve universal health coverage and decrease poverty over the past decades.[20] For example, in Chile, health system reforms have led to a health coverage of about 95%.[21] However, health systems in many Latin American countries constitute a mixture of the public and a private sector, which promotes health inequalities and could enhance the continuation of a paternalistic style in health care.[22] In 2018, a survey conducted by the Organization for Economic Co-operation and Development (OECD) indicated that the spread and degree of health care coverage are less uniform in 21 Latin American countries in comparison to other OECD countries.[23]

With regard to PCC, in 2003, the Pan American Health Organization declared strategies to implement the principles of “equity, solidarity, and the right to the highest possible standard of health” in Latin American health care systems.[24] In line with this, access to care has successfully been improved in Mexico by the introduction of a program, which provides affordable health care to uninsured individuals.[25] Another example is Chile, where PCC has been declared as one of the fundamental principles of the health system in 2006.[26] Thus, health policymakers in Latin America have recognized the need for PCC and claimed the intention to establish PCC in routine care.[24–26] In 2016, the OECD implemented a *Latin America and the Caribbean Network of Health Systems* to “identify effective policies to ensure the financial sustainability of health systems” (OECD-LAC Regional Policy Networks).

Latin American research on PCC shows little coherence in the conceptualization of PCC. For example, Guanais et al.[13] conducted a secondary analysis of a public opinion survey on the health care system which had been conducted in six Latin American countries. They chose the following variables as being related to PCC for analysis: contact with primary care clinic (access), time spent with HCP, patient-HCP communication, technical quality and problem solving, and health care coordination. In contrast, in another analysis of patient-reported experience with health care in four Latin American countries, variables that were considered to be associated with PCC were easy access, coordinated care, good HCP–patient communication, provision of health-related information and education, and emotional support.[27] The difference between variables considered to be associated with PCC in the two studies represents variations in the conceptualization of PCC in Latin American research. Moreover, it is unclear how the concept of PCC has evolved in Latin America. As Scholl et al.[5] have recognized before, a clear concept describing PCC is necessary to compare research results and to implement PCC.

Despite the advances in health care and research on PCC, researchers from Chile have shown that thorough implementation of PCC is still missing.[28] Patients reported a lack of opportunities for active participation in medical decision-making in primary care and a disbalance in the distribution of power between HCPs and patients. Moreover, patient satisfaction with public health care significantly decreased from 2010 to 2015.[29] In a survey carried out in six Latin American countries, more than 80% of participants indicated that their health care system required substantial changes.[30] One main issue recorded by these surveys was access to care, which is an aspect of PCC. One reason for the lack of implementation of PCC in practice could be that clear guidelines on how to put patients at the center of care and let them participate in decision-making are missing.[31] In line with that, Bravo et al.[32] suggest that a clear operationalization of PCC in the Latin American context is needed. Thus, the aim of this scoping review is to analyze how PCC is conceptualized in Latin America.

To date, there is no coherent definition of PCC in Latin America. Therefore, the declared aim to implement PCC in Latin America can hardly be achieved. The research question of this review is: How does the conceptualization of PCC in Latin America differ from the integrative model? The integrative model will be used as a point of reference because it is internationally established and based on international literature except in Latin America. It is thus suited for comparison and potential extension by the results of the scoping review. The comparison fosters the development of one joint conceptualization of PCC in Latin America and internationally. This enables comparability and therefore also communication and collaboration in research as well as in implementation. The result of this review can thus support the declared aim to implement PCC in Latin America.

METHODS

To address the research question, a scoping review[33] was conducted following the framework of Peters et al.[33]

Search strategy

We developed a protocol following Peters et al.[33] and defined the population as the general population in Latin America, the concept as PCC, and the context as health care in general. The protocol can be received from the authors upon request. Two reviewers (A. K. and A. M.) conducted the electronic literature searches in MEDLINE, EMBASE, PsycINFO, CINAHL, Scopus, Scielo, and Web of Science between April and May 2021. Articles were included if they were published between January 2006 and December 2021. We limited the search to 15 years, considering milestones in Latin American countries on the implementation of PCC (e.g., health reform in Chile in 2006). Articles were included if published in the regions' official languages: English, Spanish, French, and Portuguese. We carried out a secondary literature search by asking Latin American experts in PCC for relevant references. Finally, a gray literature search was conducted on the webpages of the ministries of health of each country in Latin America.

Eligibility criteria

In the initial search, we included articles that contained one of the following terms in the title and abstract: patient-centered, person-centered, family-centered (each with four spelling variations) and patient-focused (with two spelling variations). In addition, titles and abstracts of the records had to contain either the term Latin America or the name of one of the 27 Latin American countries. In addition to scientific articles, opinion articles, discussion articles, editorials, letters to the editor, statements, and books were included. There was no exclusion criterion regarding the study design or setting. During the title-abstract screening, studies and other records were excluded if they had not been carried out in Latin America or did not discuss their major content in the context of a Latin American country. Records were excluded if they did not discuss the key term, upon which they had been included in the initial search, in the context of health care. In the full-text screening, records were only maintained, if they contained a definition of the key term.

Study selection process

The identified records were imported into Endnote X9[34] and duplicates (1465) were removed. Two reviewers (A. K. and A. M.) conducted the title and abstract screening, and three reviewers (A. K., A. M., and C. T.) did the full-text screening and data extraction. We randomly distributed the articles among the reviewers. Spanish articles were read only by two (A. M. and A. K.), and Portuguese articles were read by A. M. and reviewed by P. B. Each article was double-screened and compared among the respective reviewers. The number of articles was balanced out between reviewers. Finally, A. M. and A. K. reviewed all the extracted information and codes and discussed discrepancies to reach an agreement. Doubts about terms and concepts were discussed by the team (A. K., A. M., I. S., and P. B.).

Data extraction

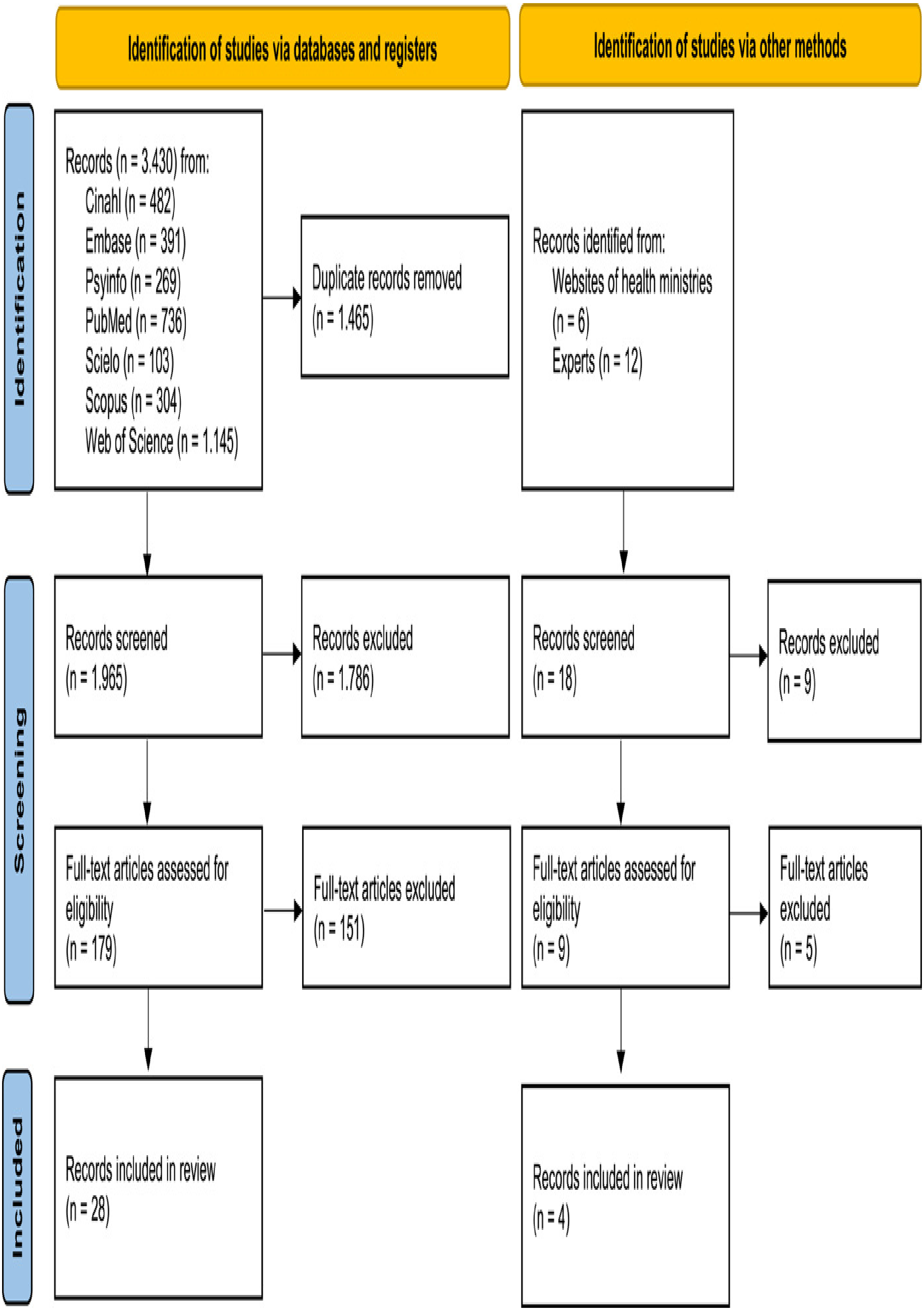
The following data were extracted using a data extraction sheet including country of publication, the description of the main concept, study design, data acquisition, sample characteristics, health setting, and the conclusion drawn by the respective paper regarding the main concept. As we suggest that one joint model of PCC based on international research is desirable, we used the integrative model by Scholl et al.[5] for the analysis of conceptualizations of PCC in Latin America. For every paper, it was extracted regarding whether the 15 dimensions of the integrative model were mentioned. This was done by the deductive coding. Aspects related to PCC that were mentioned in the selected literature, but not covered by the integrative model were extracted separately. A. K. and E. C. discussed whether these were new dimensions or could be subsumed into one of the 15 dimensions of the model. The references provided for the definitions of PCC and family-centered care (FCC) were analyzed regarding repetition in the sample and their origin.

Synthesis and analysis

To answer the research question of how the conceptualization of PCC in Latin America differs from the integrative model, the following descriptive information was analyzed for the selected literature: frequency of publication type, distribution of publication years per the central concept, frequency of publications per country in Latin America, and repetition of authors who published the included literature. The extracted main concepts were grouped based on content, and the resulting division was considered in all further analyses. To understand the origin of conceptualizations of PCC in the selected literature, the references provided for the definitions of PCC were analyzed with respect to their origin and repetition between articles. The results of the deductive coding regarding the 15 dimensions of the integrative model[5] were analyzed by A. K. with respect to the occurrence and frequency of each dimension. We carried out a content analysis[35] of the conceptual definitions of PCC and FCC, following these steps: (1) development of the research question; (2) selection of the categories of analysis; (3) collection of data in a predetermined coding agenda; (4) revision of categories and coding agenda into meaningful clusters (principles, activities, results); (5) final interpretation of the results. All analyses were done in Microsoft Excel.[36]

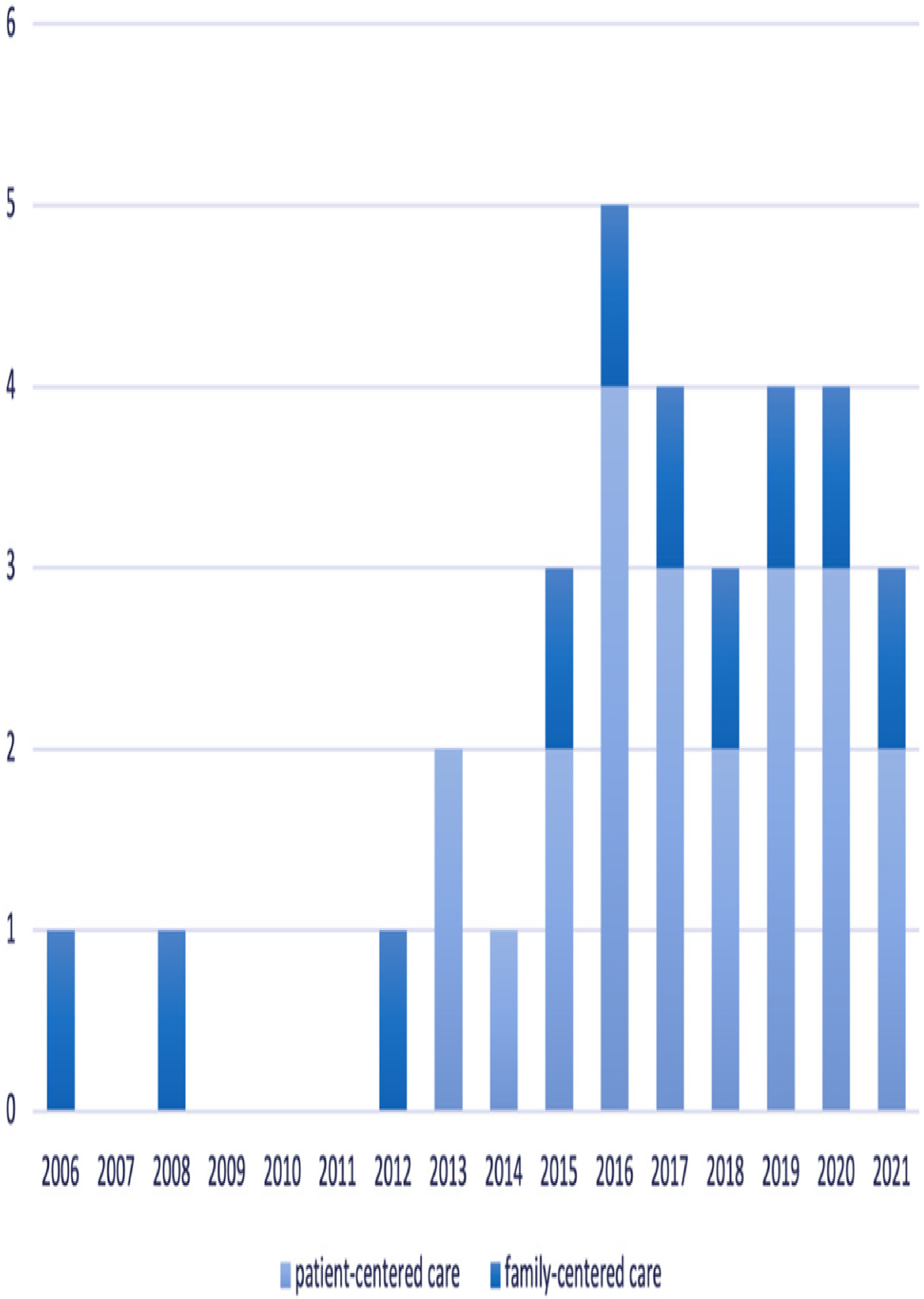
RESULTSDescriptive information

The initial electronic literature search identified 3430 articles (1465 duplicates). Based on the secondary search and gray literature search, 18 articles were added. After the full-text screening, 32 articles were included in the analysis. For the PRISMA 2020 flow chart,[37] see Figure 1.



Enlarge this image.

The reasons for excluding articles during the title and abstract screening and full-text screening were that articles turned out to be from outside Latin America. For example, studies were included based on the search term “Mexico,” but were later identified as studies from New Mexico, USA. Similarly, studies on PCC for Latin American immigrants in the United States of America, published by authors from the United States of America, were excluded. Another article was excluded because the study was completely conducted in Spain, even though one coauthor was affiliated with an institution in Latin America. At least 18 articles were excluded for missing a definition of the main concept the article was discussing (e.g., PCC). Papers focusing on person-centered research methods instead of health care were also excluded. Finally, articles on the person-centered therapy developed by Carl Rogers were excluded because the articles took a therapeutic perspective on PCC, instead of a system-based perspective, which is of interest for this study. The selected literature comprises 29 research papers,[13,27,28,32,38–57] two health policy documents,[26,58] and one conference abstract.[59] Most studies (*n* = 27) were published between 2013 and 2021. For an overview of the publication year and the main concept of the included articles, see Figure 2.



Enlarge this image.

Almost half of the articles (*n* = 15) were published by authors from Brazil,[38,39,41,42,44,45,47,49–51,53–55,57,60] six were published by authors from Chile (two health policies,[26,58] four research articles[28,32,48]), and five by authors from

Mexico (one conference abstract,[59] four research articles[43,56,61]). Four papers were published by authors from several Latin American countries,[13,27,40,62] and one article was published by authors from Colombia[46] and Honduras[63] each. In the included literature on PCC, there were authors who repeatedly occurred, either as first-, co-authors, or last-authors: Doubova, S. V. (5), Bravo, P. (3), Dois, A. (3), Martinez-Vega, I.P. (2), Ministerio de Salud Chile (2). In the literature focused on FCC, each article was published by different authors.

Main concepts

In the selected literature, PCC was discussed using diverse terms. These terms were grouped into PCC and FCC categories, which will be referred to as main concepts in the following. In most articles (*n* = 22) the main concept was PCC. Twenty-four different terms were used to refer to this main concept. One article described PCC in the context of the Biomedical Model of Care.[59] FCC was the main concept of 10 articles and within these, four different terms were used to refer to FCC. For an overview of all the terms used to refer to the main concepts in the selected literature, see Table 1.

Table 1 Main concept of the articles and their frequency (*n* = 32) are thematically ordered.

	Main concept	Count	Main concept	Count
	Patient-centered/-centered care	9	Family-centered care	6
Associated terms *(frequency if other than 1*)	Person-centered care (3) •– Patient-centered clinical model •– Patient-centered orientation for health care •– Patient-centered clinical method •– Patient-centered primary care •– Patient-centered medical practice •– Patient-centredness •– Patient/family-centered care	9	•– Family-centered care model •– Family-centered practice •– Family-centeredness	3

Associated Spanish/Portuguese terms translated in English	•– *Patient-centered medicine* (medicina centrada en la persona, 2) •– *Patient-centered care* (centralidad) •– *Patient-centered care* (centralidad en la atención) •– *Person-centered care* (cuidado centrado en las personas) •– *Family and community health model/Integrity of care* (modelo de atención integral de salud familiar y comunitaria)	*6*	*Family-centered care* (cuidado centrado na família)	1

Note: In one article (007) "patient-centredness" and "patient-centered care" were used interchangeably. In another article "patient-centered care" and "patient-centered orientation for health care" were used interchangeably. These two articles are thus represented twice in the table. In one article, "patient/family-centered care" was used, as reported in the table. In eight of the articles on family-centered care, the health context was either neonatal or pediatric care.

Dimensions of the integrative model

Each dimension of the integrative model[5] was covered in the selected literature. For an overview of the dimensions of the integrative model, see Supporting Information: Appendix S1. *Patient information* was the dimension that was covered most often, with 31 articles mentioning it. The dimension covered the least was *physical support*, with four articles mentioning it. For an overview of the frequency by which the dimensions were covered in the selected literature (see Table 2).

Table 2 Number of articles (*n* = 32) that covered the dimensions of the integrative model of patient-centeredness ordered by frequency.

Dimension of the integrative model of patient-centeredness	Count
Patient information	31
Patient involvement in care	26
Essential characteristics of the clinician	25
Clinician–patient relationship	25
Clinician–patient communication	24
Involvement of family and friends	23

Patient empowerment	21
Patient as a unique person	20
Coordination and continuity of care	19
Biopsychosocial perspective	17
Access to care	17
Emotional support	11
Integration of medical and nonmedical care	8
Teamwork and teambuilding	7
Physical support	4

In eight articles on FCC, the health context was either neonatal or pediatric care. In five of these articles, the covered dimensions of the integrative model were described as referring to the family, not only the patient. For example, in a study on FCC at neonatal intensive care units, the *clinician–patient relationship* naturally included the clinician–family relationship. Similarly, the family was included in the other dimensions. In the articles on PCC, the patient's family was referred to in a separate dimension, namely the *involvement of family and friends*, as done in the integrative model.

The dimensions *patient information* and *involvement of family and friends* were covered by all articles on FCC. However, the dimension *physical support* was not covered by any article on FCC. The dimensions *patient information, essential characteristics of the clinician, and patient involvement in care* were covered by over 80% of the articles on PCC. For a detailed overview of the frequency by which the dimensions were covered in articles on either PCC or FCC (see Table 3). For detailed overviews of the included literature and the coding of the dimensions of the integrative model, see Supporting Information: Appendices S2 and S3.

Table 3 Percentage of articles that included the dimensions of the integrative model of patient-centeredness.

Note: Dimensions are ordered by original model and grouped by main concept of the articles. Percentages of minimum 80 are colored green, percentages of maximum 20 are colored red.

Novel aspects of patient-centeredness

In the literature on PCC, the following aspects were mentioned that are not explicitly covered by any dimension of the integrative model proposed by Scholl et al.[5]: “involvement of the local community,”(2) “patient as a multidisciplinary health care team member,” “acknowledgment of the family's potential.” In the literature on FCC, the following aspects were mentioned that are not covered by any dimension of the integrative model: “family as a care unit,”(9) “infrastructure to accommodate family members and to encourage their stay,”(2) “frequent reassessment of preferences as they may change over time.” These novel aspects could be used to extend distinct dimensions of the integrative model. However, we refrain from considering them aspects of PCC specific to Latin America.

Concept analysis

We grouped the definitions of PCC and FCC into the following meaningful clusters: principles, activities, and results. Principles comprised autonomy, respect, collaboration, participation, and the form of care (coordinated and continuous). Activities included how PCC and FCC are implemented, for example, reviewing patient preferences, planning, evaluating, sharing information, and listening to the patient. As a result of the implementation of PCC and FCC, the impact on individuals and families stood out. For a complete overview of the concept analysis and the included definitions, see Supporting Information: Appendix S4.

Patient-centered care

The principles used in the definitions of PCC were dignity, respect, and participation. Autonomy and (co-)responsibility were repeatedly named as well.

PCC includes the following dimensions: biopsychosocial perspective; patient as a unique person; consideration of patient's values and beliefs; power and shared responsibility in care; therapeutic alliance to improve communication and participation in medical decision making; and the professional as a unique person.[32]

The named activities for implementation were observing the patient's preferences, needs and values, sharing information, and improving the communication for the continuity of care. The suggested results of these activities were that patients and their families feel encouraged to make joint decisions about their care, as well as increased patient satisfaction and self-management.

Family-centered care

The principles standing out in the definitions of FCC were dignity, respect and participation of the patient and family, and collaboration with them.

The central assumptions of FCC are dignity and respect, in which professionals should be able to listen to patients and their families, have respect for the knowledge and beliefs of the patient and his/her family, because these assumptions are included in care, shared information, active participation and collaboration.[60]

In addition, the family appeared as a subject of care and an essential source of support to the health care provider. The activity suggested for implementing FCC is sharing information with the family and the expected results are reduced anxiety and stress among the family members (Table 4).

Table 4 Principles, mechanisms, and results in PCC and FCC concepts.

Concept	Attributes	Mechanisms	Results

PCC	•Respect (6) •Dignity (3) •Autonomy (4) •Collaboration (3) •Participation (2) •Holistic framework (2) •Continuous, articulated and quality provision of health services (2) •Responsibility (2) •Citizens' rights (1). •Multidisciplinary, coordinated, continuous, and respectful care. •Respectful, continuous, and coordinated care. •Responsibility. •Patient as subject. •Coordination and integration of health care. •Continuity of care. •Coresponsibility (6). •Patient and the professional as a unique person. •Patient as an individual entity in a social environment. •Citizen's rights. •The role that the family plays in the development of health problems. •Partnership. •Centrality is interchangeable and their use may vary according to the context in which health services are provided.	•Patient's preferences, needs, and values (7) •Sharing information (6) •Communication (3) •Access to care (2) •Individualization of care (2). •Shared decisions making. •Community collaboration. •Cooperation and support at all levels of service provision. •Patient's participation. •Engage patients. •Patient's needs, expectations, and preferences. •Information and education. •Involvement of family and friends in decision-making. •Consider users' and their families' needs. •Therapeutic alliance. •Relationships of trust. •Meet the person holistically. •Planning, delivery, and evaluation among patients, families, and providers.	•Person-centered health education and research. •Person-centered medical education and scientific health research. •Patient satisfaction, decreased supportive care needs, and higher quality of life. •PCC improves satisfaction and quality of life, reduces health care expenditures, and can reduce the supportive care needs of patients. •Encourage patients and their families to make joint decisions about their own care. •Preventative education. •Patient-centered model involves a two-subject medicine model: the physician and patient. •Improve the quality of the processes of care, reduce hospitalizations and emergency visits. •Improve users' satisfaction and self-management. •Strengthen the doctor–patient relationship and make a realistic use of time and resources. •PCC can improve health care utilization, efficiency, quality of care, and patient satisfaction. •These attitudes and skills are, in fact, real tools that can help the person, through his own narrative, to reflect on his health–disease process.

FCC	•Respect (6) •Participation (6) •Collaboration (4) •Dignity (3) •Partnership (2). •Family as the basic unit of care. •Family as essential source of support and main focus of attention. •Autonomy. •Family as the subject of care.	•Sharing information (4). •Planning, delivering, and evaluating health care. •Listening between families. •Community engagement. •Implement services. •Evaluate outcomes.	•Opportunity for the family itself to define its own problems. •Reduce anxiety of family members. •Patient satisfaction. •To reduce the stress that hospitalization. •Give (to the family) some meaning to their own experience. •Promote health and quality of life.

Abbreviations: FCC, family-centered care; PCC, patient-centered care.

References given for the definitions of PCC and FCC

In the selected literature, 89 different references were used to define PCC and FCC. The references were published by authors from 18 countries and one by the World Health Organization. Of 60 references that were provided for the definition of PCC, 37 were international (25 from the United States of America), and 23 were from Latin America. A total of 15 of 23 Latin American references were from Brazil and almost all of these (14) were cited by authors from Brazil. A total of 4 of the 60 references were cited twice. The analysis of the references provided for the definition of FCC showed that of 29 references[19] were international (eight from the United States of America), and 10 were from Latin America, more specifically from Brazil. Three references were cited twice. Also, one reference was cited once in a definition of PCC and once in a definition of FCC.

DISCUSSION

The aim of this study was to identify how PCC is conceptualized in Latin American countries. The analysis showed that two closely related but distinguishable concepts are discussed in the literature: PCC and FCC. Even though diverse terms were used to refer to PCC and FCC, an overlap between the provided definitions and the integrative model,[5] and thus with international literature, was found. In most papers, international literature was cited to define PCC/FCC. There was little overlap in these citations, thus, no specific model of PCC was repeatedly used. Novel aspects not covered by the integrative model[5] emerged as well. Most frequently mentioned was the identification of the family members as units of care.

Most dimensions of the integrative model[5] were covered by at least two-thirds of the included literature. Despite the reported differences to international literature, this shows that the conceptualization of PCC in Latin America considerably overlaps with the conceptualization in the global north. Regarding the dimensions described in the integrative model, we found that *sharing information* and *patient involvement* are most often mentioned in the literature. *Physical support*, *teamwork and teambuilding*, and *integration of medical and nonmedical care* were mentioned least. These results might reflect priorities but also the needs of the current health care systems in Latin America, as patients might continue to be placed at a passive role in their care.

Novel aspects not explicitly mentioned in the integrative model[5] emerged from Latin American literature. The importance of infrastructure and the possibility for accommodation of family members were named. This is supposed to reduce anxiety and stress of family members. Latin America is a diverse region with different health care systems.[20] The health care systems are built on postdictatorship neoliberal economic–political models, which explains that access and infrastructure are still not fully guaranteed in all the states of the region.[19] Thus, in line with previous research, our results imply that health care infrastructure is one problem in Latin America that needs to be addressed to guarantee universal access to care and to enable a cascade of PCC activities.

The involvement of the local community has emerged as another novel aspect to the integrative model. In contrast to the involvement of the family, this aspect has not been explicitly stated in the international literature the integrative model is based on. Potential explanations are that community involvement is, dependent on the region, difficult to implement and thus less intuitive than involvement of families for example. Involvement of the local community has been proposed with the aim to make use of all given resources to improve the health care of individual patients. Another reason for the emergence of the local community as an aspect of PCC might be of historical nature. In Brazil, the Unified Health System was promoted by a health reform because there was a regionalized and decentralized network of health services, focusing on community participation.[64] Other reasons might be a cultural imprint towards collectivism or a lack of resources.

The content analysis showed that the primary principles identified in PCC and FCC in Latin America are dignity, respect, and participation. These findings are in line with the conceptualization of PCC and FCC outside Latin America.[65,66] The overlap can be explained by the fact that the references used to define PCC and FCC were primarily from non-Latin American countries, mainly from the United States of America. On the one hand, this is in line with the idea of a standard model of PCC. On the other hand, these results show that there is a scarceness of research groups specialized in PCC in Latin America, who have worked on proposing a conceptualization relevant for their own context, which is a contrast to North America, Europe, or Australia.

An international scoping review suggested FCC to be a part of PCC with a stronger focus on patient and family values, preferences, and needs.[67] In contrast, our analysis showed differences between the concepts. Firstly, in the case of PCC, the focus was the patients themselves while the patient's family was referred to separately. The emphasis was placed on the co-responsibility of the patient, excluding other significant actors such as relatives. In the definition of FCC, the focus was on the family and a collaboration established between the family and health professionals. This can be explained by the fact that the literature associates FCC with caring for children, elderly, or ailing individuals (not able to consent), thus, with the need for collaboration between family and HCPs.[68] This focus can also be observed in the Latin American context. Secondly, we found differences in the activities and results of the two concepts. In PCC, the focus is on the encouragement of patients to take part in the decisions of their care, and the patients' satisfaction and self-management. Contrary to PCC, for FCC the analysis showed that sharing information with the family is one of the most important activities aiming at the reduction of anxiety and stress of the family members, without necessarily enhancing an active involvement of the family members in the decision-making process.

This article has some limitations. Firstly, following the recommendations of Peters,[33] no quality appraisal of the included literature was conducted. However, there is literature arguing in favor of an assessment of quality in scoping reviews similarly to systematic reviews.[69] Secondly, the gray literature search involved asking Latin American experts in PCC for relevant references. The experts were identified by the Latin American coauthors. This acquisition of experts might not have been exhaustive. In future studies, multiple independent researchers could be asked to achieve an exhaustive search of experts and thus of gray literature. Thirdly, numerous articles discussed PCC but failed to provide any meaningful definition of the concept. As we required an explanation of the concept for our concept analysis, we excluded these articles. Similarly, we excluded articles that only contained a keyword in the abstract but not in the title. Even though that was a considered decision, it may have caused a loss of information about the conceptualization of PCC in Latin America. Despite the limitation to articles with keywords in the title, the full-text screening resulted in numerous articles missing a definition of PCC. Therefore, we propose that the scoping review provides a justifiably complete overview of the conceptualization of PCC in Latin American research and health policies.

Aside from the limitations, the scoping review offers distinctive strengths. The coauthors involved in the scoping review are experts in the field of PCC in Latin America and in Germany. The team jointly developed a search strategy that identifies as many sources on PCC as possible, even though the terminology in Latin America is diverse. Another strength is the identification of the conceptualization by use of a scoping review methodology. The method offers a broad overview of terminology and definitions and the opportunity to draw connections between present studies. Thus, this scoping review adds to previous research not covering studies from all over Latin America.[13,27]

Our study shows that research on PCC is limited to a few Latin American countries. A strategy to support research on PCC in multiple countries in Latin America could be transnational studies on PCC, involving researchers and data from more than one country. The results also imply that future studies should clearly define the concept they aim to investigate. These strategies can foster the development of a common conceptualization of PCC. Future research can expand the present findings by assessing the needs of Latin American health care systems regarding PCC and barriers of its implementation. Novel aspects of PCC emerged from the present study. An integration of these novel aspects into the integrative model,[5] either as new dimensions or as elements of existing dimensions, should be investigated in future empirical studies. The results also showed that few health ministries in Latin America have published documents discussing PCC, even though PCC is a declared aim. Thus, the concept should be defined and specific aims regarding PCC should be described in health care policies. The definition of PCC should be based on empirical research.

CONCLUSION

This scoping review synthesized and compared the conceptualization of PCC in 32 selected articles from Latin America published between 2006 and 2021. The analyses demonstrated a strong overlap between the integrative model and the definitions of PCC given in the literature. A conceptual distinction between PCC and FCC has been found. However, the results indicate a lack of standardization of the concept PCC in Latin America. The results will be used to develop a mixed-methods study to understand the needs, barriers, and facilitators regarding PCC in Latin America. Based on the outcomes, the integrative model will be adapted to the Latin American context. The aim is to introduce a standard model for PCC that enables comparability of research, a transfer of outcomes between countries, and increasingly efficient communication on PCC in research, health policy, and clinical practice.

AUTHOR CONTRIBUTIONS

All authors contributed to the conception and design of the study. Anne Klimesch, Alejandra Martinez-Pereira carried out the searches, and the interpretation of the results. Anne Klimesch, Alejandra Martinez-Pereira, and Cheyenne Topf were involved in the data extraction. All authors contributed to the writing up of the manuscript and approved the submitted version.

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CONFLICT OF INTEREST STATEMENT

Anne Klimesch, Alejandra Martinez-Pereira, and Cheyenne Topf declare that there are no conflict of interest. Martin Härter, Isabelle Scholl, and Paulina Bravo declare that they currently are (Martin Härter, Paulina Bravo) or have been (Isabelle Scholl) members of the executive board of the International Shared Decision-Making Society, which has the mission to foster the implementation of shared decision-making and patient-centered care. Paulina Bravo, Martin Härter, and Isabelle Scholl have no further conflict of interest.

DATA AVAILABILITY STATEMENT

All data generated during this study was included in this published article.

DETAILS

Subject:	Health care access; Research; Patient-centered care; Patient information; Databases; Coding; Health care policy; Concept formation; Communication; Patients; Health disparities; Family centered care; Caregivers; Differentiation; Patient satisfaction; Health care; Clinical medicine; Decision making; Primary care; Public opinion surveys
Business indexing term:	Subject: Public opinion surveys
Location:	Latin America; Chile
Company / organization:	Name: Organization for Economic Cooperation &Development; NAICS: 541720
Identifier / keyword:	family-centered care; Latin America; patient-centered care; person-centered care
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Issue:	5
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Environmental health perceptions of urban youth from low-income communities: A qualitative photovoice study and framework

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ABSTRACT (ENGLISH)

Background

Children are amongst the most susceptible groups to environmental exposures, for both immediate and life-course health outcomes. Despite their increased susceptibility, children's knowledge, experiences and voices are understudied. A deeper understanding of children's environmental health perceptions has the potential to better inform policy, develop targeted interventions and improve public health outcomes.

Methods

In this study, our community–academic partnership used the Photovoice research method to examine how urban children from low-income communities perceive environmental influences on their health. Twenty children, ages 10–12, took photographs and participated in focus group interviews regarding their perspectives on how the environment influences their health.

Results

Qualitative analyses revealed five major thematic categories: environmental exposures, environmental health sentiments, environmental health outcomes, interest in environmental health and environmental health solutions. We used the findings to develop an environmental health perspective theoretical framework that can inform future work designed to promote the environmental health and well-being of children from low-income communities in urban communities.

Conclusion

Photovoice enabled children from low-income communities to capture and communicate their environmental health perceptions. These findings have the potential to inform and identify potential targets and opportunities for environmental health interventions and promotion in their communities.

Patient or Public Contribution

Partnerships with community-based organizations were central to the present study. By design, these community-based partners were involved in the conduct and procedures of the study.

FULL TEXT

INTRODUCTION

Children are amongst the most susceptible groups to environmental exposures.[1] Childhood environmental exposures have significant implications for immediate health outcomes as well as health outcomes throughout the life course.[2] In the United States (US), there are striking racial, ethnic, and socioeconomic disparities in childhood environmental exposures.[3] Specifically, compared to their White, non-Hispanic, or high-income counterparts, Black, Hispanic, or children from low-income communities consistently experience higher exposure to environmental hazards and lower exposures to health-promotive environmental facets.[4,5] Such environmental hazards include exposure to lead-based paint, tobacco smoke, ambient and traffic-related air pollution, and living in closer proximity to hazardous waste.[6] Examples of promotive environmental facets include nature contact, tree shade, clean neighbourhoods, and access to healthy food.[7,8] Furthermore, individual and community-level perceptions of the environment and associated health impacts play an important role in how individuals engage with their surroundings.[9–11] Environmental health perceptions may influence the diet, physical activity, and physical safety of community members, especially children, and thus impact their development and behaviours later in life.[6,12] Currently, there is a substantial knowledge gap in the literature as children's environmental health perceptions are critically understudied. Researchers must engage, examine, and incorporate children's environmental health perceptions into public health and public policy discourse to better improve health outcomes, especially in urban and low-income communities.

Photovoice is a community-based participatory action research methodology in which researchers can understand and incorporate childhood environmental health perceptions.[13–15] Briefly, Photovoice engages research participants by asking them to take photos on a given topic and later asking them to discuss these photos during a focus group.[13–15] The Photovoice research method has been traditionally viewed as an avenue through which marginalized communities can participate in academic research and ultimately have influence over policy decisions.[13,16,17] Photovoice allows for collaboration between community members and researchers by empowering community members to capture and communicate their perceptions and knowledge.[18]

Photovoice has been shown to be an effective tool for empowering children and youth.[15,19,20] For example, Photovoice enabled minority New York City youth to reflect on food justice issues and engage in promoting positive community changes.[16] Photovoice has also been used as a participatory process for research and social change allowing children to feel 'seen' by adults.[19] Given its participatory focus, Photovoice may be a valuable tool for allowing children to express their environmental health concerns and perceptions. Therefore, the purpose of the current study was to identify and characterize the environmental health perceptions of urban, low-income US children. We utilized Photovoice methods to engage a sample of children from St. Louis, Missouri, to identify and better understand their perspectives on environmental exposures and health concerns. We used the results to develop a youth-informed environmental health perspective theoretical framework.

METHODSStudy context

A community-academic partnership between Gateway to the Great Outdoors, Columbia University's Mailman School of Public Health, Emory University Rollins School of Public Health and Washington University in St. Louis was established in 2017 to provide environmental education programming to St. Louis Public Schools, which has a student body that is 95% or more on the free and reduced lunch programme.[15,21,22] This partnership was established as St. Louis Public School students face disproportionate amounts of environmental and behavioural health disparities compared to students in neighbouring school districts.[23] The environmental education intervention run by this community–academic partnership has been described in detail in prior publications.[15,21] Briefly, the intervention consists of (1) weekly interactive, in-class science, technology, engineering, art and math lessons focused on environmental health and (2) monthly nature-based field trips.

The current study was approved by the Human Subjects Review Boards at Emory University, Columbia University, and Washington University in St. Louis, and informed consent or assent was obtained from all study participants. The in-person intervention was administered during the Fall 2020 semester (August–December, 10 weekly lessons and 3 nature-based field trips) and during the Spring 2021 semester (January–May, 10 weekly lessons and 3 nature-based field trips), to children attending the same St. Louis Public School District school. All students participating in the community-academic partnership's in-person programming during the 2020–2021 academic school year were included in this study.

The research team was multidisciplinary, consisting of researchers trained in epidemiology, biology, anthropology, environmental science and environmental education. The multidisciplinary research team included a senior author (C. C. E.) with lived experience as a Black woman growing up in St. Louis. She has an interest in issues of environmental justice for Black US communities. The senior author provided supervision and critical feedback throughout the research process. Data collection and analyses were completed by N. L. S., H. M. Z., L. J. H., R. W. and H. D. who do have a shared history with study participants. All authors aimed to amplify the voices of the child study participants, whose perspectives are often underexamined in environmental health promotion research.

Photovoice environmental education intervention

The students participated in a Photovoice community-based participatory research project (Photovoice activity). During the first class of the intervention, the students received disposable cameras and then participated in a 60-min lesson on how to use said cameras as well as how to obtain consent when photographing other humans. After the 60-min lesson, the students were instructed to take photographs of how the environment impacts their health. The students returned their cameras on week 2 of the intervention. On week 3, the developed photographs were brought to the classroom and the students were individually interviewed about the photographs that they took by trained research assistants.

We conducted individual interviews instead of focus groups because children may have been less likely to disclose their perspectives with their peers present. The interviews were semistructured interviews to explore children's perspectives in depth. Sixty minutes were allotted for the interviews during week 3 of the intervention. Interview questions focused on what the student captured in the photograph, how the photograph related to environmental health and how the photograph made the child feel (an interview guide is available upon request from the senior author). The interviews, which ranged from 20 to 52 min long, were recorded and later transcribed.

Data analysis

The study used a pragmatism paradigm.[24] As such, we undertook a mixed thematic analysis approach that aimed to identify and characterize environmental health perceptions through both codebook and coding reliability approaches.

Our thematic analysis approach was adapted from Castleberry and Nolen[25] and Braun and Clarke.[26] Briefly, Castleberry and Nolen's approach, widely used in the health sciences, consists of five steps to thematic analysis: compiling, disassembling, reassembling, interpreting and concluding.[25] Our approach also utilized what Braun and Clarke term ‘coding reliability’ and ‘codebook’ thematic analysis.[26] These approaches allowed for both a detailed accounting of participants' environmental health perceptions (coding reliability) and inductive theme development (codebook).

Four trained researchers familiarized themselves with the data through a preliminary analysis of the transcripts. Then, the four researchers independently brainstormed potential thematic codes based on the transcripts. After, the four researchers met and discussed their potential thematic codes. From that meeting, the researchers developed an official list of themes that were derived from the manuscript. A fifth researcher, who was purposefully excluded from the initial meetings, revised and approved the final list of themes. Once the final list of themes was approved, two researchers independently coded every transcript for every theme. Agreement between the two independent researcher's coding was determined through the κ statistic. The κ statistic ranges from −1.0 (complete disagreement) to 1.0 (complete agreement); where scores of 0.61–0.80 suggest substantial agreement and scores of 0.81–1.0 suggest strong agreement.[27,28] All transcripts were coded and analyzed in Microsoft Word and Microsoft Excel. We utilized the guidelines outlined in the Standards for Reporting of Qualitative Research checklist in reporting this study (Supporting Information: Appendix 1).[29]

Lastly, using the subjectivist inductive approach to research, results from this study were used to develop a youth-informed environmental health perspectives theoretical framework.[30] The framework is presented in the discussion section of this paper.

RESULTS

A total of 20 students participated in the current study. Of the 20 participants, 8 (40.0%) students were Black, 5 (25.0%) were White, 1 (5.0%) was Asian, 4 (20%) were two or more races and 2 (10.0%) were self-identified as other. The median age of the study participants was 12.

The thematic categories from the qualitative data analysis are presented in Table 1. There were five major thematic categories: environmental exposures, environmental health sentiments, environmental health outcomes, interest in environmental health and environmental health solutions. The interrater agreement for each subtheme ranged from a κ of 0.72 for environmental exposures and 0.93 for interest in environmental health.

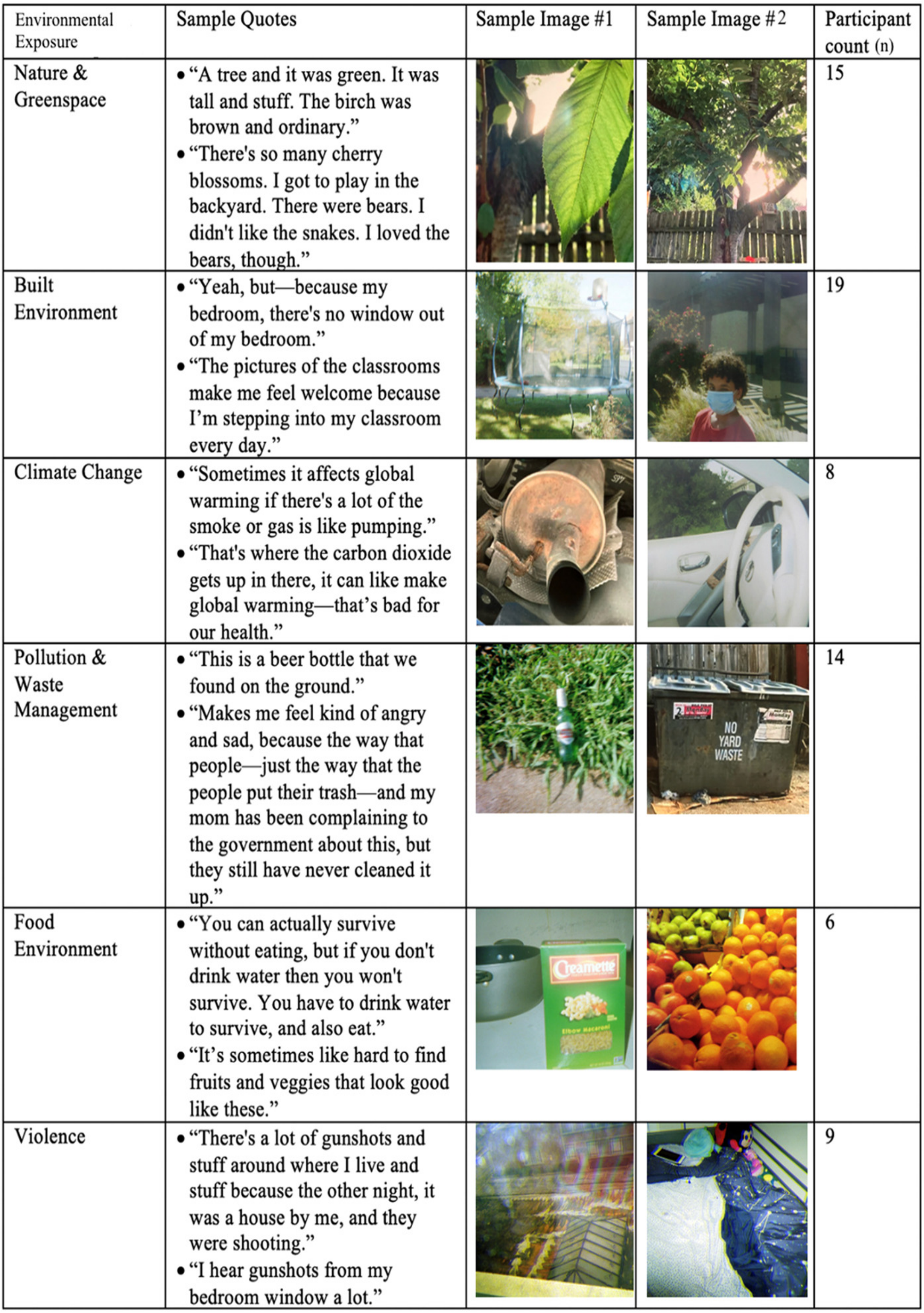
Table 1 Themes and subthemes from Photovoice focus groups.

Theme	Subtheme
Environmental exposure	Nature and greenspace
	Built environment
	Climate change
	Pollution and waste management
	Food environment
	Violence
Environmental health perceptions	Positive

	Negative
Environmental health outcomes	Emotional and mental health
	Physical activity
	Safety
Interest in environmental health	Inquisitive
	Apathetic
Environmental health solutions	Individual level
	Community level
	Global Level

Environmental exposures

The environmental exposures theme was characterized by photographs of the students' environment which they believed influenced their health. This theme included the following subthemes: nature and greenspace, built environment, climate change, pollution and waste management, food environment and violence. The environmental exposure subthemes, sample quotes and sample images are presented in Figure 1.



Environmental Exposure	Sample Quotes	Sample Image #1	Sample Image #2	Participant count (n)
Nature & Greenspace	• “A tree and it was green. It was tall and stuff. The birch was brown and ordinary.” • “There's so many cherry blossoms. I got to play in the backyard. There were bears. I didn't like the snakes. I loved the bears, though.”			15
Built Environment	• “Yeah, but—because my bedroom, there's no window out of my bedroom.” • “The pictures of the classrooms make me feel welcome because I’m stepping into my classroom every day.”			19
Climate Change	• “Sometimes it affects global warming if there's a lot of the smoke or gas is like pumping.” • “That's where the carbon dioxide gets up in there, it can like make global warming—that’s bad for our health.”			8
Pollution & Waste Management	• “This is a beer bottle that we found on the ground.” • “Makes me feel kind of angry and sad, because the way that people—just the way that the people put their trash—and my mom has been complaining to the government about this, but they still have never cleaned it up.”			14
Food Environment	• “You can actually survive without eating, but if you don't drink water then you won't survive. You have to drink water to survive, and also eat.” • “It’s sometimes like hard to find fruits and veggies that look good like these.”			6
Violence	• “There's a lot of gunshots and stuff around where I live and stuff because the other night, it was a house by me, and they were shooting.” • “I hear gunshots from my bedroom window a lot.”			9

Enlarge this image.

Nature and greenspace

Encounters with nature and greenspace, such as parks and trees in their neighbourhoods, were described by study participants. One student stated that they ‘took pictures of nature. I took pictures of leaves. I took pictures of trees, like trees in the cold time. They didn't have no leaves on there. I took pictures of the sky’ (participant 1). This quote demonstrates students' awareness of the nature surrounding them, as well the conditions and appearances of that nature. Another student took a picture of a tree ‘Because a tree can help you calm down and lose stress’ (participant 2). This quote reveals students' understanding of nature and greenspace's impact on their mental health.

Built environment

Participants also described aspects of their environment that were structural or manmade, as opposed to exposures to nature. Examples included participants' schools, homes and other aspects of their built urban environment. One student described enjoying travelling on the highway, saying, ‘I feel kind of happy, 'cause it's sunny, and whenever we're driving to, like, Walmart you can just smell the fresh air as we're driving on the highway, and it just always gives me a good vibe for some reason. I just feel happy knowing we're on the highway’ (participant 3). This quote demonstrates the feelings of joy the student receives when engaging with features of the built environment (a highway and car).

Climate change

Climate change and its influence on health were also discussed. Some students discussed their personal experiences with climate change in their own environment, while others discussed climate change on a global level. For example, one student voiced concerns about the health impacts of forest fires, as she stated ‘Australia is on fire! People are losing their homes and it can't be good for breathing’ (participant 4). This quote shows that students are aware of the global effects of climate change on human health and wellbeing.

Pollution and waste management

Pollution and waste management were identified as environmental exposures that impact health. Specifically, students focused on exposure to air pollution, litter and noise pollution. Students discussed being exposed to air pollution. For example, one participant took a photo of a car's exhaust pipe (participant 5). Another student took a picture of his local Walmart and described the air as ‘polluted’ (participant 3). This reveals that students associate human activities, such as large-scale production and car exhaust, with environmental and health harm.

Students also took photographs and discussed the accumulation of litter and trash in their environment. One student stated that they would ‘pick all the trash up’ to improve their environment (participant 6). This quote shows that students identify litter as a relevant environmental exposure. Another student described the negative effects of litter, saying ‘Some people are throwing trash on the ground, like this right here, that's going to affect our environment sooner or later. It might take some time, but if this keeps up, it will affect our environment’ (participant 7). This quote demonstrates this student's knowledge of the effects of environmental exposure accumulation. One student said of a picture of a pile of litter, ‘Why this picture is important to me is that you should use a dumpster and not just put trash in a pile. Just use it like a pile like—just the ground as a dumpster. You should use it like a trash can’ (participant 8). Another participant (4), who took a photo of a recycling bin, said ‘Well, the recycling that—'cause reuse—the three Rs, we can help reduce, reuse, and recycle, of course, and that's good for the environment and it helps the environment’. The two previous quotes show that students are knowledgeable about the proper management of trash as an environmental exposure. Participants' descriptions of exposure to noise pollution were also categorized under this subtheme. One participant referenced gunshots as a source of noise pollution.

Food environment

Participants' mentions of nutrition and diet, and the effects of nutrition on their health, were categorized in the nutrition subtheme. One student took a picture of water and stated that ‘water is actually really healthy for you, and also you can actually survive without eating, but if you don't drink water then you won't survive. You have to drink water to survive, and also eat’ (participant 9). In this quote, the student is drawing connections between nutritional exposures and health outcomes.

Violence

Participants' references to violence in their environment were categorized under this subtheme. One student referenced gunshots in a nearby house, stating ‘I feel bad about it because there's a lot of gunshots and stuff around where I live and stuff' (participant 10). This quote reveals that students view violence in their community as an environmental exposure that directly impacts their mental health.

Environmental health sentiments

This thematic category was characterized by the direction in which participants viewed how their environment influenced their health outcomes. We coded these emotions into two subthemes: positive and negative.

Positive sentiments

When describing pictures of their environment, many participants expressed positive emotions toward the people, places and natural objects captured in their photos. Several participants shared pictures of their friends and family, while others captured outdoor spaces in their community. When asked how her picture of a tree made her feel, one participant answered, 'It just makes me feel [a] sense of worth', (participant 11) indicating that interaction with nature can improve feelings of self-efficacy and personal worth. Several participants credited their environments for a positive impact on their mental, physical, or emotional health. One participant described her feelings towards her picture of spinach as 'excited' because 'it helps me with my health, and also spinach is actually really good' (participant 12). This quote highlights the positive emotions that students feel when they enjoy activities that they also identify as health promotive.

Negative sentiments

Several participants expressed negative emotions toward their environmental health when describing their photos. Much of the negative sentiment stemmed from the presence of environmental harm or the absence of environmental amenities. One participant lamented that 'environments with not enough grass bother me for lots. The smells of the city are horrible and I hate it' (participant 2). The quote reveals environmental exposures within their city that students feel negatively towards. Others expressed negative sentiments towards their environment due to safety issues like violence and shootings. Another common cause of negative sentiment was the presence of litter in their environments. When asked why it was important to him to capture a picture of litter, one participant responded, 'the trash one is important to me because it affects the earth. It affects me because I don't like seeing trash out. It just looks messy' (participant 7). This quote demonstrates that both health and aesthetic conditions influence students' feelings toward their environment.

Environmental health outcomes

Participants' perceptions of the health effects from environmental exposures were categorized under the environmental health outcomes theme. This theme included three subthemes: emotional and mental health, physical activity and safety.

Emotional and mental health

Many students expressed that their environment affected their emotional and mental health, both positively and negatively. Many students believed that being in nature had positive impacts on their mental health. For example, one student stated that nature enhances his mental health 'cause the sun is always shining and stuff, so yeah, it affects me in a good way' (participant 13). This quote reveals that students acknowledge that their environmental exposures may positively impact their mental health outcomes. Another student stated that a tree in her backyard 'makes me feel special' (participant 2). This is another comment on how greenspace may promote positive mental health benefits for students by increasing their sense of worth. Conversely, pollution and litter in the students' environment negatively influenced their emotional and mental health. For example, one student took a photograph of trash in his neighbourhood and said that 'It makes me feel kind of angry and sad, because the way that people—just the way that the people put their trash… It just makes me angry and sad. It makes me sad that people just put trash there for no reason' (participant 6). This quote shows that the presence of trash as well as human behaviour towards the environment can negatively impact students' mental health.

Physical activity

Students also expressed that their environment influenced their physical activity level. For example, one student describes exercising in their home environment alone in their bedroom: 'I don't tell my mom these things, but I actually practice my jumping, kicking, punching, and chopping on my doors and rug, and practising my wall walk' (participant 14). In this quote, the student reveals environmental features (doors, rugs, privacy) that promote physical activity. Another student took a photo of a trampoline in their yard, ‘This is a trampoline. I say it helps your health because if you jump on it, you can get exercise and that gets your heart pumpin' so it can help your health’ (participant 15). In this quote, the student identifies a feature of their built environment (a trampoline) that directly impacts their physical activity levels.

Safety

Some students discussed how their environment influenced their safety. Some students described feeling safe in their environments, while others described feeling unsafe. One student described being happy about having a place to live, saying ‘‘Cause if we didn't have something to live, we might be in danger’ (participant 8), This reveals that students directly tie their environment to safety. Another student described gunshots as part of their environment: ‘the other night, it was a house by me and they were shooting. I don't know why’ (participant 16). This quote shows that students may have safety concerns about their surrounding environments.

Interest in environmental health topics

Participants expressed differing levels of engagement and curiosity toward their environment and its effect on their health. We coded these emotions into two subthemes: inquisitive and apathetic.

Inquisitive

Participants expressed curiosity toward the elements captured in their photos and how they might affect their health. When asked how the trees she captured affected her health, one participant (1) asked, ‘Don't trees give you oxygen?’ This quote shows students asking inquisitive questions to clarify how their environmental surrounding impacts their health. Other participants made observations and/or hypothesized about their environmental health based on their photos. One participant conjectured that the build-up of trash she observed in her environment would ‘affect our environment sooner or later’ (participant 7). This quote highlights that students can draw conclusions based on prior knowledge and forecast future outcomes.

Apathetic

Participants also expressed apathy towards their photos and/or the concept of environmental health in general. When asked why their photos were important to them, some participants could not name a reason. Others declared their photos unimportant altogether. When asked how the environment affects their health, seven participants responded with ‘I don't know’. This response indicates that some participants had never previously considered the impact of their environment on their health and did not express interest in doing so during the interview. While the participants had feelings of apathy toward how their environment impacts their health, they were able to discuss their photographs in detail.

Environmental health solutions

Several participants (n = 17) offered solutions to improve their environments and promote positive health outcomes. These solutions ranged in scale and mentioned a variety of stakeholders. We coded these solutions into three subthemes: individual level, community level and global.

Individual-level solutions

Some participants offered examples of actions they could take as individuals to improve their environments and promote positive health outcomes. Most examples focused on the elimination of trash and litter. When asked how they protect their environment, one participant answered, ‘I try to pick up trash when I can. Every time my mom or my granny wants to litter without noticing it, I tell them, “No, don't litter”’ (participant 18). In this quote, the student is highlighting their ability to take individual-level action to prevent littering and reduce the negative environmental exposure of litter. Several participants expressed the desire for more environmental amenities to improve their health outcomes. When asked if they would change anything about his environment, another participant noted, ‘I would plant more trees’ (participant 19). This quote highlights a specific action that a student would do to promote health in their environment.

Community-level solutions

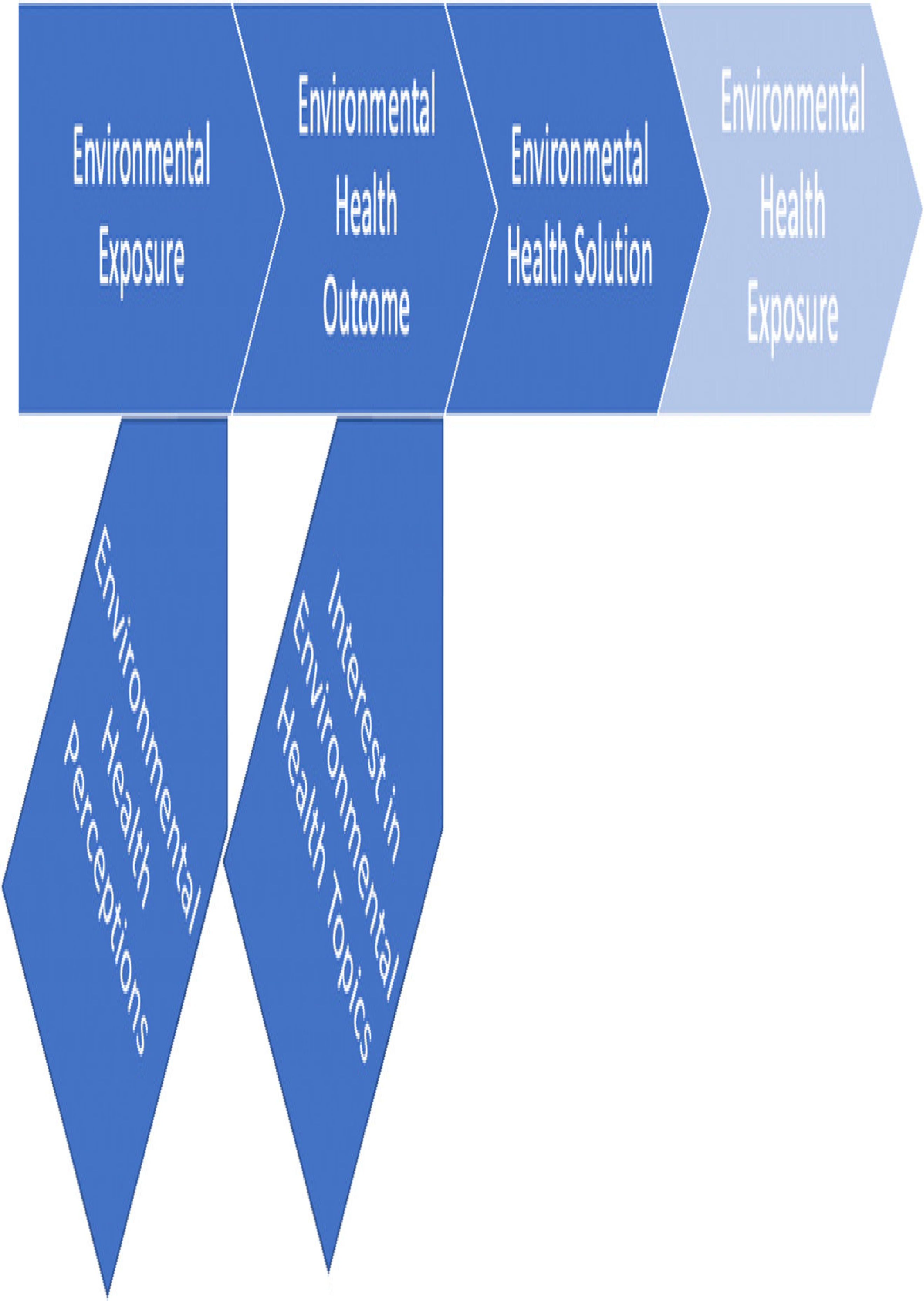
Other participants offered ideas to improve their community, neighbourhood or city. These solutions would often require a group actor, such as a government or neighbourhood association, to offer more environmental amenities. For example, one participant stated that they would, '…get more trees and have all the houses more away from each other. I don't know. Just have more trees, more grass, and just more stuff where people can breathe better and just have more space to have fun and stuff, I guess, outside' (participant 1). In this quote, the student is demonstrating a community-level intervention to improve overall environmental health.

Global solutions

Some participants offered solutions to improve the environment on a global scale. One participant showed a picture of the tailpipe on their family's car and said, '…if we continue to change from this to electric cars, all-electric cars, then we can stop all the pollution' (participant 20). They predicted that electric cars would become the standard around the globe within the next few decades.

DISCUSSION

This study examined the environmental health perceptions of urban children from low-income communities through the Photovoice research methods. We chose to use the Photovoice research method as this and other community engagement research strategies are paramount for communicating associated health risks with those living in areas of poor environmental health.[31] The qualitative analysis of the Photovoice method revealed five major thematic categories: (1) environmental exposures, (2) environmental health sentiments, (3) environmental health outcomes, (4) interest in environmental health and (5) environmental health solutions. These findings have informed the development of a theoretical framework to characterize the environmental health perspectives of children from low-income households in urban settings (Figure 2).



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We believe that this study is one of the first efforts to incorporate the knowledge and perspectives of children from low-income US communities to inform the development of an environmental health perspective theoretical framework. Although community-engaged studies often incorporate the experiences of community members, very few focus on the perspectives of children. Prior work has shown that environmental perceptions have just as large of an impact on health outcomes as actual environmental exposures.[32,33] This study innovatively incorporates the knowledge and perceptions of youth to develop an environmental health perspective theoretical framework. Our child-informed environmental health perspective theoretical framework will inform future research and intervention efforts with children from low-income households in St. Louis.

As depicted in Figure 2, both environmental exposures and environmental health sentiments influence environmental health outcomes. Existing research suggests that environmental exposures may promote both positive and negative health outcomes.[34,35] For example, studies have found that nature and greenspace exposures improve a wide array of health outcomes (such as sleep, mental health, well-being, attention, cardiovascular, pain, vision and respiratory).[36,37] Alternatively, exposure to environmental toxins may cause negative health outcomes.[38] For example, living in a neighbourhood with limited access to supermarkets and fresh produce has been associated with increased risks for obesity and related health outcomes.[39,40] Exposures to ambient and household air pollution have been associated with a number of adverse health outcomes (including asthma, respiratory disease, cardiovascular disease, lung cancer and mortality).[41,42] There is a strong existing body of evidence base supporting the causal association between environmental exposures and health outcomes.

Research has also highlighted the significant impact of environmental health sentiments on environmental health outcomes.[32,33] One study investigated the relationship between environmental exposures, perceptions, and outcomes for indoor and outdoor air quality in Seoul, Korea by collecting data and surveying 396 elementary school students (average age = 11) and 64 parents.[32] This study found that environmental health sentiments significantly influenced environmental health outcomes, even in areas with comparable environmental exposures.[32] The current evidence base supports our child-inform theoretical framework, with both environmental exposures and perceptions influencing outcomes (Figure 2).

Also shown in the theoretical framework (Figure 2), environmental health outcomes ideally lead to multilevel (individual, community, global) environmental health solutions. However, the creation of environmental health solutions is dependent on the level of interest in environmental health issues (inquisitive or apathetic) amongst individuals, activists, educators, communities and/or legislators. For example, for several decades, the negative effects of lead exposure on children's health (such as cognition, school performance and mortality) have been well established.[43] Despite the knowledge of the negative impacts of lead poisoning, the United States has continued to see extensive human exposure to lead poisoning, threatening the health and livelihood of children.[44] While the effects of lead on human health were well established, interest in children's environmental health issues increased during the 2014–2015 crisis of lead-contaminated drinking water in Flint Michigan.[44] This crisis elevated the awareness and issue of lead poisoning and ignited a public outcry worldwide.[45,46] Studies suggest that these events caused an increase in the public interest.[46] In the United States, this elevated awareness (concern over lead water in drinking water) forced school districts to take action and create environmental health solutions (testing school drinking water and shutting down any drinking fountain with potential lead pollution),[46,47] leading to calls for more community-oriented, creative and intersectional solutions. For children, evidence suggests that engaging in environmental health education is an effective intervention for increasing inquisitive interest in young people,[48] and could thus lead to informed solutions.

Our theoretical framework indicates that environmental health solutions may lead to new, positive environmental exposures (Figure 2). For example, the development of new greenspaces may promote improved mental and physical health outcomes.[49] One study investigated the changes in children's physical activity patterns before and after a large-scale playground greening intervention at a low-income Los Angeles Public School.[49] The study found a 10.0% decrease in sedentary activity and a 48% increase in vigorous activity participation after the playground greening intervention was complete.[49] This is an example of an environmental health solution (greening playgrounds) altering the environmental exposure (playgrounds and greenspace) and, in turn, altering environmental health outcomes (physical activity).[49]

The main strengths of this study include its use of participatory research methods to examine children's perceptions and develop a children-informed environmental health perspective theoretical framework. Using a mixed thematic analysis approach to develop thematic codes allowed for the children's voices to lead the research, rather than deferring solely to a potentially biased predetermined framework. The limitations of this study should also be noted. First, this study was conducted during the COVID-19 pandemic, which may have limited children's outdoor activities and therefore influenced perceived environmental exposures and sentiments. Another limitation includes the transferability of these study findings. The study was conducted in a sample of children from low-income families in St. Louis and the theoretical framework may or may not be applicable to children in other settings. Future studies in other study settings with children of different socioeconomic, racial and ethnic backgrounds are warranted.

CONCLUSION

The knowledge, experiences and voices of children are underexamined in environmental health research. The findings of this study have implications for our understanding of children's perceptions and can assist in informing the work of researchers, educators and health and social professionals who interact with children from low-income households in St. Louis. We developed an environmental health perspective theoretical framework that can inform future survey instruments that include questions about environmental health exposures, sentiments and/or outcomes. Further, the use of Photovoice and the development of this theoretical framework should be considered as the first steps in a series of research strategies aimed at improving our understanding of child environmental health outcomes through improved measurements and assessments. As such, our findings have the potential to inform and identify potential targets and opportunities for interventions aimed to promote child health in an urban, low-income community.

AUTHOR CONTRIBUTIONS

The authors confirm their contribution to the paper as follows: *Study conception and design: Conceptualization*: Nadav L. Sprague and Christine C. Ekenga. *Data curation*: Nadav L. Sprague and Christine C. Ekenga. *Formal analysis*: Nadav L. Sprague, Hannah M. Zonnevylle, Lexi Jackson Hall, Rosalind Williams, Hannah Dains and Christine C. Ekenga. *Funding acquisition*: Nadav L. Sprague and Christine C. Ekenga. *Investigation*: Nadav L. Sprague and Christine C. Ekenga. *Methodology*: Nadav L. Sprague, Hannah M. Zonnevylle and Christine C. Ekenga. *Project administration*: Nadav L. Sprague, Hannah M. Zonnevylle, and Christine C. Ekenga. *Resources*: Nadav L. Sprague and Christine C. Ekenga. *Software*: Nadav L. Sprague and Christine C. Ekenga. *Supervision*: Christine C. Ekenga. *Validation*: Nadav L. Sprague, Hannah M. Zonnevylle and Christine C. Ekenga. *Writing—original draft*: Nadav L. Sprague, Hannah M. Zonnevylle, Lexi Jackson Hall, Rosalind Williams, Hannah Dains, Donghai Liang and Christine C. Ekenga. *Writing—review and editing*: Nadav L. Sprague, Hannah M. Zonnevylle, Donghai Liang and Christine C. Ekenga. All authors have read and agreed to the published version of the manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data generated during the study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

This study was approved as exempt from written consent by the Institutional Review Boards at Emory University, Washington University in St. Louis, and Columbia University.

DETAILS

Subject:	Agreements; Health promotion; Intervention; Students; Susceptibility; Photographs; Public health; Field trips; Health status; Data analysis; Children; Environmental aspects; Climate change; Hispanic Americans; Qualitative analysis; Cameras; Community involvement; Focus groups; Low income groups; Research methodology; Health education; Photography; Children &youth; Health information; School districts; Environmental health; Environmental education; Community; Child poverty; Researchers; Outdoor air quality; Urban areas; Interviews; Qualitative research; Low income areas; Partnerships; Income; Empowerment; Perceptions; Target recognition; Life course; Frame analysis
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Bibliography

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Sheikhan, N. Y., Kuluski, K., McKee, S., Hiebert, M., & Hawke, L. D. (2023). Exploring the impact of engagement in mental health and substance use research: A scoping review and thematic analysis. Health Expectations, 26(5), 1806-1819. doi:https://doi.org/10.1111/hex.13779

BackgroundThere is growing evidence demonstrating the impact of engaging people with lived experience (PWLE) in health research. However, it remains unclear what evidence is available regarding the impact of engagement specific to mental health and substance use research.MethodsA scoping review of three databases and thematic analysis were conducted. Sixty-one articles that described the impact of engagement in mental health and substance use research on either individual experiences or the research process were included.ResultsKey topics include (a) the impact of engagement on individual experiences; (b) the impact of engagement on the research process; and (c) facilitators and barriers to impactful engagement. Studies largely focused on the perceived positive impact of engagement on PWLE (e.g., personal and professional growth, empowering and rewarding experience, feeling heard and valued), researchers (e.g., rewarding experience, deeper understanding of research topic, changes to practice), and study participants (e.g., added value, fostered a safe space). Engagement activities were perceived to improve facets of the research process, such as improvements to research quality (e.g., rigour, trustworthiness, relevance to the community), research components (e.g., recruitment), and the research environment (e.g., shifted power dynamics). Facilitators and barriers were mapped onto the lived experience, researcher, team, and institutional levels. Commonly used terminologies for engagement and PWLE were discussed.ConclusionEngaging PWLE—from consultation to co-creation throughout the research cycle—is perceived as having a positive impact on both the research process and individual experiences. Future research is needed to bring consistency to engagement, leverage the facilitators to engagement, and address the barriers, and in turn generate research findings that have value not only to the scientific community, but also to the people impacted by the science.Patient or Public ContributionPWLE were engaged throughout the scoping review process, including the screening phase, analysis phase, and write-up phase.

Kerry, E., Collett, N., & Gunn, J. (2023). The impact of expert by experience involvement in teaching in a DClinPsych programme; for trainees and experts by experience. Health Expectations, 26(5), 2098-2108. doi:https://doi.org/10.1111/hex.13817

IntroductionThere is a growing acknowledgement of the value of creating partnerships between those delivering and those accessing health services. Less is known about this in the context of clinical psychology doctoral training programmes. This study explores the models of involvement of experts by experience (EbEs) in teaching on a DClinPsych course in England; the impact of this both for EbEs and trainee clinical psychologists and whether improvements are required to better meet their needs.MethodsAn audit of current involvement was conducted by reviewing course records. Two survey questionnaires designed around commonly used frameworks of participation and reflective learning were completed by EbEs and trainees. Thematic Analysis was used to evaluate the written feedback from the surveys.ResultsRecords of current EbE involvement were found to be lacking in detail and sometimes missing. Key themes extrapolated from the surveys highlighted the importance of EbE involvement in supporting the wellbeing of EbEs and the learning experiences of trainees.ConclusionsRecommendations with regard to the processes for future involvement of EbEs in teaching are put forward.Patient or Public ContributionA carer of a service user was consulted about the design of the participant information sheet, consent form and the survey questionnaire which was sent to the EbEs. A trainee clinical psychologist was also consulted to provide a trainee perspective on the above forms and the survey questionnaire that was sent to trainees. Further to this, the first author's supervisor identifies as a user of physical and mental health services and provided continued supervision and support regarding the direction of the study including the research questions, design, methodology and interpretation of results.

Hawke, L. D., Putterman, C., Dawthorne, N., Pascoe, S., & Pind, S. (2023). The elephant in the room: Family engagement in mental health and substance use research. Health Expectations, 26(5), 1789-1792.

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Turin, T. C., Kazi, M., Rumana, N., Lasker, M. A. A., & Chowdhury, N. (2023). Conceptualising community engagement as an infinite game implemented through finite games of 'research', 'community organising' and 'knowledge mobilisation'. Health Expectations, 26(5), 1799-1805. doi:https://doi.org/10.1111/hex.13801

Meaningful community engagement process involves focusing on the community needs, building community capacity and employing culturally tailored and community-specific strategies. In the current practices of community-engaged health and wellness research, generally, community engagement activities commence with the beginning of a particular research project on a specific topic and end with the completion of the project. The outcomes of the community engagement, including the trust, partnership and contribution of the community to research, thus remain limited to that specific project and are not generally transferred and fostered further to the following project on a different topic. In this viewpoint article, we discussed a philosophical approach to community engagement that proposes to juxtapose community engagement for the specific short-term research project and the overarching long-term programme of research with the finite game and infinite game concepts, respectively. A finite game is a concept of a game where the players are known, rules are fixed and when the agreed-upon goal is achieved, the game ends. On the other hand, in infinite games, the players may be both known and unknown, have no externally fixed rules and have the objective of continuing the game beyond a particular research project. We believe community engagement needs to be conducted as an infinite game that is, at the programme of research level, where the goal of the respective activities is not to complete a research project but to successfully engage the community itself is the goal. While conducting various research projects, that is, finite games, the researchers need to keep an infinite game mindset throughout, which includes working with the community for a just cause, building trust and community capacity to maximise their contribution to research, prioritising community needs and having the courage to lead the community if need be.Patient or Public Contribution: While preparing this manuscript, we have partnered actively with community champions, activists, community scholars and citizen researchers at the community level from the very beginning. We had regular interactions with them to get their valuable and insightful inputs in shaping our reflections. Their involvement as coauthors in this paper also provided a learning opportunity for them and facilitated them to gain insight on knowledge engagement. All authors support greater community/citizen/public involvement in research in an equitable manner.

Politi, M. C., Forcino, R. C., Parrish, K., Durand, M., O'Malley, A. J., Moses, R., . . . Elwyn, G. (2023). The impact of adding cost information to a conversation aid to support shared decision making about low-risk prostate cancer treatment: Results of a stepped-wedge cluster randomised trial. Health Expectations, 26(5), 2023-2039. doi:https://doi.org/10.1111/hex.13810

BackgroundDecision aids help patients consider the benefits and drawbacks of care options but rarely include cost information. We assessed the impact of a conversation-based decision aid containing information about low-risk prostate cancer management options and their relative costs.MethodsWe conducted a stepped-wedge cluster randomised trial in outpatient urology practices within a US-based academic medical center. We randomised five clinicians to four intervention sequences and enroled patients newly diagnosed with low-risk prostate cancer. Primary patient-reported outcomes collected postvisit included the frequency of cost conversations and referrals to address costs. Other patient-reported outcomes included: decisional conflict postvisit and at 3 months, decision regret at 3 months, shared decision-making postvisit, financial toxicity postvisit and at 3 months. Clinicians reported their attitudes about shared decision-making pre- and poststudy, and the intervention's feasibility and acceptability. We used hierarchical regression analysis to assess patient outcomes. The clinician was included as a random effect; fixed effects included education, employment, telehealth versus in-person visit, visit date, and enrolment period.ResultsBetween April 2020 and March 2022, we screened 513 patients, contacted 217 eligible patients, and enroled 117/217 (54%) (51 in usual care, 66 in the intervention group). In adjusted analyses, the intervention was not associated with cost conversations (β = .82, p = .27), referrals to cost-related resources (β = −0.36, p = .81), shared decision-making (β = −0.79, p = .32), decisional conflict postvisit (β = −0.34, p= .70), or at follow-up (β = −2.19, p = .16), decision regret at follow-up (β = −9.76, p = .11), or financial toxicity postvisit (β = −1.32, p = .63) or at follow-up (β = −2.41, p = .23). Most clinicians and patients had positive attitudes about the intervention and shared decision-making. In exploratory unadjusted analyses, patients in the intervention group experienced more transient indecision (p < .02) suggesting increased deliberation between visit and follow-up.DiscussionDespite enthusiasm from clinicians, the intervention was not significantly associated with hypothesised outcomes, though we were unable to robustly test outcomes due to recruitment challenges. Recruitment at the start of the COVID-19 pandemic impacted eligibility, sample size/power, study procedures, and increased telehealth visits and financial worry, independent of the intervention. Future work should explore ways to support shared decision-making, cost conversations, and choice deliberation with a larger sample. Such work could involve additional members of the care team, and consider the detail, quality, and timing of addressing these issues.Patient or Public ContributionPatients and clinicians were engaged as stakeholder advisors meeting monthly throughout the duration of the project to advise on the study design, measures selected, data interpretation, and dissemination of study findings.

Giebel, C., Tetlow, H., Faulkner, T., & Eley, R. (2023). A community of practice to increase education and collaboration in dementia and ageing research and care: The liverpool dementia & ageing research forum. Health Expectations, 26(5), 1977-1985. doi:https://doi.org/10.1111/hex.13806

BackgroundToo often, dementia research is conducted in research silos without thorough integration and the involvement of people with lived experiences, care professionals and the Third Sector. Research can also get lost in academic publications, without reaching those benefiting most from the evidence. The aim of this methods and evaluation paper was to outline the aims, components and evaluation of the public-facing and -engaging Liverpool Dementia & Ageing Research Forum, to provide a blueprint for setting up similar communities of practice.MethodsThe Forum was set up in 2019 with the aim to (a) connect different stakeholders in dementia and ageing and co-produce research and to (b) inform and educate. This paper provides an account of the Forum model and evaluates the following key elements: (1) engagement; (2) experiences of the Forum and its impact (via an online evaluation survey and three reflections). All Forum members and attendees were asked to complete a brief evaluation survey about their experiences from October to November 2022. Three regular Forum attendees provided a case study about their involvement and its impact.FindingsThe Forum has reached out to diverse stakeholders and the general public, generating growing interest and engagement since its initiation. Forty-four members and attendees completed the survey. Most attendees completing the evaluation survey have so far engaged in between 5 and 20 activities (47.8%), and 91% felt the aims of the Forum have been met. Engaging in the Forum has produced various benefits for attendees, including increased research capacity and knowledge, as well as improved connectivity with other stakeholders. Eleven percent of respondents, 39% of lived experts, stated they experienced improved access to postdiagnostic care.ConclusionsThis is the first reported multistakeholder Community of Practice (CoP) on dementia and ageing. We make key recommendations for setting up and running similar dementia CoP, as they provide a noninterventional format for raising awareness, capacity and access to dementia care.Patient and Public InvolvementThis paper reports on the involvement and engagement of people with dementia, unpaid carers, health and social care providers and Third Sector organisations in a CoP.

McMullen, S., Panagioti, M., Planner, C., Giles, S., Angelakis, I., Keers, R. N., . . . Tyler, N. (2023). Supporting carers to improve patient safety and maintain their well-being in transitions from mental health hospitals to the community: A prioritisation nominal group technique. Health Expectations, 26(5), 2064-2074. doi:https://doi.org/10.1111/hex.13813

IntroductionCarers of people with mental illness may face distinct challenges, including navigating fragmented health and social services during discharge from mental health hospitals. Currently, limited examples of interventions that support carers of people with mental illness in improving patient safety during transitions of care exist. We aimed to identify problems and solutions to inform future carer-led discharge interventions, which is imperative for ensuring patient safety and the well-being of carers.MethodsThe nominal group technique was used which combines both qualitative and quantitative data collection methods in four distinct phases: (1) problem identification, (2) solution generation, (3) decision making and (4) prioritisation. The aim was to combine expertise from different stakeholder groups (patients, carers and academics with expertise in primary/secondary care, social care or public health) to identify problems and generate solutions.ResultsTwenty-eight participants generated potential solutions that were grouped into four themes. The most acceptable solution for each was as follows: (1) ‘Carer Involvement and

Improving Carer Experience' a dedicated family liaison worker, (2) 'Patient Wellness and Education' adapting and implementing existing approaches to help implement the patient care plan, (3) 'Carer Wellness and Education' peer/social support interventions for carers and (4) 'Policy and System Improvements' understanding the co-ordination of care.ConclusionThe stakeholder group concurred that the transition from mental health hospitals to the community is a distressing period, where patients and carers are particularly vulnerable to safety and well-being risks. We identified numerous feasible/acceptable solutions to enable carers to improve patient safety and maintain their own mental wellbeing.Patient and Public ContributionPatient and public contributors were represented in the workshop and the focus of the workshop was to identify the problems they faced and co-design potential solutions. Patient and public contributors were involved in the funding application and study design.

Fichtner, U. A., Arslanow, A., Binder, H., Galle, P. R., Labenz, C., Lammert, F., . . . Farin-Glattacker, E. (2023). How do (false) positively screened patients experience a screening programme for liver cirrhosis or fibrosis in germany? A qualitative study. Health Expectations, 26(5), 1923-1930. doi:https://doi.org/10.1111/hex.13800

ObjectiveThis study aimed to explore psychosocial consequences of (false) positive liver screening results and to identify influencing factors for perceived strain within a multistage screening programme for liver cirrhosis and fibrosis in Germany.MethodsBetween June 2018 and May 2019, all positively screened patients were asked to participate in the study (n = 158). N = 11 telephone interviews and n = 4 follow-up interviews were conducted. Semi-structured telephone interviews were carried out. The analysis followed a structuring content analysis approach. Thereby, categories were first defined deductively. Second, the categories were revised inductively based on the data.ResultsThe main themes found regarding the consequences of the screening were categorised in emotional reactions and behavioural reactions. Few respondents described negative emotional consequences related to screening. Those seem to be mostly driven by suboptimal patient–provider communication and might be worsened when transparent information transfer fails to happen. As a result, patients sought information and support in their social environment. All patients reported positive attitudes towards liver screening.ConclusionTo reduce the potential occurrence of psychosocial consequences during the screening process, medical screening should be performed in the context of transparent information. Regular health communication on the side of health professionals and increasing patients' health literacy might contribute to avoiding negative emotions in line with screening.Patient or Public ContributionThis study recognises the wide-ranging patients' perspectives regarding the consequences of liver screening which should be taken into consideration when implementing a new screening programme to ensure a patient-centred approach.

Young, A., Levitt, A., Kodeeswaran, S., & Markoulakis, R. (2023). 'Just because we're younger doesn't mean our opinions should be any less valued': A qualitative study of youth perspectives on a youth advisory council in a mental healthcare context. Health Expectations, 26(5), 1883-1894. doi:https://doi.org/10.1111/hex.13794

IntroductionRecognition of the importance of youth engagement in youth mental health and/or addiction (MHA) service design and delivery is increasing. Youth Advisory Councils embedded in MHA organizations represent one strategy that allows youth to be involved in MHA at the individual, organization and systemic levels. This level of involvement can facilitate positive outcomes for both the youth and the organization. As these councils become more common, it is important that organizations are prepared to partner with the participating youth. This study uses a descriptive qualitative approach to understand the motivations and expectations of youth with lived experience with MHA concerns who were beginning to work on a Youth Advisory Council in an MHA setting in the Greater Toronto Area.MethodsSemistructured interviews were conducted with each youth, ages 16–26, on the advisory council (N = 8) to understand their motivations, expectations and goals coming into the work. Interviews were transcribed verbatim and analysed using a reflexive thematic analysis.ResultsAnalysis resulted in five overarching themes: providing opportunities for youth learning and growth, platforming youth, empowering youth, embracing youth leadership and promoting youth-driven change. The findings illustrate that these youth came into the Youth Advisory Council motivated to create positive change in the mental health system, take on leadership roles and had high expectations for organizational support. Our analyses provide insight for organizations planning and implementing Youth Advisory Councils in the MHA sector with the goal of best supporting youth in driving positive change across the system.ConclusionYouth want to be provided authentic opportunities for their engagement to make a difference.

MHA organizations must embrace youth leadership and move towards listening to youth experience and acting on youth recommendations to enhance service design and implementation to improve access and to better meet the needs of youth utilizing these services.Patient or Public ContributionsThis study incorporated service users, including youth ages 16–26 with lived experience of MHA concerns who served on the Youth Advisory Council at the Family Navigation Project, Sunnybrook. Youth Advisory Council members contributed to two relevant research activities: (1) youth reviewed the draft interview guide before data collection, and their feedback was prioritized in the final version and (2) youth contributed to knowledge translation through contributing to academic conference presentations.

Nicholson, E., McDonnell, T., Conlon, C., De Brún, A., Doherty, E., & McAuliffe, E. (2023). Parent's preferences for unscheduled paediatric healthcare: A discrete choice experiment. Health Expectations, 26(5), 1931-1940. doi:https://doi.org/10.1111/hex.13802

BackgroundUnscheduled healthcare is a key component of healthcare delivery and makes up a significant proportion of healthcare access, with children being particularly high users of unscheduled healthcare. Understanding the relative importance of factors that influence this behaviour and decision-making is fundamental to ensuring the system is best designed to meet the needs of users and foster appropriate cost-effective usage of health system resources.ObjectiveThe aim of the study was to identify the parent's preferences for unscheduled healthcare for a common mild childhood illness.DesignA discrete choice experiment (DCE) was developed to identify the preferences of parents accessing unscheduled healthcare for their children.Setting and ParticipantsData were collected from parents in Ireland (N = 458) to elicit preferences across five attributes: timeliness, appointment type, healthcare professional attended, telephone guidance before attending and cost.ResultsUsing a random parameters logit model, all attributes were statistically significant, cost (β = −5.064, 95% confidence interval, CI −5.60, −4.53]), same-day (β = 1.386, 95% CI 1.19, 1.58]) or next-day access (β = 0.857, 95% CI 0.73, 0.98]), coupled with care by their own general practitioner (β = 0.748, 95% CI 0.61, 0.89]), identified as the strongest preferences of parents accessing unscheduled healthcare for their children.DiscussionThe results have implications for policy development and implementation initiatives that seek to improve unscheduled health services as understanding how parents use these services can maximise their effectiveness.Patient or Public ContributionThe development of the DCE included a qualitative research component to ensure that the content accurately reflected parents experiences when seeking healthcare. Before data collection, a pilot test was carried out with the target population to gather their views on the survey.

Farre, A., Morris, J. H., Irvine, L., Dombrowski, S. U., Breckenridge, J. P., Ozakinci, G., . . . Jones, C. (2023). Exploring the views and experiences of people recovering from a stroke about a new text message intervention to promote physical activity after rehabilitation—Keeping active with texting after stroke: A qualitative study. Health Expectations, 26(5), 2013-2022. doi:https://doi.org/10.1111/hex.13809

BackgroundParticipating in exercise following a stroke is essential for recovery. When community-based rehabilitation services end, some people struggle to remain active. We codesigned Keeping Active with Texting After Stroke (KATS), a text message intervention to support home-based, self-directed plans to continue exercising. KATS delivers a series of automated text messages over a 12-week period from the point of discharge from National Health Service-funded therapy. The aim of this study was to explore the views and experiences of the first cohort of participants to complete the KATS intervention about the meaning, engagement, workability and worth of the intervention.MethodsWe undertook a qualitative study, theoretically informed by Normalisation Process Theory. We conducted semi-structured telephone interviews with people with stroke from two Health Boards in Scotland. Data collection took place over two phases, with each participant being interviewed twice: first, halfway through intervention delivery (Week 6) and then again at the end of the intervention (Week 12). All interviews were audio-recorded, transcribed and analysed thematically.ResultsA total of 24 interviews were conducted with 12 participants. Our findings were organised around four overarching analytical themes: (1) making sense of KATS: timing and complementarity in the rehabilitation journey; (2) engaging with KATS: connection and identification with others; (3) making KATS work: flexibility and tailorable guidance; (4) appraising the worth of KATS: encouragement and friendliness. Participants differentiated KATS from current rehabilitation practice, finding it relevant, fitting and worthwhile. Variations were reported in engagement with behaviour change techniques, but participants were able to tailor KATS use, making it work for them in different ways.ConclusionsPerceived benefits went beyond promoting physical activity, including feeling supported and connected. Future research will test the effectiveness of KATS in promoting physical activity and explore any associations with relevant social and emotional secondary outcomes.Patient or Public ContributionA research funding proposal was developed in collaboration with five people with stroke and three spouses. After securing funding, six people with stroke were invited to join the project's Collaborative Working Group, alongside health professionals and stroke rehabilitation experts, to codevelop the intervention and support the feasibility study.

Blair, G., Smith, J. E., Barham, F., & Latour, J. M. (2023). Involving patients and caregivers to develop items for a new patient-reported experience measure for older adults attending the emergency department. findings from a nominal group technique study. Health Expectations, 26(5), 2040-2049. doi:https://doi.org/10.1111/hex.13811

ContextPatient experience is an important component of high-quality care and is linked to improved clinical outcomes across a range of different conditions. Patient-reported experience measures (PREMs) are psychometrically validated instruments designed to identify where strengths and vulnerabilities in care exist. Currently, there is no validated instrument available to measure patient experience among people aged over 65 years attending the emergency department (ED).ObjectiveThis paper aims to describe the process of generating, refining and prioritising candidate items for inclusion in a new PREM measuring older adults' experiences in ED (PREM-ED 65).DesignOne hundred and thirty-six draft items were generated via a systematic review, interviews with patients and focus groups with ED staff exploring older adults' experiences in the ED. A 1-day multiple stakeholder workshop was then convened to refine and prioritise these items. The workshop entailed a modified nominal groups technique exercise comprised of three discrete parts—(i) item familiarisation and comprehension assessment, (ii) initial voting and (iii) final adjudication.Setting and ParticipantsTwenty-nine participants attended the stakeholder workshop, conducted in a nonhealthcare setting (Buckfast Abbey). The average age of participants was 65.6 years. Self-reported prior experiences of emergency care among the participants included attending the ED as a patient (n = 16, 55.2%); accompanying person (n = 11, 37.9%) and/or as a healthcare provider (n = 7, 24.1%).ResultsParticipants were allocated time to familiarise themselves with the draft items, suggest any improvements to the item structure or content, and suggest new items. Two additional items were proposed by participants, yielding a total of 138 items for prioritisation. Initial prioritisation deemed most items ‘critically important’ (priority 7–9 out of 9, n = 104, 75.4%). Of these, 70 items demonstrated suitable inter-rater agreement (mean average deviation from the median < 1.04) and were recommended for automatic inclusion. Participants then undertook final adjudication to include or exclude the remaining items, using forced choice voting. A further 29 items were included. Thirty-nine items did not meet the criteria for inclusion.ConclusionsThis study has generated a list of 99 prioritised candidate items for inclusion in the draft PREM-ED 65 instrument. These items highlight areas of patient experience that are particularly important to older adults accessing emergency care. This may be of direct interest to those looking to improve the patient experience for older adults in the ED. For the final stage of development, psychometric validation amongst a real-world population of ED patients is now planned.Patient and Public ContributionInitial item generation was informed using qualitative research, including interviews with patients in the ED. The opinions of patients and members of the public were integral to achieving outcomes from the prioritisation meeting. The lay chair of the Royal College of Emergency Medicine participated in the meeting and reviewed the results of this study.

Bocquier, A., Bruel, S., Michel, M., Anne-Sophie Le Duc-Banaszuk, Bonnay, S., Branchereau, M., . . . Thilly, N. (2023). Co-development of a school-based and primary care-based multicomponent intervention to improve HPV vaccine coverage amongst french adolescents (the PrevHPV study). Health Expectations, 26(5), 1843-1853. doi:https://doi.org/10.1111/hex.13778

IntroductionDespite various efforts to improve human papillomavirus (HPV) vaccine coverage in France, it has always been lower than in most other high-income countries. The health authorities launched in 2018 the national PrevHPV research programme to (1) co-develop with stakeholders and (2) evaluate the impact of a multicomponent complex intervention aimed at improving HPV vaccine coverage amongst French adolescents.ObjectiveTo describe the development process of the PrevHPV intervention using the GUIDance for rEporting of intervention Development framework as a guide.MethodsTo develop the intervention, we used findings from (1) published evidence on effective strategies to improve vaccination uptake and on theoretical frameworks of health behaviour change; (2) primary data on target populations' knowledge, beliefs, attitudes, preferences, behaviours and practices as well as the facilitators and barriers to HPV vaccination collected as part of the PrevHPV Programme and (3) the advice of working groups involving stakeholders in a participatory approach. We paid attention to developing an intervention that would maximise reach, adoption, implementation and maintenance in real-world contexts.ResultsWe co-developed three components: (1) adolescents' and parents' education and motivation using eHealth tools (web conferences, videos, and a serious video game) and participatory learning at school; (2) general practitioners' e-learning training on HPV using motivational interviewing techniques and provision of a decision aid tool and (3) easier access to vaccination through vaccination days organised on participating middle schools' premises to propose free of charge initiation of the HPV vaccination.ConclusionWe co-developed a multicomponent intervention that addresses a range of barriers and enablers of HPV vaccination. The next step is to build on the results of its evaluation to refine it before scaling it up if proven efficient. If so, it will add to the small number of multicomponent interventions aimed at improving HPV vaccination worldwide.Patient or Public ContributionThe public (adolescents, their parents, school staff and health professionals) participated in the needs assessment using a mixed methods approach. The public was also involved in the components' development process to generate ideas about potential activities/tools, critically revise the successive versions of the tools and provide advice about the intervention practicalities, feasibility and maintenance.

Dionne-Odom, J., Kent, E. E., Rocque, G. B., Azuero, A., Harrell, E. R., Gazaway, S., . . . Ornstein, K. A. (2023). Family caregiver roles and challenges in assisting patients with cancer treatment decision-making: Analysis of data from a national survey. Health Expectations, 26(5), 1965-1976. doi:https://doi.org/10.1111/hex.13805

BackgroundWe aimed to describe the roles and challenges of family caregivers involved in patients' cancer treatment decision-making.MethodsFamily caregiver-reported data were analyzed from a national survey conducted in the United States by CancerCare® (2/2021–7/2021). Four select-all-that-apply caregiver roles were explored: (1) observer (patient as primary decision-maker); (2) primary decision-maker; (3) shared decision-maker with patient and (4) decision delegated to healthcare team. Roles were compared across five treatment decisions: where to get treatment, the treatment plan, second opinions, beginning treatment and stopping treatment. Ten challenges faced by caregivers (e.g., information, cost, treatment understanding) were then examined. χ2 and regression analyses were used to assess associations between roles, decision areas, challenges and caregiver sociodemographics.ResultsOf 2703 caregiver respondents, 87.6% reported involvement in patient decisions about cancer treatment, including 1661 who responded to a subsection further detailing their roles and challenges with specific treatment decisions. Amongst these 1661 caregivers, 22.2% reported an observing role, 21.3% a primary decision-making role, 53.9% a shared decision-making role and 18.1% a role delegating decisions to the healthcare team. Most caregivers (60.4%) faced ≥1 challenge, the most frequent being not knowing how treatments would affect the patient's physical condition (24.8%) and quality of life (23.2%). In multivariable models, being Hispanic/Latino/a was the strongest predictor of facing at least one challenge ($b = -0.581$, $\text{Wald} = 10.69$, $p < .01$).ConclusionsMost caregivers were involved in patients' cancer treatment decisions. The major challenge was not understanding how treatments would impact patients' physical health and quality of life. Challenges may be more commonly faced by Hispanic/Latino/a caregivers.Patient or Public ContributionThe CancerCare® survey was developed in partnership with caregiving services and research experts to describe the role of cancer family caregivers in patient decision-making and assess their needs for support. All survey items were reviewed by a CancerCare advisory board that included five professional patient advocates and piloted by a CancerCare social worker and other staff who provide counselling to cancer caregivers.

Shahmari, M., Alireza, N. N., Rezaie, E., Dashti, S., Nasiri, E., & Zare, L. (2023). Lived experiences of young adults facing a recent diagnosis of cancer: A phenomenological study. Health Expectations, 26(5), 1874-1882. doi:https://doi.org/10.1111/hex.13793

IntroductionYoung adulthood is a period of prosperity and freshness characterized by developmental achievement, which can be inhibited by various diseases such as cancer. Typically considered a terminal disease, if diagnosed in young adulthood, cancer may trigger a tremendous psychosomatic shock. The nature of facing a recent cancer diagnosis affects the whole coping process. Addressing young adults' experiences at the confirmation point of cancer diagnosis will facilitate supporting them through the early recognition of probable problems in the future. Therefore, the present study aimed to analyse the lived experiences of young adults facing a recent cancer diagnosis.MethodsThis qualitative study adopted an interpretive phenomenology design. In this study, 12 patients (with an age range of 20–40) were selected using the purposive sampling method. Data collection was done through in-depth, semistructured interviews. The data were analysed following the method proposed by Diekelmann et al.FindingsThree main themes and nine subthemes were extracted from the data: (1) spiritual detachment and then acceptance through spirituality in the form of denial and then forced acceptance, sense of guilt and spiritual help-seeking, and anger towards God and then humbleness, (2) the shock of facing an extraordinary life shaped by disturbed role-play and unusual lifestyle, (3) anticipatory anxiety concerning the sense of rejection, negative perspective towards future, inability to afford the costs and worries about the future of the family members.ConclusionThis was the first study providing significant insights into the experiences of young adults facing a recent cancer diagnosis. The diagnosis of cancer can shadow all aspects of young adults' lives. The findings of the present study empower healthcare professionals to provide newly diagnosed young adults with appropriate health services.Patient ContributionsTo identify and recruit the participants, we explained the objectives of the present study to the unit managers either by phone or in person. The participants were approached and interviewed by three authors. Participation was voluntary and the participants received no financial contribution for their time.

Harris, H., Clarkin, C., Rovet, J., Crawford, A., Johnson, A., Kirvan, A., . . . Soklaridis, S. (2023). Meaningful engagement through critical reflexivity: Engaging people with lived experience in continuing mental health professional development. Health Expectations, 26(5), 1793-1798. doi:https://doi.org/10.1111/hex.13798