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Children's perspectives and experiences of the COVID-19 pandemic and UK public health measures

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ABSTRACT (ENGLISH)

Background

The COVID-19 pandemic has had profound impacts on how we live our lives; yet, the implications for children and the effects on children's everyday lives have been relatively underacknowledged. Understanding children's views on COVID-19 and related restrictions on their lives provides an important opportunity to understand how children have responded to the pandemic, including the impacts on their social and emotional well-being.

Objective

This study explored the experiences and perspectives of children in relation to the COVID-19 pandemic and related restrictions on everyday life.

Method

A qualitative study using semistructured online interviews with participatory drawings was undertaken between May and July 2020. Eighteen children from England and Wales, aged 7–11 years, participated in interviews.

Findings

Themes included children's reflections on (1) COVID-19 as a deadly contagion; (2) fears and sadness and (3) social responsibility and opportunities to respond positively.

Conclusions

Young children offer insightful reflections on their experiences during the first wave of the COVID-19 pandemic in the United Kingdom. Children and young people's perspectives must be considered in future public health discourse.

Patient or Public Contribution

This work was informed by conversations with my own three primary school-aged children and the children of friends. A formal Patient and Public Involvement (PPI) group was not established due to the speed with which the project was undertaken. Any future research in this area would benefit from formal PPI in the design, methods and questions.

FULL TEXT

INTRODUCTION

Across the globe, the COVID-19 pandemic has profoundly affected the ways in which we all live our lives. In the United Kingdom, and other many other countries, much of the political and public health response has been adult-centric, with the roles and perspectives of children on the pandemic and how best to respond to this less well considered. Rather, children and young people have been differentially positioned as either ‘resilient’, able to simply and unproblematically ‘bounce back’ from the pandemic, or as ‘deviant’ and largely culpable for (ongoing) transmission of the virus because of their ‘failure’ to adhere to public health guidance and maintain social distancing. The relative absence of children's perspectives within the development of public health strategies not only serves to downplay the impacts that COVID-19 has, and continues to have, on young lives but also runs the risk of failing to engage sensitively and meaningfully with the different ways in which children understand and respond to the pandemic, including what this might mean for their engagement with public health advice.

Drawing on a qualitative study with 18 children in England and Wales, this paper explores children's understandings of, and reflections on, COVID-19 and the related political and public health responses to the pandemic. The findings reported here highlight children's thoughts and fears about the scale and impacts of the pandemic, and explore how they have taken up key public health messages to protect themselves and others. The findings also highlight the importance of reframing health promotion messages to better capture children's own perspectives on, and roles within, public health responses to the pandemic. We begin by foregrounding children's contributions to health promotion and the value of attending to these perspectives within the development of public health programmes, before detailing the study and its main findings.

CHILDREN'S PERSPECTIVES AND THE DEVELOPMENT OF PUBLIC HEALTH PRIORITIES

The development of public health priorities is usually underpinned by an assessment of epidemiological measures including morbidity and mortality rates, and related indicators of health practices or individual risk behaviours (e.g., smoking, exercise, diet, alcohol use). Dominant forms of health promotion thus aim to educate people about the risks tied to harmful health practices and encourage them to adhere to official health advice. These traditional forms of health education typically depict an uncritical, compliant health consumer who engages in proscribed behaviour change, often without due regard to the (differing) meanings attached to health and related health practices.[1,2] Health education with children has followed these models, adopting a didactic approach to providing formal health knowledge. Children are expected (uncritically) to follow instructions and modify their behaviours accordingly.[3] These approaches position children as ‘empty vessels’ to be ‘filled’ with ‘appropriate’ health information to make expert-defined ‘right’ choices.[1,4] Children's ‘failure’ to follow such advice is often attributed to assumptions about their lack of knowledge, ‘immaturity’ and inabilities to know what is best for them and their health.[2] Because of this, adult frames of reference often define the forms of health promotion deemed most appropriate for children. Not only do such approaches downplay children and young people's own understandings of health and health promotion[1,5] but they also neglect the relevance of the context in which health is experienced and enacted.

Critiques of adult-centric health promotion agendas have emerged in recent times.[5,6] Drawing on contributions to the sociology of childhood,[7,8] these perspectives foreground children and young people's capacities and capabilities with respect to their health-related decision-making and health practices. In line with Article 12 of the United Nations (UN) Convention on the Rights of the Child,[9] these contributions underscore the importance of capturing children's own views on health and the subsequent grounding of health promotion within the lived realities of young lives. Indeed, in recent times, there have been concerted efforts to engage children and their perspectives in health care planning as part of broader Patient and Public Involvement (PPI) initiatives in health care, especially within the UK context.[10,11]

Despite the increasing recognition of the importance of eliciting children and young people's views on topical health concerns and public health priorities, there has been a notable absence and failure to engage with children's perspectives on COVID-19 within political and public health decision-making (The New Zealand Prime Minister, Jacinda Arden, offers an exception to this and held briefings and conversations with children at the beginning of the pandemic[12]). The impacts of COVID-19 on children's present and future lives in terms of their socio-emotional and mental health, their education and future career prospects are beginning to emerge.[13–15] Indeed, children (increasingly termed the COVID generation) are likely to experience the impacts and consequences of the pandemic for many years to come and as education and career prospects are compromised and reconsidered. To address the absence of young perspectives in the pandemic discourse, we undertook a qualitative study with young children in England and Wales during the first wave of the pandemic to better understand their experiences of COVID-19 and how these perspectives may help to inform future health promotion strategies.

METHODS

A qualitative study with 18 children (9 boys and 11 girls) aged 7–11 years in England and Wales was conducted between May and July 2020. During this period, most children in England and Wales were experiencing a prolonged period of home schooling as part of a national lockdown, with schools having been closed since late March 2020. None of the children involved in the study were currently attending school in person due to the national lockdown.

Recruitment and sampling

The study was advertised on two parent support groups on the social media platform, Facebook. Interested parents were encouraged to contact the researcher, J. T., via email. Following contact, an information sheet and consent form were emailed to parents. All those who expressed an interest in the study were interviewed.

Data collection

Twelve semistructured online interviews with participatory drawings were conducted with 18 participants (six paired interviews were conducted, with siblings being interviewed at the same time). This method has been successfully used in other research exploring children's understandings of health.[16–18] Drawings encourage children to share their thoughts to some initial questions in a visual format. In practice, some children in this study were more enthusiastic about drawing than others, with some children simply preferring to talk about their experiences. Difficulties were experienced, for example, in angling cameras for the researcher to see drawings. Because of this, the researcher asked the children to describe what they were drawing and to hold up their drawings at different points during the interview.

To aid discussions, a flexible interview guide was developed and focused on the following broad topic areas: children's understandings of COVID-19 and its transmission (e.g., ‘Have you heard of COVID-19 or the coronavirus’?, ‘What do you think it is’?, ‘How does it get into people's bodies’?); symptoms of COVID-19 (e.g., How do people feel if they have COVID-19?); those most at risk from the virus (e.g., ‘Do you think that there are some people who are more likely to get poorly with COVID-19?’); and children's everyday lives during lockdown (e.g., ‘Tell me what you did last week’?, ‘What are some of the things that you like about lockdown’?, ‘What are some of the things that you don't like about lockdown’?).

Interviews were conducted by J. T. and lasted between 30 min and 1 h. Some parents remained present during the interviews, with some actively contributing to discussions (the implications and impacts of this are discussed later in the paper). Others left their children, enabling them to talk privately to the researcher. All interviews were audio-recorded with participants’ consent (and their parents’). Following the interviews, parents were asked to email photographs of their children's drawings to J. T.

Data analysis

Interviews were transcribed verbatim by a professional transcription company. Transcripts were fully anonymized, and participants were given pseudonyms (some were the child's own choice) and thematically analysed.[19] First, transcripts were (re)read and descriptive codes were attached to the data by J. T. Codes were then discussed and cross-checked with G. S. and P. C. to enable alternative ‘readings’ of the data. Descriptive codes were then scrutinized, refined and grouped by J. T. and P. C. to identify topical categories emerging from the data. Categories were then compared within and across transcripts to identify synergies and departures. Topical categories were developed into core thematic areas. The drawings were analysed alongside the children's transcripts and to reflect the specific issues that the children were discussing at the time.

Ethical considerations

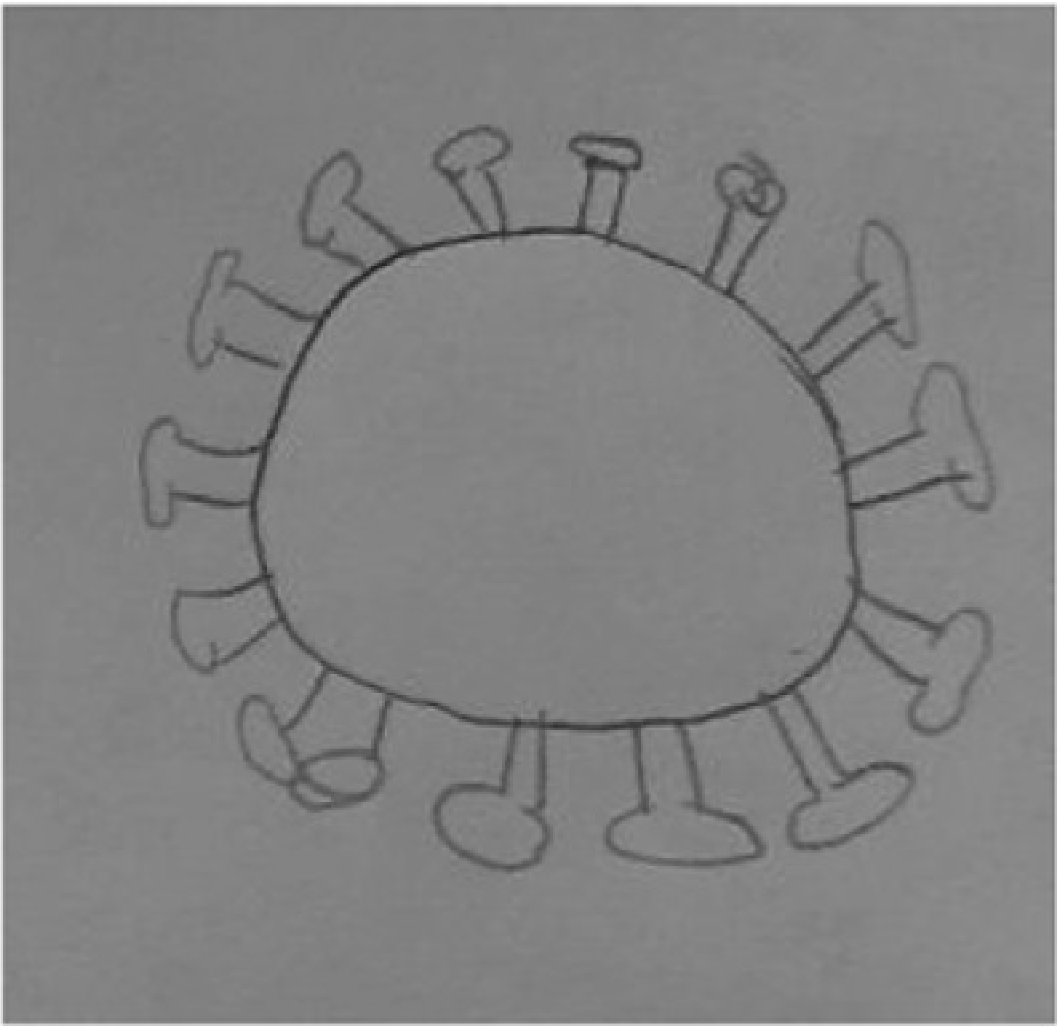
Ethical approval for the study was received from the Health Sciences School ethics committee at The University of Sheffield. Verbal consent from parents and assent from children were taken at the time of the interview. Participants and their parents were advised about the aims of the study, the nature of their involvement and what would happen with their data in line with data protection requirements. Participants were free to withdraw from the interview at any time and without needing to give a reason.

FINDINGS

Our analysis revealed three key themes that captured the ways in which children spoke about and experienced the pandemic, namely, (1) A deadly global contagion, (2) Fears and sadness and (3) Social responsibility and opportunities to respond positively.

A deadly global contagion

Participants provided clear verbal descriptions and drawings of what they thought the COVID-19 virus looked like and how this was spread, which often reflected mainstream media images of the virus, as seen in Rose's drawing (Figure 1). When probed about their drawings, children confirmed that they had seen similar images of the virus in the news.



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Other children, such as Ray (aged 10), likened the virus to a monster killing people and thus something to be defeated (Figure 2), whilst Ben's (aged 9) description hinted at the notion of contagion as he described coronavirus as an invisible yellow gas surrounding people:

…sometimes I imagine people kind of had the invisible gas around them. That in my head is yellow, the gas is sometimes imagined 2 metres spread and that's the Coronavirus. (Ben, aged 9)

I'm drawing a monster and it has the Coronavirus on different parts of it because Coronavirus is a monster…Because it's killing loads of people, it's trying to be stopped and kept captive. (Ray, aged 10)

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When asked what COVID-19 does to people, some children talked about the physical impacts and symptoms of the virus including a cough and a high temperature. As Ben's description above highlights, participants often talked about the deadly nature of COVID-19, often sharing their concerns and fears about the virus harming others. Abigail's (aged 8) drawing of the impacts of COVID-19 (Figure 3), for example, illustrates a person laying in a bed asking, ‘Is the [Corona] deadly’? The person standing above the bed replies, ‘Yes. The [Corona] is deadly’:

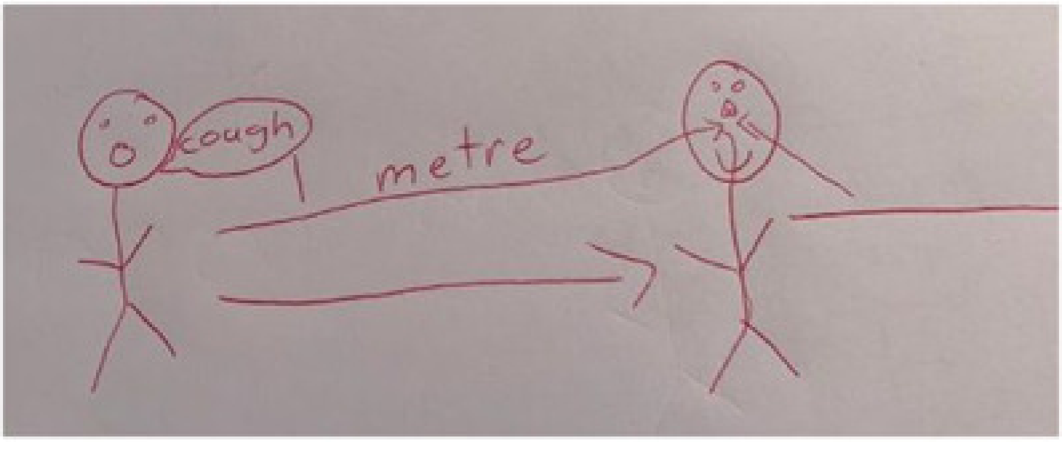
Enlarge this image.

Children's discussions about the harmful physical effects of COVID-19 were further evident in their accounts of how the virus was transmitted. Children described how the virus could be spread from one body to another, although there was considerable variability in children's understandings of how the virus may enter the body. When Sophie described her drawing (Figure 4), she talked about how germs entered the body through the nose and mouth and because of poor hygiene on the part of the individual. Others suggested that COVID-19 might enter the body through the skin or mouth and nose.

…they've kept touching the bar and then they didn't wash their hands and then they touched their mouth and their nose and their face and then he's coughed from 1 metre, not 2 metres, and not covering with his elbow and its gone down into his body and gets the germs into their nose. (Sophie, aged 9)

I think there's like these tiny cracks in your skin and they can just travel through and get into your body. (Emma, aged 8)

It could get into cuts and through your mouth and nose. (Oscar, aged 9)



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These accounts can be read as evidence of children's uptake of key public health messages in response to COVID-19 and about how to mitigate personal risks and the risk presented to others. For example, dominant health advice stresses the importance of adhering to handwashing and observing guidance on social distancing, as echoed in Albie's and Sophie's (both aged 9) responses:

Social distancing, wear masks, try not to go out too much and don't meet up with people.

Social distance, stay in the house and only the mums and dads are allowed to go to the shops and only go out for walks, not going to big group meetings and stuff.

As well as displaying their knowledge of public health messages, children also demonstrated their political and global astuteness as they discussed the origins of the virus (locating this in China) and the global spread. Other children reflected carefully and critically on the different political responses to the pandemic and in doing so, criticized in-country governments (e.g., the UK government) for poor handling of the pandemic, which contributed to the virus spreading:

It's [COVID-19] come from China because they were eating bats…Because the bats, I think the bats had a disease that's spreadable that humans can get and because Chinese people were eating them, they were getting the disease and passing it on to loads of people and they were going to different places in the world. (Rose, aged 11)

…why is the government making such bad decisions about it? I mean, if Boris Johnson already has Coronavirus, government you are doing a beeping job! …They're doing a rubbish job—New Zealand's doing great. I mean the Coronavirus has gone in New Zealand. (Ray, aged 10)

Sadness and fears

Children's discussions of the virus often signalled their deep fears and anxieties about the pandemic. Fears were triggered by a sense of the unknown, and especially not knowing when life would get back to normal. For instance, when asked if anything worried Oscar (aged 9) about the pandemic, he replied, 'About getting it, and it not stopping and having to live like this forever'. As previously noted, talk of death and the scale of deaths was commonplace in children's reflections:

I think it's really, a really terrible virus. And lots and lots of people are dying, it's really, really sad. And I'm not really, really, really used to it [death]. (Thomas, aged 7)

Some children shared their anxieties about their own risk to COVID-19 and impacts on their health. Rose (aged 11) reported, 'It makes me feel a bit scared that if I was to get it, I could get really ill'. However, more often, children reported their concerns for other more vulnerable people, in particular, family and friends:

Maria: I don't like it that my friends could be poorly and dead if they're poorly of the Coronavirus

Interviewer: Do you feel worried about Coronavirus? What worries you?

Ben: I worry that it's going to start affecting people in my family. And my friends and maybe when I get back, maybe when the Coronavirus ends, I won't have all the people that my friends—I might not have all the people that I love in my family. (Ben aged 9, Maria aged 7; siblings, interview 10)

Reports about losing the people they love highlighted some of the worrying and unintended impacts that dominant public health narratives may have on children's mental well-being. Along with concerns about virus risk for family members and friends, children's accounts also reflected their sadness about the things that they missed due to COVID-19 restrictions. They described how they longed for physical contact with others, along with missing out on sports and extracurricular activities or key school events, such as their final year of primary school and residential trips. For example, Rose spoke about her sadness following the abrupt end to her primary education and how she missed out on important opportunities that would aid her transition to secondary school:

When I last went to school, I was really sad that we were going to have to go and then when I didn't know that school was going to close, I was really excited to have a leavers' assembly and leavers' jumpers and my SATS. But obviously when I found out that I couldn't have leavers' jumpers or assembly, I was really upset. I'm not really excited that much to go to high school because it's a bit too early, I haven't done SATS or anything. (Rose, aged 11)

Children's reflections on the things that they missed and aspects of previous life were clearly marked with sadness.

Thomas (aged 7) talked about a recent bike ride with a friend and how he had wanted to hug him, but could not, stating, ‘[it] makes me feel seriously devastated’, whereas Maria (aged 7) described current life as:

Terrible, because I can't see my friends, or my teacher. Because I am really sad, I can't see my bestest friend. I can't see her when the Coronavirus has stopped either—she's moved to another house and school.

Missing physical contact with others such as hugs with friends also featured in participants’ accounts. Children were clearly grappling with what they wanted to do and what they were being told they could do.

Abigail: You didn't have to social distance and you could have people that could touch you. Or I want to touch something and you're allowed to touch and you're like ‘oh that's my friend, can we go and meet them?' And then you hear ‘no we're not allowed to do that’.

Laura: Yeah, so all them regular things that we used to do have turned into ‘try not to touch anything when you want’.

Interviewer: How does that make you feel?

Laura: Well sometimes sad because I can't like hug my cousins and my friends and I want to, and then other times I think, yeah, I understand.

Children's positivity and social responsibility

Despite sharing their anxieties, participants also highlighted some of the more positive aspects of the pandemic and the opportunities that it could afford. Some children talked positively about their broader social responsibility and, when doing so, pointed to examples of the apparent lack of responsibility of others. During these discussions, participants appeared to align with dominant responsibilization narratives in relation to older children and young people as they described them as ‘naughty’ for not observing social distancing rules.

…I've been seeing like lots of teenagers and naughty people just going like high fives, cuddles—what are they doing? If they want this to end, just stop touching each other! [W]henever I see people touching each other, I just get really upset, cos it's kind of getting things worse. (Eva, aged 9)

Others spoke more positively and reflected their sense of pride at being part of a larger movement and time in history.

I actually feel excited and curious because this time on lockdown will be remembered for thousands and thousands of years. (Rose, aged 11)

[I]t's sort of nice to be, like, living through something that might not happen again, people are going to, like, write about it in history books and so people of the future will learn about it. (Alice, aged 11)

I'm happy that we're all safe and that we're all working together to stop it …I just feel so proud that everyone's working together…and we're all doing our bit. (Eva, ages 9)

Many participants spoke fondly about lockdown, including opportunities to spend more time with family. When asked about the things that made her happy during this time, Laura (aged 9) said:

Spending more time with my mum and dad because at school we are away from them for at least 7hours because we have to get collected by someone else, so it's nice to get a full day with them.

Children also described the benefits of spending more time outdoors, playing in their gardens, riding their bikes or taking walks with their family, often discovering new outdoor spaces. There was a clear sense that many children enjoyed the freedoms afforded to them by not being in school and the opportunities to fill their own time.

I like that we're still allowed to walk outside, and like have some fresh air and explore new places. (Eva, aged 9)

We have quite a big garden and we own part of a field and so we've been going outside a lot, which is really fun. (Alice, aged 11)

Emma (aged 8) highlighted the greater sense of freedom that some children enjoyed during the lockdown and school closure period:

Interviewer: And is there anything that you enjoy about being at home now?

Emma: Maybe that we get to do more things than we did at school. I've done some baking and we have played outside a lot more. And we've started doing a lot of drawing.

Discussions with children also revealed how some were engaging with new and emerging technologies, which helped them maintain a sense of social connectedness with their friends and play remotely and synchronously. Rose (aged 10) discussed using mobile phones, ‘so we can play a game and call at the same time’. Similarly, Ben (aged 9) talked about playing interactive games with friends on his Nintendo Switch and using video conferencing and other new interactive apps to play live games with his friends. Thomas shared how he was using video conferencing and interactive games to connect with friends in virtual ‘worlds’:

I've been talking to a lot of people from Zoom. Even on Minecraft I manage to friend people so they can play in my worlds. (Thomas, aged 7)

These accounts, and others, point to the ways in which some children were actively seeking out opportunities for alternative ways to play ‘freely’, for example, by inviting friends to play within their own virtual worlds, where they may have felt a greater sense of control and the opportunity to create their own rules. Indeed, these children offered frequent examples of how they had embraced the changes and harnessed their agency to reflect on what they could do, rather than focus on what they could not.

DISCUSSION

The findings reported in this study illustrate that young children are knowledgeable about the COVID-19 pandemic, its transmission, the risks and related public health harm reduction strategies. Such knowledge is evident despite the obvious omission of children's perspectives in the political and public health discourse surrounding COVID-19. The British Science Association[20] recently warned of the possibility that young people may feel alienated and disassociate with pandemic guidance if they are not included in the conversations. Our research highlights the important insights that children can bring to the policy-making arena and we would strongly recommend that children are engaged in any future discussions that reflect on the UK's approach to managing the pandemic and also discussions about future global challenges that will have direct impact on children's lives.

Such calls to involve children and young people in matters that impact significantly on their daily lives, including health research and policy, are not new. Numerous authors have pointed repeatedly to the important insights that children can offer regarding their own health and well-being. However, over 30 years since its inception, Article 12 of the UNCRC is still not enforceable in UK courts.[21,22] Clearly, much work remains to be undertaken to ensure that children's views on all aspects of their lives are given the prominence that they deserve.

Throughout the COVID-19 pandemic, the measures used to ‘protect’ the nation have impacted significantly on children's health and well-being[23] and arguably will have a continued impact throughout many children's lives in terms of missed education and opportunities.[24] Whilst there have been pledges from the UK government to invest in children's futures, through an education catch-up fund, there is still little attempt to engage with children and young people's hopes and fears about the pandemic, including their views on the vaccination programme, or how schooling and educational settings should ‘look like’ and safely operate in the year(s) ahead.[25]

Whilst the UK's response to the pandemic has not been specifically tailored for children, it was clear that children in this study had a strong sense of the role that they could and should take. Their social responsibility in relation to their family, school and wider community came through clearly. Such findings have been echoed by Bray et al.[26,27] in their international survey of young children's health-related knowledge during the COVID-19 pandemic. Bray et al.[27] reported children's strong sense of altruism, highlighting children's willingness to make sacrifices to their own lives to support others. Such contributions remain unacknowledged in the wider public sphere. Similarly, some children in our study reflected positively on the opportunities afforded by the pandemic and reported feeling proud to be part of a collective effort. In some ways, these inclusive narratives of belonging and feeling part of a wider national effort may perhaps reflect participants’ uptake of some of the early pandemic messaging that focused on a collective effort to support the NHS. They also provide further evidence of the children's positive contributions to the pandemic response and the insights that they can bring to the post-COVID recovery period and beyond.

Despite the often adult-centric nature of the public health discourse, participants had a clear sense of what they should be doing in relation to infection control. Similar findings have been reported by Bray et al.[26,27] However, our study also highlights some of the potential unintended consequences of children's successful uptake of the public health messaging. There was a clear sense of fear expressed by children for their families and friends, with a particular emphasis on death and dying. Although the children in this study had a tendency to reflect on the assets and positive aspects of their ‘new normal’, we should not underestimate the potential longer-term mental health impacts posed both by the pandemic and from the public health discourse. As this study was undertaken during the first wave of the pandemic, lockdown was still very much a novel concept. It would be important to explore children's experiences and the impact on their lives from the ongoing and longer-term COVID-19 measures.

Yet, despite children's expressed fears and sadness, our findings point to the ways in which children have forged new narratives within the public health restrictions. Accounts of outdoor play, creative approaches to keeping in touch with their friends and the use of technologies as a form of ‘freedom’ in an otherwise restricted world reflect the ways in which these children continued to engage with their peers, albeit in different virtual contexts. Evidence of this kind points to children's tenacity and positivity, despite the significant disruption to their childhoods. Harnessing these positive narratives within future public health measures may help to counter some of the more negative aspects of lockdown and the broader impacts of the pandemic on young lives, crucially enabling children to feel more ‘in control’ at a time of considerable uncertainty.

As with all research, there are limitations to our findings. The research was carried out during the first wave of the COVID-19 pandemic and thus reflects the state of the pandemic and the related responses during that time. We appreciate that it has been a continuously evolving situation and that public health discourses and responses may have shifted since we collected our data. Second, the children drawn on for this study clearly did not reflect a diverse group, especially those children who come from more marginalized and vulnerable circumstances and who are likely to experience more significant (adverse) impacts as a result of the pandemic. Second, the necessary use of technology for children to take in the study sometimes hindered the potential to develop rapport with children and also limited the potential to engage with the drawing method. Further, the presence and/or proximity of parents within some interviews could have impacted on some children's responses. We are reflecting on these and broader methodological and ethical issues of conducting online research with children during a pandemic in a forthcoming paper. Despite these shortcomings, the findings from this study highlight the importance of creating opportunities to harness children's perspectives and engage them in debates about contemporary global challenges that directly impact on their lives.

DATA AVAILABILITY STATEMENT

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

DETAILS

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Research on the factors that influence patients with colorectal cancer participating in the prevention and control of surgical site infection: Based on the extended theory of planned behaviour

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ABSTRACT (ENGLISH)

Background

The most common and severe type of nosocomial infection in patients with colorectal cancer is surgical site infection (SSI). Patient-related factors are an important components of SSI. So it is necessary to participate in SSI prevention and control. It is important to identify the factors that influence patients' participation behaviour and to explore the mechanism of these effects.

Methods

A total of 580 patients with colorectal cancer completed relevant measures. Based on the extended theory of planned behaviour, a structural equation model was used to analyse the relationship among the influencing factors.

Results

The factors influencing participation of patients with colorectal cancer in SSI prevention and control were participation intention, participation ability, self-efficacy, participation attitude, perceived medical staff support, trust in physicians and social support. The direct effect coefficients of participation intention, participation ability and physician trust on SSI prevention and control behaviour were 0.67, 0.21 and 0.11, respectively. Self-efficacy, participation attitude, perceived medical staff support and social support indirectly affect participation behaviour through participation intention, and their effect values are 0.21, 0.11, 0.11 and 0.08, respectively.

Conclusions

Based on the structural equation model developed in this study, targeted intervention measures should be implemented to mobilize the intention and enthusiasm of patients with colorectal cancer to participate in the prevention and control of SSI.

Patient or Public Contribution

Patients or public contribute to spreading research findings, and promote broad participation in the implementation of policies or strategies.

FULL TEXT

BACKGROUND

Colorectal cancer (CRC) is a malignant tumour occurring in the colon or rectum, and it is the most common type of malignant tumour in the digestive tract. The incidence and mortality of CRC are still on the rise. According to the cancer statistical report of 2018, the incidence and mortality of CRC ranked third and fifth among malignant tumours in China, respectively, with 376,000 new cases and 191,000 deaths a year.[1] CRC is usually treated by surgical resection supplemented by radiotherapy and chemotherapy. The incidence of surgical site infection (SSI) is approximately 20%[2,3]; the incidence of SSI is significantly higher in low- and middle-income countries than in high-income countries.[4] SSI is one of the most common health-related infections, but its importance as a global health priority is not fully understood.[5] CRC patients with SSI usually result in prolonged hospital stay, heavy expenditure, poorer life quality, higher mortality and lower long-term survival rate. A study showed that the risk of death in patients with SSI is 2–11 times higher than that of patients without SSI, and the annual cost of health care-related economic expenditure is approximately $3.5 billion to 10 billion. Because of the time lag of returning to work, it will lead to indirect economic losses due to missing work or unemployment.[6]

SSI is one of the most common health care-related infections worldwide and poses a heavy burden on health care systems and individual patients. Various risk factors for SSI have been identified, which can be divided into patient- and procedure-related risk factors and other risk factors. Among them, patient factors account for a large proportion.[7,8] Yokoe et al.[9] found that up to 60% of SSIs can be avoided through evidence-based interventions, and patients play an important role in these interventions. Wang et al.[10] also found that patient participation could significantly reduce the incidence of SSI and improve satisfaction. From an international point of view, the World Health Organization posited that ‘patients have the right and responsibility to participate in their own health care’ at the primary health care conference in 1978 and proposed the Patient for Patient Safety action plan in 2004 to encourage patients to participate in the improvement of care quality and safety. Patient participation is considered to be one of the main factors in improving quality and safety and is considered to be an effective intervention to promote safe care.[11]

Patient is the center of medical practice. Ensuring the safety of patients is the bottom line to improve medical quality. Encouraging patients to participate in patient safety is the focus of continuous efforts in various countries and medical systems, and patients' participation in nosocomial prevention and control is the initial core content in patient safety. Participation is a vague concept in medical practice, and patient participation can be defined as a concept that involves three scientific concepts of care: learning, caring relationship and reciprocity (defined attributes).[12] At present, as the basic rights of patients and an important measure to ensure the safety of patients, patient participation has received increasing attention in the field of health. Increasing attention has been paid to patients' participation in the prevention and control of nosocomial infections, especially the high incidence of SSI, but there is a relative lack of research on the influencing factors and mechanism of patients' participation in the prevention and control of SSI.

The theory of planned behaviour (TPB) was developed by Ajzen on the basis of the rational behaviour theory. This theory holds that individual behaviour intention is the best predictor of behaviour and has a direct influence on behaviour; besides, intention is influenced by behaviour attitude, subjective norms and perceptual behaviour control. All of these have an indirect effect on behaviour through intention. In particular, perceptual behaviour control can also act directly on behaviour. In this study, support from medical personnel, relatives and friends reflects subjective norms. Perceptual behaviour control reflects patients' perception of factors that promote or hinder participation in behaviour, including their own knowledge, ability and health status. Self-efficacy and participation ability belong to this category. Wu[13] found that trust between medical staff and patients can affect patient participation, thus adding to the theoretical model.

Currently, perioperative nursing care has changed from a task-oriented, problem-centred discipline to a patient-centred professional discipline. This change involves the research and implementation of evidence-based practice to improve the quality of patient care. There is still a lack of literature that directly uses the TPB to describe and explain perioperative practice behaviour. Medical staff can use this theory to understand the intention behind the behaviour of surgical patients to ensure the safety of care and optimize clinical outcomes.[14] Therefore, this study is based on the extended TPB to establish a mechanism model for influencing factors of CRC patients' participation in the prevention and control of SSI to provide a reference basis for medical institutions and related departments to formulate strategies for SSI.

METHODSStudy design, setting and participants

The current study used a cross-sectional design and a questionnaire survey. The inclusion criteria were as follows: Colonoscopy or pathological examination that finally led to the diagnosis of colon cancer or rectal cancer, and elective laparoscopic surgical treatment; age over 18 years; without mental disorder; stable physical status; and provision of agreement to participate in this study. The exclusion criteria were as follows: Patients who underwent laparotomy or robot-assisted surgery, or withdrew from the study due to unexpected reasons.

Structural equation modelling was used as the main statistical analysis method. A structural equation model is suitable for analysing large samples. If the sample size is analysed by the number of observed variables in the model, the ratio of the sample size to the observed variables should be at least 20:1.[15] This study includes 21 observed variables, calculated 20 times, and the required sample size is 420. Taking into account a potential 20% attrition rate, the final sample size is determined to be 525.

Measures

In addition to the general information questionnaire, the following measures were used in this study: The promoting patient participation scale, the intention and behaviour measures of CRC patients participating in the prevention and control of SSI, the Chinese patient participation ability scale, the patient participation attitude questionnaire, the Wake Forest physician trust scale, the general self-efficacy scale and the perceived social support scale.[13,16–21] These measures have been shown to have good reliability and validity.

Data collection

From May 2020 to October 2020, data were collected in the gastrointestinal surgery ward in a Tertiary Hospital affiliated with the university in Chongqing, China. Before the investigation, the researchers contacted the head of the investigation department, explained the purpose and significance of the research, obtained the ethical approval certificate and obtained support and assistance. During the survey, the researchers explained to the patients how to fill in the study objectives, emphasized the anonymous nature of the study and collected data for scientific purposes only. After the questionnaires were completed, the researchers checked the completeness of the answers and collected the questionnaires.

Statistical analysis

The statistical software package IBM SPSS Statistics 23.0 (IBM Corp.) was used for data entry and analysis. The demographic data of the patients were described by frequency and percentage. The Pearson correlation coefficient was used to estimate the correlation between variables. Confirmatory factor analysis (CFA) was used to test the relationship between latent variables and observed variables of the measurement model. We used IBM SPSS Amos 24.0 software to build the model, used the maximum likelihood estimation method to estimate the model parameters and optimized the model according to the revised index. $p < .05$ was considered statistically significant.

RESULTSDemographic characteristics

In this study, a total of 608 questionnaires were distributed, and 580 valid questionnaires were collected, with an effective response rate of 95.39%. Among the respondents, there were 346 males (59.66%) and 234 females (40.34%). A total of 125 patients (21.55%) were over 71 years old; 44.83% had an abnormal body mass index and 54.31% had complications. Only 47 (8.10%) CRC patients accepted preoperative neoadjuvant therapy, including radiotherapy, chemotherapy and radio- and chemotherapy in combination, as shown in Table 1.

Table 1 Sociodemographic characteristics ($N = 580$)

Variables		N
Percent (%)	Gender	
Male		346
59.66	Female	
234	40.34	Age (years)
18–30		8
1.38	31–50	
130	22.41	51–70
317	54.66	≥71
125	21.55	BMI (kg/m^2)
<18.5		62
10.69	18.5–23.9	
320	55.17	24–27.9
169	29.14	≥28
29	5.00	Occupation
Civil servant		25
4.31	Business manager	
34	5.86	Worker
70	12.07	Farmer
141	24.31	Freelancer
40	6.90	Self-employed person
24	4.14	Retired personnel

160	27.58	Other
86	14.83	Marital status
Unmarried		4
0.69	Married	
524	90.34	Widowed
28	4.83	Divorce
24	4.14	Education level
Elementary school and below		163
28.10	Junior high school education	
199	34.31	High school or technical secondary school degree
114	19.66	College degree
54	9.31	Bachelor's degree and above
50	8.62	Residence
City		347
59.83	Township	
134	23.10	Rural area
99	17.07	Medical burden
Completely unburdened		7
1.21	Basically no burden	
115	19.83	Have a certain burden
258	44.48	Heavy burden

200	34.48	Length of hospital stay before surgery (days)
<3		130
22.42	3–7	
229	39.48	>7
221	38.10	Complications
No		265
45.69	Yes	
315	54.31	Preoperative neoadjuvant therapy
No		533
91.90	Yes	

Abbreviation: BMI, body mass index.

Descriptive analysis of the influencing factors of CRC patients participating in the prevention and control of SSI

The intention, behaviour, trust, attitude, self-efficacy, perceived medical staff support, social support and participation ability scores were 110.32 ± 12.69, 94.32 ± 15.59, 36.50 ± 4.61, 21.34 ± 4.51, 25.99 ± 5.66, 30.64 ± 3.96, 63.14 ± 10.15 and 65.57 ± 10.1, respectively (Table 2).

Table 2 Descriptive analysis of influencing factors for patients with colorectal cancer to participate in the prevention and control of surgical site infections

Variable	Mean	Standard deviation	Skewness	Kurtosis
Physician trust	36.50	4.61		
Charity	19.23	2.95	0.03	−0.07
Technical competence	17.27	2.12	0.04	−0.05
Participation attitude	21.34	4.51		
Medical support	30.64	3.96		
Social support	63.14	10.15		

Intrafamily support	22.47	3.31	−0.03	0.01
Out-of-family support	40.66	7.41	−0.09	0.02
Participation ability	65.57	10.10		
Information acquisition	11.28	2.04	−0.02	−0.08
Independent decision	9.42	3.52	0.05	−0.04
Communication	19.26	3.37	−0.02	−0.06
Emotional management	25.61	3.04	−0.05	−0.36
Self-efficacy	25.99	5.66		
Intention	110.32	12.69		
Appeal participation	29.25	4.11	−0.04	−0.05
Decision participation	31.35	5.52	−0.18	−0.06
Inquiry supervision	16.70	2.59	−0.07	−0.23
Information interaction	14.04	1.69	−0.08	0.05
Caring participation	18.98	1.56	−0.05	0.02
Behaviour	94.32	15.59		
Appeal participation	24.60	4.58	0.19	−0.07
Decision participation	26.33	5.94	0.11	−0.06
Inquiry supervision	14.08	2.69	0.03	−0.04
Information interaction	12.99	2.28	0.01	−0.18
Caring participation	16.30	2.57	0.08	0.06

Correlation coefficients among variables

Physician trust, participation attitude, perceived medical staff support, perceived social support, participation ability and self-efficacy were positively correlated with the intention and behaviour of infection prevention and control at the surgical site, as detailed in Table 3.

Table 3 Correlation coefficient between variables in patients with colorectal cancer (*N* = 580)

Variable	Physician trust	Participation attitude	Medical support	Social support	Participation ability	Self-efficacy	Intention
Physician trust	1						
Participation attitude	0.525*	1					
Medical support	0.027	0.139*	1				
Social support	0.384*	0.391*	0.074	1			
Participation ability	0.52*	0.65*	0.205*	0.395*	1		
Self-efficacy	0.431*	0.493*	0.051	0.342*	0.651*	1	
Intention	0.297*	0.367*	0.208*	0.282*	0.393*	0.421*	1
Behaviour	0.409*	0.491*	0.222*	0.392*	0.52*	0.495*	0.73*

*

p <.001.

Structural equation modelling of the factors affecting CRC patients' participation in the prevention and control of SSI

Confirmatory factor analysis

Table 4 shows the CFA test of each structure of the model. All standardized factor load estimates were over 0.4 (p <.05). The analysis indicated that the data are suitable for modelling.

Table 4 Confirmatory factor analysis

		Factor loading	p	IFI	CFI	RMSEA
McDonald's ω	Participation attitude					
Total						
0.868	Medical support					
Total						
0.867	Self-efficacy					
Total						
0.866	Physician trust				0.910	0.909

0.079	0.804	Charity		0.861	<.001	
			Technical competence		0.752	<.001
				Social support		
	0.905	0.905	0.079	0.902	Intrafamily	
0.867	<.001					Out-of-family
0.876	<.001					Participation ability
		0.957	0.957	0.068	0.912	Information acquisition
0.703	<.001					Independent decision
0.728	<.001					Communication
0.870	<.001					Emotional management
0.803	<.001					Intention
		0.948	0.948	0.072	0.946	Appeal participation
0.801	<.001					Decision participation
0.913	<.001					Inquiry supervision
0.747	<.001					Information interaction
0.433	<.001					Caring participation
0.619	<.001					Behaviour
		0.951	0.951	0.075	0.939	Appeal participation

0.942	<.001					Decision participation
0.887	<.001					Inquiry supervision
0.869	<.001					Information interaction
0.469	<.001					Caring participation

Abbreviations: CF, comparative fit index; IFI, incremental fit index; RMSEA, root mean squared error of approximation.

Initial model assumption

In the model, we established the following hypothesis based on an extended TPB: Participation ability and general self-efficacy directly affect participation behaviour, participation attitude and perceived medical staff support and social support affects participation behaviour through participation intention, as shown by the solid line in Figure 1. Physician trust can affect patient participation, which is shown by the dotted line in Figure 1. The general self-efficacy scale, the promoting patient participation scale and the patient participation attitude questionnaire measures were all unidimensional and included only one observed variable, without a latent variable, so we replaced the latent variable with the observed variable; see Figure 1 (ovals, rectangles).

Figure 1. Initial model assumptions

Model modification

Before constructing the initial model, according to the results of the correlation coefficient, the relevant variables with p >.05 were deleted (i.e., perceived medical staff support and physician trust, perceived medical staff support and perceived social support, perceived medical staff support and self-efficacy). After constructing the initial model, three paths with p >.05 were deleted: 'physician trust → intention' (β = .010, p = .878), 'participation ability → intention' (β = .063, p = .474), and 'self-efficacy → behaviour' (β = .026, p = .523). In the final model, the total effect values of self-efficacy, participation attitude, perceived medical staff support, social support, participation ability, physician trust and intention on behaviour were 0.21, 0.11, 0.11, 0.08, 0.21, 0.11 and 0.67, respectively. These variables explained 69.00% of the variation in behaviour. The modification of the index is based on Table 5.[15] The final model is shown in Figure 2. The p value was less than .05 for all path coefficients.

Figure 2. Final model path and standardized regression coefficients

Table 5 Modification basis for model indices

Index	χ^2	χ^2/df	GFI	PGFI	NFI	IFI	CFI	RMSEA
Initial model	1257.328	7.396	0.861	0.609	0.843	0.862	0.861	0.105
Revised model	724.459	4.509	0.901	0.623	0.91	0.929	0.928	0.078
Reference model		1–5	>0.90	>0.50	>0.90	>0.90	>0.90	<0.08

Abbreviations: *df*, degrees of freedom; GFI, goodness-of-fit index; NF, normed fit index; PGFI, parsimony goodness of fit index.

DISCUSSIONCRC patients have the intention to participate in the prevention and control of SSI, but participation

behaviour is inferior to the intention

For surgical patients, SSI of postoperative complications has always been the focus of medical attention. This study focuses on CRC patients with a high incidence of SSI. Through investigation, it was found that CRC patients intentionally participated in the prevention and control of partial infection after the operation, with a score of 110.32 ± 12.69. It is suggested that CRC patients have a high level of intention to participate in the prevention and control of SSI, and there is a need to participate in such behaviour. Levinson et al.[22] also found that almost all respondents (96%) had a strong behavioural intention with respect to disease diagnosis and treatment and wanted to communicate with health care providers. Although CRC patients have a strong intention to participate in the prevention and control of SSI, the actual behaviour is less common, with a score of 94.32 ± 15.59, which is lower than that of intention. The scores of all dimensions involved in surgical infection prevention and control are also lower than those of intention, which is consistent with the conclusions of Keating et al.[23]

The behaviour of CRC patients participating in the prevention and control of SSI varies according to the content. The order of participation behaviour score is as follows: decision participation (26.33 ± 5.94) >appeal participation (24.60 ± 4.58) >caring participation (16.30 ± 2.57) >inquiry supervision (14.08 ± 2.69) >information interaction (12.99 ± 2.28). Female, well-educated and healthy individuals were more likely to play an active role in decision participation.[22] The previous research[24] found that, because of the gradient of authority and patients' concern that the appeal will affect the harmonious relationship between medical staff and patients, the score of appeal participation is generally low and the scores of information interaction and caring participation are rather high; however, we obtained different results. With the concept of 'patient-centred care' deeply rooted in the hearts of the people and due to the renewed focus on patients' awareness of rights, the behaviour of CRC patients participating in SSI prevention and control is gradually becoming different from patient behaviour in ordinary health care.

Participation behaviour is affected by many factorsAnalysis of the influence of intention on behaviour

The intention of CRC patients to participate in the prevention and control of SSI refers to the behavioural motivation and ideological tendency before participating in the behaviour of SSI prevention and control. Intention is the most important behaviour predictor in the planned behaviour theory. In this study, the correlation coefficient between CRC patients' intention to participate in SSI prevention and control and prevention and control behaviour was .73 (p <.001). In the structural equation model constructed in this study, the effect of intention on behaviour is the largest, 0.67, which is consistent with the conclusion of Hagger's research.[25] According to the model, self-efficacy, participation attitude, medical support and social support have a direct effect on CRC patients' intention to participate in SSI prevention and control, and the effect coefficients were .31, .17, .16 and .12, respectively. This result suggests that measures can be taken to improve the self-efficacy and participation attitude of CRC patients, to strengthen medical support and social support, to directly improve participation intention and indirectly promote their participation in SSI prevention and control.

Analysis of the influence of participation attitude on behaviour

This study found that participation attitude indirectly positively affects participation behaviour through participation intention, and the total effect value on behaviour is 0.11. Patient participation in the prevention and control of SSI has changed the role of patients from the traditional 'receiver' to the current role of 'collaborator'. Patients' attitudes and cognition towards this new role have a significant impact on their intention to participate in prevention and control and their actual participation behaviour. Davis et al.[26] found that 1 in 10 hospitalized patients suffered an adverse event as a result of treatment or surgery. If patients can consciously and actively participate in the diagnosis, treatment and nursing activities, the risk of adverse events will be reduced. However, such a positive attitude does not directly affect the participation behaviour, but plays a role through the participation intention. It should be a priority for medical institutions to mobilize the attitude of patients to participate, strengthen their participation intention and optimize their participation behaviour.

Analysis of the influence of medical support on behaviour

Medical staff who promote patient participation and patient perception to support their participation in medical care is an important embodiment of 'patient-centred' practice. In this study, the score of the perceived medical support of

CRC patients was 30.64 ± 3.96. Through participation intention and indirect positive prediction of participation behaviour, the total effect value was 0.11. A qualitative study shows that CRC patients expect the support of health care staff during hospitalisation.[27] Most medical staff support patients' participation in medical safety and are willing to actively communicate with patients on related issues. Patient participation can enable medical staff to fully understand patient information, clarify safety issues, help to meet the needs of patients and achieve better results.

Analysis of the influence of physician trust on behaviour

The results of this study showed that the correlation coefficient between CRC patients' trust in physicians and their participation in SSI prevention and control behaviour was 0.409 ($p < .001$), which was moderately positively correlated. The trust of CRC patients in physicians can directly predict their participation in SSI prevention and control behaviour (the path coefficient is 0.11). Trust is an important influencing factor of patient participation, patient satisfaction and physician–patient relationships. If a mutual trust relationship established between CRC patients and medical staff during perioperative stage, they may develop good compliance of SSI prevention and control behaviour, and better participation in many areas of health care. Trachtenberg et al.[28] found that patients' trust in physicians promotes patients' participation in their own health care, and patients who trust health care staff are more likely to reach a consensus with them, thus reducing conflicts in health care decision-making.

Analysis of the influence of participation ability on behaviour

Patient participation ability includes self-management ability and health literacy.[29] Patient self-management refers to patients' ability to choose treatment options and cope with psychological and physiological changes, as well as lifestyle changes, according to their own symptoms in daily life. The ability of self-management is not limited to compliance with treatment; more importantly, the physical and psychological coping abilities of patients should be integrated into the long-term process of dealing with diseases. Self-management ability will contribute to recovering faster for CRC patients after surgery. Katz et al.[30] found that patients with high health literacy showed stronger ability to collect information, and they asked health care workers more questions. Patients with low health literacy are less likely to ask questions because they are worried that health care workers will think that their ability to understand the disease and treatment information is limited. The current study found that participation ability plays a direct positive predictive role in participating in SSI prevention and control behaviour, and the total effect value is 0.21. How to improve the participation ability of CRC patients is a topic worth discussing.

Analysis of the influence of social support on behaviour

In this study, it was found that the score of perceived social support in CRC patients was 63.14 ± 10.15, which was indirectly positively predicted by participation in SSI prevention and control intention. Patients undergoing surgery often have the need for love and belonging, especially the support and care of relatives and friends, because they are anxious and worried about postoperative recovery. Relatives and friends are an important part of the patient's social support system, and the attitude and behaviour of relatives and friends will affect the patient's participation behaviour. A previous study found that inpatients obtained the support and encouragement from families, which promoted their active participation and positive cooperation with treatment.[31]

Analysis of the influence of self-efficacy on behaviour

This study showed that the total effect value of self-efficacy on the behaviour of infection prevention and control at the surgical site was 0.21, which indirectly affected the behaviour by affecting the intention of participation. The expression of self-efficacy is the subjective judgement and evaluation of an individual's behavioural ability. Empowering surgical patients to improve self-efficacy is a new concept in the health care field. This action can effectively improve medical quality. McAlearney et al.[32] found that empowerment is a process through which patients are better able to weigh decisions and behaviours that affect their health.

Thoughts and suggestions on promoting rational participation in the prevention and control of SSI in CRC patients

This study found that CRC patients have a high intention to participate in the prevention and control of SSI, which is a good and noteworthy aspect. Medical institutions and medical staff should respect their intention to participate. A study of SSI-related knowledge and awareness of prevention and control among 52 patients found that only 60% of patients had received a brochure on SSI knowledge in the hospital, and 16% of the respondents said that they had not received any training in related knowledge at all.[33] Knowledge training and health education on the prevention and control of SSI during the perioperative period should be strengthened, enthusiasm for participation should be promoted and surgical patients should be empowered. Medical personnel should initiatively communicate with patients, encourage patients to express confusions, consider patients as the cooperative partner. Anderso et al.[34] found that cooperative participation will be developed and accepted as a mainstream form of patient participation; therefore, medical staff should also actively pay attention to the desire of patients to participate in information interaction, meet the information needs of patients in a variety of ways and take the initiative to provide patients with disease- and treatment-related information in the process of communication and interaction between medical staff and patients. Different communication skills should be utilized to optimize the communication process, to improve the quality of communication, to ensure that patients correctly understand the information provided on SSI and, with the help of mobile medical technology, to provide patients with continuous and comprehensive information to fully grasp the relevant knowledge.

CONCLUSION

In this study, structural equation modelling revealed that the total effect of participation intention was the largest among the influencing factors of CRC patients participating in SSI prevention and control behaviour, which directly affected participation behaviour. Participation ability and physician trust directly positively predict participation behaviour. Self-efficacy, participation attitude, perceived medical staff support and social support indirectly positively predict participation behaviour by influencing the intention to participate in SSI prevention and control. It is suggested that to promote the implementation of CRC patients' participation in the prevention and control of SSI, it is necessary to maximize their willingness to participate, pay attention to the relationship between family and social networks and strengthen social support and medical staff support. CRC patients should be encouraged to develop a desire to participate in the prevention and control of SSI and strengthen their sense of self-efficacy. Effective measures can be taken to intervene directly and improve the trust and communication between medical staff and patients. In addition, based on the model constructed in this study, controllable and effective policies can be implemented to ensure that CRC patients participate in the prevention and control of SSI.

LIMITATIONS

A limitation of this study is that we adopted convenience sampling instead of random sampling. The representativeness of the sample may be insufficient, and there are certain limitations in the extrapolation of results. In addition, due to limited time, resources and funding, only one medical institution was investigated. In future studies, the sample size should be expanded, and multicentre and large-sample surveys should be conducted.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

All authors have made substantial contributions to the work are as follows: Lili Yao contributed to study design and article drafting. Yetao Luo contributed to data analysis and data interpretation. Lili Yao and Lupei Yan contributed to data collection. Mingzhao Xiao, Qinghua Zhao and Yuerong Li contributed to design of the study and thoroughly revised the manuscript. All authors have read and approved the final manuscript.

ETHICS STATEMENT

This study was approved by the Ethics Committee of the First Affiliated Hospital of Chongqing Medical University (No. 2019-131). Informed consent was obtained from all participants.

DATA AVAILABILITY STATEMENT

Data are available upon reasonable request. Data can be shared upon reasonable request.

DETAILS

Subject:	Software; Prevention programs; Nosocomial infection; Professional attitudes; Infectious diseases; Cancer therapies; Mortality; Patients; Risk factors; Questionnaires; Physicians; Medical personnel; Efficacy; Prevention; Colorectal cancer; Surgery; Medical practices; Expenditures; Cancer; Infections; Statistical analysis; Social support; Hospitals; Patient safety; Participation; Nosocomial infections; Attitudes; Surgical site infections; Staff participation; Colorectal carcinoma; Patient participation; Multivariate statistical analysis; Social interactions; Policy implementation; Public participation; Radiation therapy; Chemotherapy; Theory of planned behavior
Location:	China
Identifier / keyword:	colorectal cancer; health and safety; infection control; patient participation
Publication title:	Health Expectations; Oxford
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Patient engagement in care: A scoping review of recently validated tools assessing patients' and healthcare professionals' preferences and experience

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ProQuest document link

ABSTRACT (ENGLISH)

Background

Patient engagement in care is a priority and a key component of clinical practice. Different approaches to care have been introduced to foster patient engagement. There is a lack of a recent review on tools for assessing the main concepts and dimensions related to patient engagement in care.

Objective

Our scoping review sought to map and summarize recently validated tools for assessing various concepts and dimensions of patient engagement in care.

Search Strategy

A scoping review of recent peer-reviewed articles describing tools that assess preferences in and experience with patient engagement in care was conducted in four databases (Ovid Medline, Ovid EMBASE, Cochrane Database of Systematic Reviews, CINAHL-EBSCO). We adopted a broad definition based on the main concepts of patient engagement in care: patient-centredness, empowerment, shared decision-making and partnership in care.

Main Results

Of 2161 articles found, 16, each describing a different tool, were included and analysed. Shared decision-making and patient-centredness are the two main concepts evaluated, often simultaneously in most of the tools. Only four scales measure patient-centredness, empowerment and shared decision-making at the same time, but no tool measures the core dimensions of partnership in care. Most of the tools did not include patients in their development or validation or just consulted them during the validation phase.

Discussion and Conclusion

There is no tool coconstructed with patients from development to validation, which can be used to assess the main concepts and dimensions of patient engagement in care at the same time.

Patient and Public Contribution

This manuscript was prepared with a patient expert who is one of the authors. Vincent Dumez, who is a patient expert and codirector of the Center of Excellence on Partnership with Patients and the Public, has contributed to the preparation of the manuscript.

FULL TEXT

INTRODUCTION

Patient engagement in health policies, healthcare planning and improvement and direct care is recognized as a cornerstone of quality and safety.[1] Engaging patients in care has become a priority and a key component of clinical practice in many countries around the world.[2] Evidence suggests that engaging patients can help (re)shape their care and treatment in ways that fit their needs and preferences, ultimately resulting in improved outcomes.[3–6] Over the last few decades, various approaches to care have been introduced in clinical practice to foster the integration of patient engagement into the delivery of healthcare.

In the 1990s, the patient-centred care approach gradually replaced the medical paternalism that has dominated healthcare for decades.[7] The patient-centred care model involves integrating patients' needs and preferences into the delivery of care, ‘moving away from a logic of “care to patients” towards one of “care for patients”’.[7] Patient-centred care is based on a patient-oriented perspective of care that includes what patients consider important for their life project.[7]

In the last two decades, collaborative approaches have emerged, moving towards a logic of ‘care with patients’. For example, shared decision-making encourages patients to take part in decisions on their care,[8,9] while self-management or patient education approaches seek to strengthen patients' knowledge and skills to better empower them in their care process.[10,11] More recently, the ‘partnership in care’ approach has considered patients as full-fledged members of healthcare teams.[12] This new model builds on aspects of each care approach, including the integration of patient needs and preferences into care delivery, the participation of patients in care decisions, the coconstruction of a care plan with them and the development of patients' capacities to manage their own care.[13] A previous empirical study on patient partnership from the patients-as-partners perspective was able to define partnership in care as the proactive efforts by patients to fill the gap between their preferences or expectations in the care relationship and what they experience during a consultation with a healthcare professional (HCP).[12]

All these approaches to care are part of a continuum of engagement, from consultation to partnership in care, that reflects the increasingly important role played by patients in their own care.[1]

As patient engagement in care has become a clinical standard in healthcare settings, a growing number of scales have been developed in recent decades for effective quality improvement. Previous reviews have identified, synthesized and appraised the tools used to assess some dimensions of care/approaches to care. A recent systematic review by Philipps et al.[14] focuses on studies published between 2005 and 2014 that described tools for assessing patient participation in healthcare. Their review only includes tools that measure approaches related to self-management and decision-making, without including tools that assess patient-centred care. Conversely, a review by Ree et al.[15] synthetizes information on patient-centred care tools, with a special focus on how patients are involved in the care. Lastly, a review by Jerofke-Owen et al.[16] identifies and appraises tools that measure self-reported patients' preferences in engagement, without considering tools that assess patient experience in engagement or HCPs' preferences in and experience with engaging patients. However, as patient engagement is part of the care relationship between patients and HCPs, it is important to identify the various tools used to assess both patients' and HCPs' preferences and experience in this area. In addition, the literature lacks a broad review of the recently validated scales used to assess the central dimensions on which the different approaches to care (from consultation to partnership in care) are based and that coexist in clinical practices.

The objective of this scoping review was therefore to map and summarize recently validated tools that assess patient engagement in care. To this end, several specific objectives were pursued: (1) to identify tools used to assess both patients' and HCPs' preferences in and/or experiences with patient engagement in care; (2) to summarize the evidence on recently validated tools that assess various concepts and dimensions of patient engagement in care; and (3) to report on various characteristics of scale development and validation (patient involvement, reliability of the scales).

METHODSConceptual framework

In this review, we adopted a broad definition of patient engagement in care that reflects the continuum of such engagement and the coexistence of different approaches to enhancing it. The definitions proposed here are based on Castro et al.'s[17] conceptual analysis of the main concepts related to patient engagement in care: patient-centred care, empowerment and shared decision-making. These concepts refer to different approaches to patient engagement in care, and together, they form the higher concept of partnership in care. According to Pomey et al.,[18] the concept of partnership in care is an approach that considers the patient as ‘a caregiver of herself and, as such, a genuine member of the treatment team, endowed with competencies and limitations just like any other member of the team’. We believe that the concept of partnership can be summarized by all the dimensions on which each approach to care is based,[7] including individualized care, empathy, interpersonal trust, communication, experiential knowledge and self-care. A summary of these concepts' definitions and dimensions is presented in Table 1.

Table 1 Definitions of the main concepts related to patient engagement in care, adapted from Castro et al.[17]

Concept	Partnership in care main dimensions: Individualized care, empathy, interpersonal trust, communication, experiential knowledge and self-care[7]

	Patient centredness	Shared decision-making	Empowerment
Definition	'Biopsychosocial approach and attitude that aims to deliver care that is respectful and individualized. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy and shared knowledge'[17]	'Patient's rights and opportunities to influence and engage in the decision-making about his care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional's expert knowledge'[17]	'Process that enables patients to exert more influence over their individual health by increasing their capacities to gain more control over issues they themselves define as important'[17]
Main dimensions	- Person-centred care/climate - Individualized care (considering needs, values and preferences) - Empathy - Therapeutic alliance - Interpersonal trust	- Shared decision-making - Patient–provider communication - Experiential knowledge	- Self-care/self-management - Patient education - Patient enablement - Patient activation - Experiential knowledge

We used the continuum of patient involvement in research[18] to identify the level of patient involvement in tool development and validation. We considered three levels of involvement: (1) consultation of patients, which refers to asking for patients' input during the validation of the tool; (2) collaboration with patients, which corresponds to involving them in the selection and wording of items; and (3) partnership, which refers to coconstructing the tool with patients, from its development to its validation.

Review approach

We conducted a scoping review to map recent evidence on validated scales for assessing patient engagement in care.[19] We chose to conduct a narrative synthesis of the literature to describe the major characteristics of the tools, including the measurement objective, the concepts and dimensions assessed, the clinical context of utilisation and the development and validation characteristics of the tools. We followed the PRISMA extension for scoping reviews to apply a systematic approach when conducting the review and reporting the results.[20]

Searches and screening

We searched for articles published between 2014 and 2021 in four major health and social science databases: Ovid MEDLINE, Ovid EMBASE, the Cochrane database of systematic reviews and EBSCO-CINAHL. We decided to search for articles published starting from 2014 since a previous systematic review by Philipps et al.[14] searched for articles published from 2005 to 2013 that described tools for measuring patient participation in care. As Philips et al. [14] adopted a rather broad definition of patient engagement in care (shared decision-making, self-care and patients having self-knowledge), we wanted to ensure that our review would not duplicate any previous reviews on this topic. The initial search was conducted on 19 January 2021. The search terms used are presented in Table 2. These correspond to the six major concepts searched for, related to patient, engagement, assessment, scale, clinical care and validation. Our search strategy was limited to published and peer-reviewed literature and we did not conduct any searches in the grey literature. The search strategies developed for Ovid MEDLINE are available in File S1. The search strategies developed for the three other databases are available upon request. Two reviewers (N. C. and J. P.) independently screened articles based on their titles and abstracts. A pilot round was conducted with 50 references to verify the authors' (N. C. and J. P.) agreement on the inclusion and exclusion criteria before performing a full screening of the rest of the articles.

Table 2 Search terms

Patient	Engagement	Assessment	Scale	Clinical	Validation
Patient	Engagement	Assessment	Scale	Clinical care	Validation
User	Involvement	Measurement	Tool	Care	Psychometry
Client	Participation	Evaluation	Survey	Clinical level	Reliability
	Centred care		Questionnaire		Validity
	Shared decision-making				Factor analysis
	Empowerment				
	Self-management				
	Patient education				
	Partnership				
	Activation				
	Enablement				

Inclusion and exclusion criteria

We included both original and review articles describing the development and validation of scales assessing patient engagement in adult inpatient or outpatient care. The inclusion and exclusion criteria are detailed in Table 3.

Table 3 Inclusion and exclusion criteria

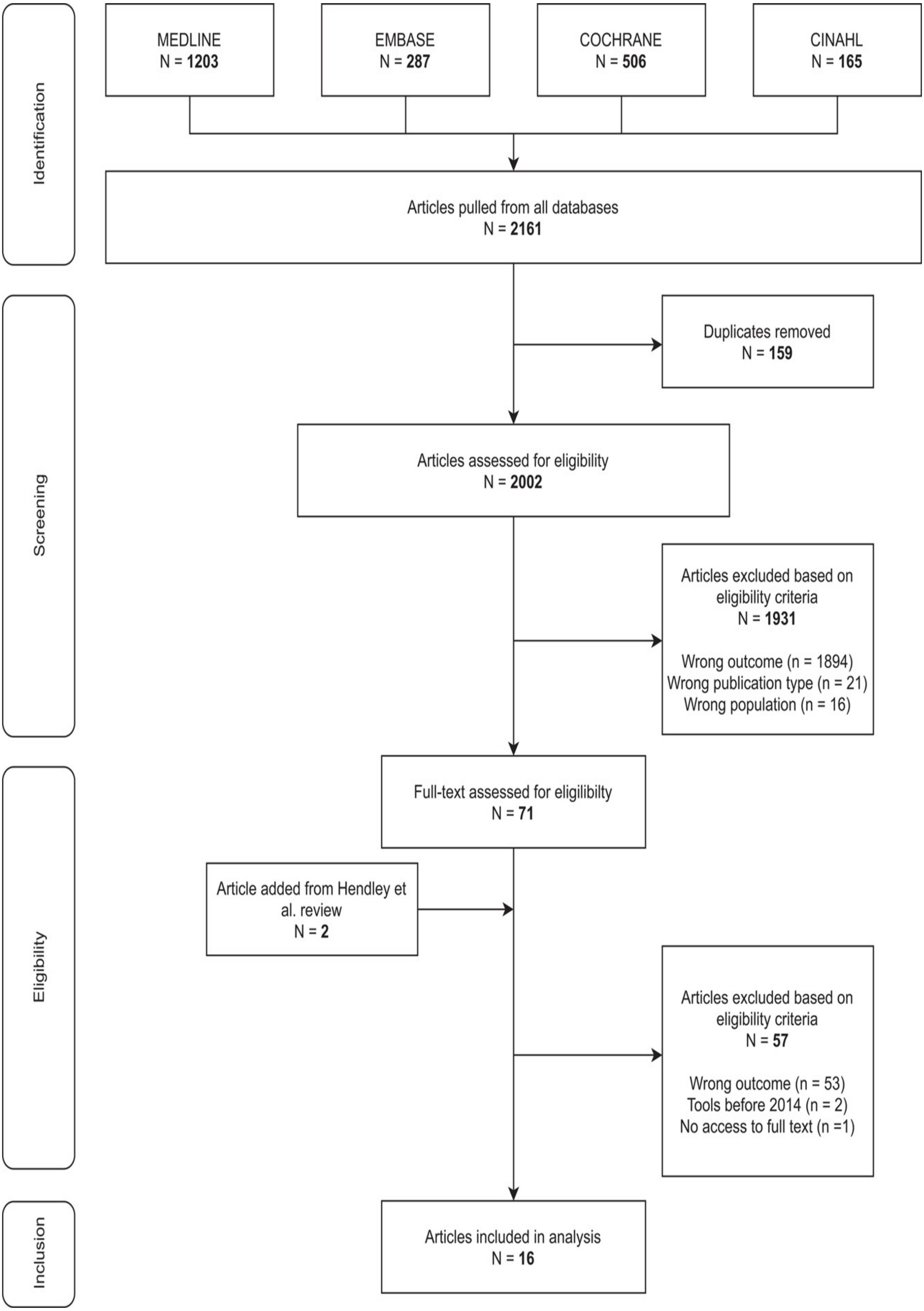
Inclusion criteria	Exclusion criteria
Original or review articles describing the development and validation of scales assessing patient engagement in care	Published in a language other than English or French
Studies describing tools used in adult inpatient or outpatient care (all clinical settings)	Studies describing tools developed to be used with specific chronic or acute disease patients
Studies published between 2014 and 2021	Studies describing tools used in paediatric care with children or adolescents
	The reviewers could not access the full text (the authors were contacted, but did not respond)

Extraction methods

Data from the included articles were charted on an extraction grid (File S2) according to the following categories: (1) the general presentation of the scales (e.g., first author, year of publication, title of the article and journal of publication), (2) the specific characteristics of the scales (e.g., name of the scale; measurement objective; patients', family members' or health professionals' perspective; preferences in or experience with patient engagement; context of utilisation; number of items; and scale measurement) and (3) the methodological aspects of tool development and validation (e.g., level of patient involvement in tool development or validation and reliability of the scale). Furthermore, the extraction grid included Castro et al.'s[17] three main concepts related to patient engagement in care: (1) patient-centred care, (2) empowerment and (3) shared decision-making. One author (J. P.) classified each tool's main factors/dimensions or items according to the corresponding concepts, and a second author (N. C.) reviewed each component attribution.

RESULTSSearch results

Our initial search yielded a total of 2161 articles. After removing duplicates, a total of 2002 articles were screened. This process resulted in a total of 71 full-text articles to be assessed for eligibility. One of them, a review of surveys for measuring patient-centred care in the hospital setting,[21] included two tools published after 2014: the Family Inventory of Needs[22] and the Person-Centred Climate Questionnaire-Family Version (PCQ-F).[23] Consequently, we have added the two articles corresponding to the development and validation of these tools to assess them against our full eligibility criteria. Following reviews of 73 full-text articles, 16 articles fulfilled the inclusion criteria. The PRISMA flow diagram is shown in Figure 1.



Enlarge this image.

Study characteristics

We identified a total of 16 articles, representing 16 different tools, based on the eligibility criteria for assessing patient engagement in care. All the findings are presented in Tables 4 and 5. The data extraction table containing all the information that we extracted from the tools can also be accessed from File S2. The included studies were published between 2015 and 2020, and all use a quantitative design based on psychometric data analysis to describe the development and validation of tools assessing patient engagement in care. The studies were from eight different countries around the world: the United States (*n* = 5), China (*n* = 2), Denmark (*n* = 2), Italy (*n* = 2), Sweden (*n* = 2), Belgium (*n* = 1), the Netherlands (*n* = 1) and Taiwan (*n* = 1). The included studies were published in 12 different journals, some of which were represented more than once: the *Journal of Advanced Nursing* (*n* = 2), the *Journal of Nursing Care Quality* (*n* = 2), the *Journal of Nursing Management* (*n* = 2) and *Patient Education &Counseling* (*n* = 2). The scales contain between 9 and 55 items, most of which are rated on a five-point Likert scale (56%, *n* = 9).

Table 4 Tools included in the scoping review assessing the concepts and dimensions related to patient engagement in care (2014–2021)

Table 5 Characteristics of the tools included in the scoping review, including context of utilisation, number of items, scale measurement and index of reliability

Perspectives on patient engagement as measured by the tools

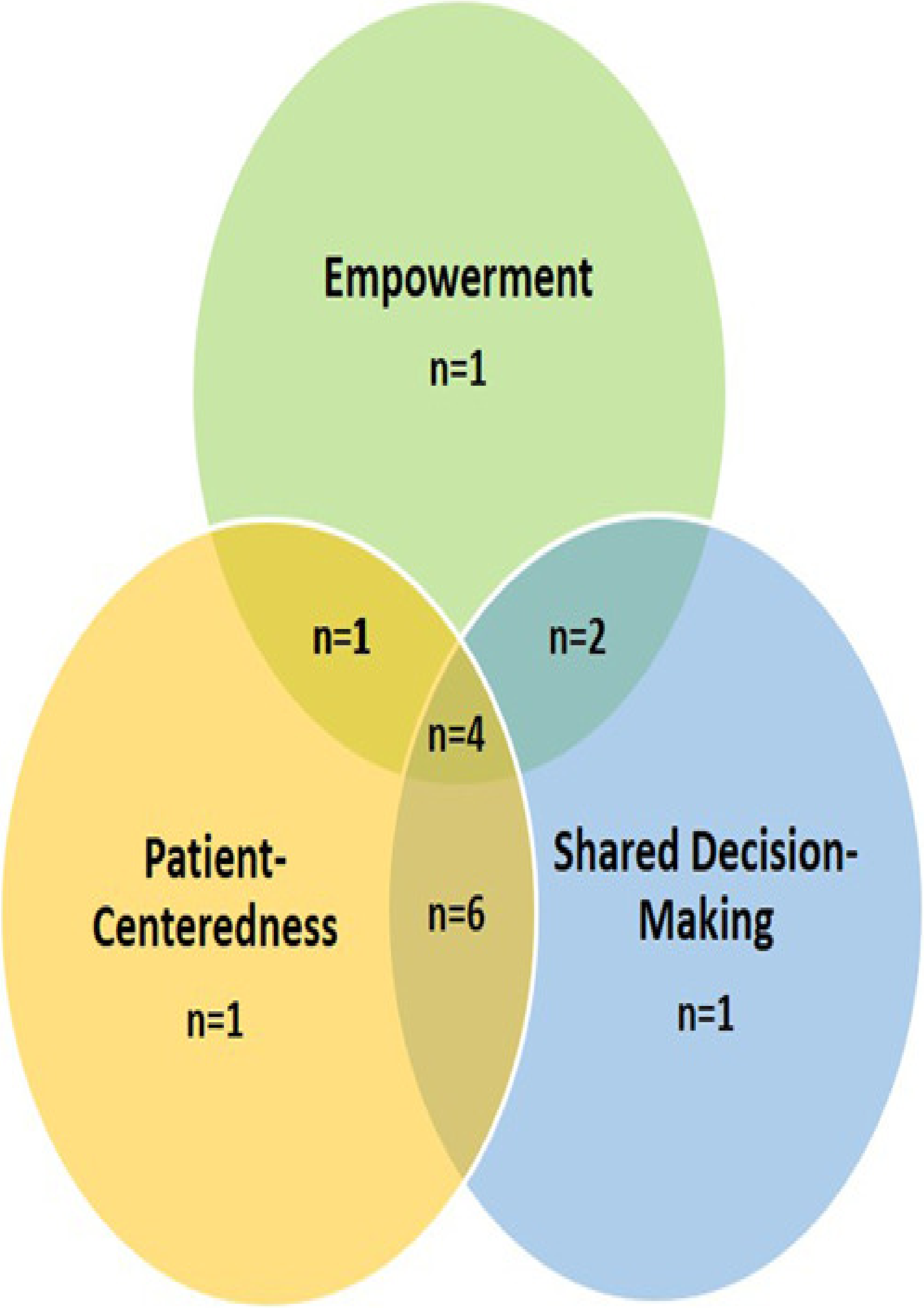
Nearly all tools measure experience in patient engagement (88%, *n* = 14), most of which comes from the patients' perspective (56%, *n* = 9).[24–27,31,33–36] Tools that inquire about health professionals' perspectives are also mostly based on their own experience in engaging patients (25%, *n* = 4),[28,29,32,38] but one tool, PaCT-HCW,[32] evaluates both preferences in and experience with patient engagement. Finally, two tools assess how family members perceived engagement in care: the PCQ-F tool [23] measures their experience with engagement and the WeCares tool[37] evaluates their preferences.

Concepts and dimensions assessed with the tools

We categorized the dimensions assessed in each tool into the main concepts of engagement, which include patient centredness, empowerment and shared decision-making. The results reveal that the two main concepts evaluated in the included scales are shared decision-making (81%, *n* = 13)[24–27,29,30,32,34–38] and patient centredness (75%, *n* = 12), [23–31,36–38] while empowerment is present in 50% (*n* = 8) of the included tools.[27,28,30,33–37]

Nine tools evaluate two concepts simultaneously.[24–26,28,29,31,34,35,38] Of these, six evaluate (37%) both patient-centredness and shared decision-making. These tools, including the Patient–Professional Interaction Questionnaire, [25] the Provider–Patient Relationship Questionnaire,[29] the Patient Participation Questionnaire,[24] the Patient-Centred Primary Care instrument,[26] the Patient Perceptions of Patient-Empowering Nurse Behaviours Scale[31] and the Student and physician self-efficacy in patient-centeredness,[38] assess common dimensions of patient-centredness (empathy/human approach, individualized care/patients' preferences, trust and information exchange) and shared decision-making (patient involvement in care decisions, patients encouraged to ask questions and effective communication). Three of these tools measure the patient experience of engagement from the patient's perspective [24–26] and two from the HCP's point of view.[29,38] Four tools have been developed to be used in inpatient care,[24,25,29,38] while one has been validated in primary care settings.[26] The three main concepts of patient engagement in care are evaluated in four of the scales (25%): the Generic Person-Centred Care Questionnaire,[27] the Five-Dimension Patient-Centred Innovation Questionnaire,[30] the Patient Engagement in Health Care Questionnaire[36] and the WeCares survey.[37] Three of them measure the patient experience of engagement,[27,30,36] three assess the patient and/or the family perspective[27,36,37] and one evaluates the point of view of the HCPs.[30] Three tools have been validated in inpatient care settings[30,36,37] and one is a generic tool that can be used in both inpatient and outpatient care.[27] Finally, three scales (18%) only evaluate a single concept.[23,32,33]

Figure 2 shows the number of tools assessing one or several concepts of patient engagement in care.



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Involvement of patients in tool development or validation

A total of eight tools (50%) did not include patients in their development or validation or did not report having involved patients, and eight were partly developed with patients. For five of them (31%), the involvement of patients consisted mostly of consulting them to validate the tool, including with respect to face or content validity.[24,27,31,32,36] Three tools (19%) were developed in collaboration with patients for item development through focus groups or in-depth interviews or by including patients in expert panels.[26,34,37] Nevertheless, none of the tools were coconstructed in partnership with patients from item development to the validation phase.

Table 4 presents details on perspectives on patient engagement as measured by the tools, the concepts and dimensions assessed and patient involvement in tool development and validation.

Context of utilisation of the tools

Most of the tools (75%, *n* = 12) have been validated in inpatient care,[23–25,29–32,34–38] while a few (13%, *n* = 2) were developed for use in outpatient care.[26,28] Only two tools have been validated in both inpatient and outpatient clinical settings.[27,33] Figure 2 shows information on the context of utilisation of the tools included in our scoping review.

Psychometric properties of the validated tools

Lastly, in terms of psychometric properties, the reported reliability indices of the tools (Cronbach's *α*, the reliability index for multidimensional scales and the person separation index) were between 0.71 and 0.98. Based on these coefficients, we consider the reliability of the tools to be moderate to excellent.[14]

Table 5 presents information on various characteristics of the tools, including the context of their use, the number of items, the measurement scale and psychometric properties (index of reliability).

DISCUSSION

To the best of our knowledge, this is the first systematic scoping review to have identified and summarized recently validated tools assessing various concepts and dimensions of patient engagement in care from both the patients' and HCPs' perspectives. Unlike the systematic review by Jerofke and Weiss,[31] which identified instruments measuring patient preferences regarding engagement in healthcare, our broad review included scales that assessed preferences in or experience with patient engagement from the patients' and HCPs' perspectives.

This scoping review identified and summarized 16 studies that reported on the development and validation of 16 tools assessing patient engagement in care. Nearly all of these tools measure experience with patient engagement and a few measure preferences in patient engagement or both preferences in and experience with engagement simultaneously. The results also show that most of the tools were validated in inpatient care settings and did not involve patients in their development or only consulted them during the validation phase. We identified four important findings concerning the development and validation of the tools included in our scoping review. First, a few tools simultaneously measure some dimensions related to all of the concepts of patient engagement. Second, tools that assess preferences regarding patient engagement in care are relatively scarce. Third, our scoping review has also shown that no tool has been developed in coconstruction with patients, from development to validation. Lastly, very few of the tools were generic, meaning that they could be used in various contexts of care.

Dimensions measured in tools assessing patient engagement in care

Most of the tools assess dimensions related to one or two concepts of patient engagement (patient centredness or empowerment or shared decision-making), and only a few tools simultaneously measure some dimensions related to all of the concepts of patient engagement.[27,30,36,37] Furthermore, we found that no tool simultaneously assesses the core dimensions of the partnership in care presented in our conceptual framework (individualized care, empathy, interpersonal trust, communication, experiential knowledge and self-care).[7]

Tools assessing preferences regarding patient engagement in care are relatively scarce. Two out of 16 scales only or partly measured preferences in engagement: One from the HCPs' point of view and the other from both the patients' and family members' perspective. Only one tool, PaCT-HCW,[32] evaluates both preferences in and experience with patient engagement, but only from the HCPs' point of view. The assessment of patient engagement in care should consider both preferences in and experience with such engagement. From our previous empirical work, which consisted of understanding how patients perceived the partnership in care, we have shown that partnership can be understood as the fit between patients' preferences or expectations for engagement in their care and their experience with such engagement with their HCP.[12] Consequently, measurement of partnership in care could be achieved using a tool capable of assessing the congruence between patients' needs or preferences in their relationship with their HCPs and their perceptions of those interactions.

Context of tool development, validation and utilization

Our scoping review has also shown that no tool has been developed in coconstruction with patients, from development to validation. For only three tools, patients collaborated in the tool's development, in terms of item selection, through expert panels or focus groups or through in-depth interviews. There is a consensus that patients should be more actively involved in research to ensure that studies focus on issues that are relevant to them.[39,40] It seems particularly important to co-construct tools with patients when the tools are designed for them. Furthermore, developing a tool to assess patient engagement in care requires a bottom-up or coconstruction approach with patients and HCPs[41] to identify important dimensions of patient engagement based on the patients' conceptions of being engaged in care and the HCPs' perspectives of engaging patients.

Lastly, very few of the tools were generic. Most of the tools were validated in specific hospital settings, and only two tools were validated in both inpatient and outpatient settings. As most of the tools were not generic, they cannot be used in various contexts of care, in inpatient or outpatient clinical settings, or with patients who have various chronic or acute diseases. As patient engagement in care has become a clinical standard in healthcare settings, it would be important to develop a generic tool that can be used to measure patient engagement in various clinical contexts. This could help monitor the situation and improve patient–HCP relationships, which is one of the core dimensions of quality.[42]

Strengths and limitations

The main strengths of this scoping review are its broad search strategy, which was based on a broad conceptual framework. This allowed us to include various tools assessing the various concepts related to patient engagement in care, and their identification of the levels of patient involvement in tool development and validation. We also used systematic methods to conduct our scoping review, as two reviewers independently screened articles and extracted data,[43] and we complied with the PRISMA extension for scoping reviews.[20] Lastly, we mapped our findings with the broad conceptual framework used to develop our search strategies.

There are two main limitations to our scoping review that may have limited our ability to identify all the relevant tools. First, we only searched for articles published in English or French, which could have led to missing publications in other languages. However, this bias appears to be limited since there is no evidence of systematic bias from using only English-language articles in systematic reviews.[44] Second, we decided to limit our search to articles published starting from 2014 because a previous systematic review by Phillips et al.[14] covered articles published from 2003 to 2014 on tools for measuring patient participation in care. Philipps et al.'s[14] conceptual framework on patient engagement was not strictly identical to the one that we adopted for our scoping review. However, in their systematic review, Phillips et al.[14] included two of the three main concepts of patient engagement (shared decision-making and self-care) that we included in our own conceptual framework. For this reason, we may have missed some relevant tools measuring patient-centred care by applying this limit.

Conclusion and implications for clinical practice and research

A growing number of tools have been developed and validated in recent years for assessing patient engagement in care. This scoping review offers a broad identification and description of various tools assessing central concepts in the various approaches to care (patient centredness, empowerment and shared decision-making) that coexist in clinical practices and settings. No tool offers an exhaustive assessment of the various concepts and dimensions related to both preferences in and experience with engagement in care. However, four tools stand out because they measure the three major concepts of patient engagement in care (patient centredness, empowerment and shared decision-making).[27,30,36,37] Three of them, and the most recently developed, have involved patients in their tool development or validation.[27,36,37] Involving patients in the development and validation of tools that assess the quality of care can contribute to uncovering complementary aspects of quality that are not necessarily considered as important by researchers or HCPs. Engaging patients in healthcare research is largely encouraged as it adds value, quality and appropriateness to the research process and outputs.[45] This practice is even more essential when developing a tool that specifically seeks to measure the key dimensions of patient engagement in care. Lastly, the tools that were found in this scoping review only assess preferences in or experience with engagement in care. Nevertheless, measurement of engagement should focus on both patients' preferences in and experience with engagement as a means to appropriately identify the gap between their expectations and experience with their HCPs. A tool measuring this gap in patient engagement could help HCPs to improve the way they interact with patients during consultations, thus improving the quality of care.

The partnership in care approach, which builds on and integrates various approaches to care and dimensions of patient engagement, has started to be applied in clinical practices and different clinical settings. We therefore argue that there is a need for an exhaustive tool that (1) assesses the core dimensions of the partnership in care, (2) measures both preferences in and experiences with engagement, (3) evaluates patients', family members' and HCPs' perspectives to improve partnership practices between patients and their HCPs and (4) has been developed in partnership with patients.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Nathalie Clavel is the first author of this manuscript. All authors contributed to at least some component of the scoping review and/or manuscript. Nathalie Clavel shaped all aspects of the study design with feedback from Jesseca Paquette and Marie-Pascale Pomey. Nathalie Clavel and Jesseca Paquette screened independently the titles and abstracts of articles found in the databases and extracted data from full-text articles. Nathalie Clavel and Jesseca Paquette wrote the manuscript and Vincent Dumez, Claudio Del Grande, Djahanchah Philip (Sacha) Ghadiri, Marie-Pascale Pomey and Louise Normandin gave substantial suggestions and feedback. All authors have read and approved the final manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available in the Supporting Information Material of this article.

DETAILS

Subject:	Databases; Collaboration; Clinical medicine; Communication; Patients; Patient-centered care; In care; Activities of daily living; Concepts; Literature reviews; Decision analysis; Health care; Systematic review; Empowerment; Partnerships; Knowledge; Decision making; Tools; Empathy; Medical personnel; Patient education; Treatment preferences
Identifier / keyword:	clinical care; healthcare professionals; patient engagement; patients; scoping review; validated tools
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Sociocultural influences on asthma self-management in a multicultural society: A qualitative study amongst Malaysian adults

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ProQuest document link

ABSTRACT (ENGLISH)

Background
Supported self-management improves asthma outcomes, but implementation requires adaptation to the local context. Barriers reported in Western cultures may not resonate in other cultural contexts. We explored the views, experiences and beliefs that influenced self-management among adults with asthma in multicultural Malaysia.

Methods
Adults with asthma were purposively recruited from an urban primary healthcare clinic for in-depth interviews. Audio-recordings were transcribed verbatim and analysed thematically.

Results
We interviewed 24 adults. Four themes emerged: (1) Participants believed in the ‘hot and cold’ concept of illness either as an inherent hot/cold body constitution or the ambient temperature. Hence, participants tried to ‘neutralize’ body constitution or to ‘warm up’ the cold temperature that was believed to trigger acute attacks. (2) Participants managed asthma based on past experiences and personal health beliefs as they lacked formal information about asthma and its treatment. (3) Poor communication and variable advice from healthcare practitioners on how to manage their asthma contributed to poor self-management skills. (4) Embarrassment about using inhalers in public and advice from family and friends resulted in a focus on nonpharmacological approaches to asthma self-management practice.

Conclusions
Asthma self-management practices were learnt experientially and were strongly influenced by sociocultural beliefs and advice from family and friends. Effective self-management needs to be tailored to cultural norms, personalized to the individuals' preferences and clinical needs, adapted to their level of health literacy and underpinned by patient–practitioner partnerships.

Patient and Public Contributions

Patients contributed to data. Members of the public were involved in the discussion of the results.

FULL TEXT

INTRODUCTION

Globally, asthma is a common noncommunicable disease, affecting an estimated 339 million people.[1] This number is expected to increase to 400 million by 2025,[2] posing a significant and growing healthcare burden.[1,3] In Malaysia, asthma is among the top 20 causes of disability-adjusted life years.[4]

Asthma self-management refers to individuals with asthma making therapeutic, behavioural and environmental adjustments in accordance with advice from healthcare professionals.[5] It includes discussion about self-management and provision of a personalized written asthma action plan,[6–8] and when supported by healthcare professionals, improves asthma outcomes such as reduced unscheduled clinic visits and use of healthcare resources, and improved asthma control and quality of life across all levels of asthma severity.[8,9] The Global Initiative for Asthma (GINA)[10] and the Malaysian Clinical Practice Guidelines for asthma[11] recommend that all patients should be provided with education and skills to self-manage their asthma effectively.

Despite this, relatively few people have asthma action plans. For example, the UK National Review of Asthma Deaths showed that 33% of patients who died had no record that they sought medical assistance during their final attack; of these, only 17% had been provided with an asthma action plan.[12] In Malaysia, only 29% of patients had an asthma action plan and of these, only half were confident about using it.[13] A metasynthesis of qualitative data showed that medically focused action plans that did not engage the patients and include their views and preferences would remain underused.[14]

Sociocultural beliefs have been shown to influence asthma self-management. For example, two qualitative studies from the United Kingdom highlighted the importance of social-cultural beliefs in determining self-management behaviour amongst minority South Asians.[15,16] Patients have their own unique beliefs and experiences, and there is a need to understand this socio-cultural context to tailor education and support for asthma self-management.[17,18] This has particular challenges in a multicultural country like Malaysia, in which the population is made up of three main ethnic groups, the Malay, Chinese and Indian, and native minorities, each with their own language and culture.[19] A recent study revealed the extent to which socio-cultural practices and traditional medicines were used to complement (or at times replaced) evidence-based asthma management amongst Malaysian children with asthma.[13] Building on this evidence, we aimed to explore the views, beliefs and experiences that influenced the self-management practices of adults with asthma in the three major ethnic groups in Malaysia.

METHODS

This qualitative study was undertaken from 2018 to 2019. Ethical approval was obtained from the National Medical Research and Ethics Committee (NMRR-18-1087-40634). Participants were given a participant information sheet and an opportunity to ask questions and time to consider before providing written informed consent.

Study setting

The study was conducted in a primary health clinic located in Klang District, Selangor, Malaysia, which is densely populated with multiracial communities and groups with various levels of income. This clinic was chosen as it runs a dedicated asthma clinic and provides emergency asthma care. About 240 people with asthma are reviewed regularly by doctors in charge of the asthma clinic; during these reviews, their asthma control is assessed, peak flows are recorded and asthma education is provided.

Participant recruitment

Adults (18 years and over) with physician-diagnosed asthma were approached by the doctors in charge either during their asthma review, an emergency visit for an acute exacerbation or if they had missed a scheduled appointment at the clinic. We used purposive sampling to achieve a maximum variation sample based on age, gender, ethnicity, asthma duration and ownership (or not) of an asthma action plan. Participants who agreed to participate were given a date and time for an interview that was convenient to them. They were offered an honorarium of RM 100 (≈ £18.50) to cover their time and travel expenses.

Data collection

To provide context and characterize the participants, we collected basic sociodemographic, asthma duration and control based on GINA symptom control[10] using a self-completed questionnaire.

We used a topic guide to facilitate individual in-depth interviews that aimed to understand participants' personal illness experiences. The topic guide was developed based on the Theory of Planned Behaviour,[20] the known features of asthma self-management, including how they learnt to live with a variable illness, attitudes to taking preventer medication, how they recognize and respond to worsening asthma symptoms, signs (and peak flows) and the use (if any) of an asthma action plan.[21,22] The Theory of Planned Behaviour has been widely used in predicting and explaining self-management behaviour.[23] The topic guide is provided in the Supporting Information S1.

The interviews lasted up to 90 min and were audio-recorded. The researcher (W. M. K.) conducted the interviews in the participants' preferred language, Malay, English or Mandarin or a mixture of these languages (as is the norm in Malaysia). During the interview, W. M. K. encouraged participants to expand and elaborate on their views to gain a better understanding of the responses given. Inhalers, peak flow meters and spacers/aero-chambers and asthma action plans were shown to the participants to avoid any misunderstandings. Field notes were made to capture nonverbal cues, gestures and emotions of the participants, and to record devices and medications that participants referred to. This information was incorporated into the verbatim transcripts to add context to the participants' views. Interviews were continued until data saturation was reached with respect to views on living with asthma.

Data analysis

Data were managed and coded using NVivo version 11.4.3. An interpretative–descriptive approach to thematic analysis was used to describe and understand the views and experiences of participants on asthma self-management.[24] The first two transcripts were coded independently by three authors (W. M. K., E. M. K., A. I. A. B.) and an agreed initial list of codes was developed. Next, W. M. K. used this coding framework to code all the remaining transcripts. Any new codes that emerged were added into the existing coding framework and checked by E. M. K. and A. I. A. B. Any discrepancies were resolved by consensus to produce a final coding frame. All codes were then categorized into themes.

Interviews were transcribed by a transcriber fluent in the appropriate language, coded and analysed by the trilingual researcher (W. M. K.) in the language(s) in which the interview was conducted. Malay- and Mandarin-language transcripts were translated into English by an independent translator. Representative quotes related to the research questions were selected for the paper.[25]

Reflexivity

W. M. K. is a primary care physician. Throughout 8 years of work experience, she has managed many cases of asthma with varying degrees of control. The researcher postulated that many of the patients had poor knowledge about asthma self-management and poor adherence to asthma medications, which might have led to her making assumptions about the participants while conducting the study and analysing the data. The use of a field journal that documented the researcher's reflections, thoughts and ideas generated when in contact with the participants reminded the researcher to be aware of these assumptions and constantly reflected on their influence on the study.

Saturation and transferability considerations

Data saturation was reached by the 21st interview, by which no new information or themes were observed in the data. However, interviews were carried on till the 24th interview to further confirm data saturation. Participants recruited were of three major ethnic groups (Malay, Chinese and Indians) that made up the major populations in Malaysia; their social and cultural practices were assimilated to a large extent.

RESULTS

Twenty-four participants were interviewed. Table 1 summarizes their characteristics.

Table 1 Characteristics of the participants

Characteristics	Number (*n* = 24)

Age (years)	
18–30	5
30–40	6
40–50	5
50–60	3
60–70	5
Gender	
Male	10
Female	14
Ethnicity	
Malay	10
Chinese	7
Indian	7
Education level	
No formal education	1
Primary	3
Secondary	14
Tertiary	6
Occupation (ISCO-08)[26]	
Professionals	5
Clerical support worker	1
Services and sales worker	2
Craft and related trade worker	4

Plant and machine operators	3
Others (housewife, retiree)	9
Ownership of asthma action plan	
Yes	6
No	18
Asthma duration (years)	
1–5	4
5–10	7
10–20	4
>20	9
GINA asthma controla,[10]	
Well controlled	2
Partly controlled	11
Uncontrolled	11

Abbreviations: GINA, Global Initiative for Asthma; ISCO-08, International Standard Classifications of Occupations.[26]

a

GINA[10] classifies asthma control according to responses to four questions (in the past 4 weeks, has the patient had: Daytime asthma symptoms more than twice/week; any night waking due to asthma; reliever needed for symptoms more than twice/week; and any activity limitation due to asthma?). Well controlled is defined as 'None of these symptoms'; Partly controlled is defined as '1–2 symptoms'; and uncontrolled is defined as '3–4 symptoms' in the past 4 weeks.

Four themes emerged: (1) the 'hot and cold' concept of asthma self-management; (2) poor understanding of asthma and misconception on asthma control and its treatment; (3) variable support on asthma self-management by healthcare practitioners; and (4) social influences on asthma self-management.

The 'hot and cold' concept of asthma self-management

Participants viewed this concept in two ways. One was the belief in an inherent body constitution of 'hot or cold' that contributed to asthma, while the other was the ambient temperature of 'hot' or 'cold'.

From this perspective, one aim of self-management was to neutralize the 'hot or cold' body constitution by eating food that was believed to have opposite properties. Complementary medication was often based on the belief of inherent 'hot and cold' properties of food that neutralized the 'cold' effect of asthma.

If 'heaty asthma', you take that ginger with that liver then you will become worse. So, before (previously)*… soya beans, kangkong, tofu, that salted vegetable I cannot take… Now I build up my body… is heaty already… So,* *cooling… not much effect ah… now soya beans, just everything I can take….* (60–70 years old/Chinese/retiree/uncontrolled asthma)

The villagers (told me)*, because these faeces are 'hot', and because goat is 'hot', my body is cold, eating (goat) faeces will warm up my body… but it didn't work ….* (40–50 years old/Malay/driver/uncontrolled asthma)

Some viewed the 'hot and cold' concept as differences in temperature such as hot or cold food and beverages, as well as washing, which caused coldness in the hands. If asthma symptoms were considered to be due to cold, strategies were used to 'warm up' the body with hot food, hot rubs, use of gloves and socks and adjusting the timing of showers to avoid cold.

Food and beverages that are cold, such as ice-cream and cold drinks, were identified as asthma triggers from past experience and were avoided to prevent attacks.

When I get the wheezing and difficulty of breathing… canned milk, one spoon, put hot water to make up to one cup, 500mls to 200mls, mix it and drink. Reduces (symptoms) *a bit*. (18–30 years old/Indian/housewife/uncontrolled asthma)

Lack of understanding of asthma and misconceptions about asthma control and its treatment

There was often a lack of understanding about asthma and misconceptions about the treatment based on their beliefs, family advice and previous experience. There was concern about the side effects of inhaler use that included headache, kidney damage, carcinogenicity and fear of dependency.

The blue colour pump (salbutamol) *is to open my lungs and after 15 minutes you must use the red colour pump* (budesonide) *to close. If* (my lungs are left) *open, I will vomit*. (30–40 years old/Indian/factory worker/partly controlled asthma)

…I don't want to be too dependent on this medication (salbutamol inhaler)*… if keep depending on it, I will always get* (attacks)*….* (18–30 years old/Malay/housewife/partly controlled asthma)

…I stopped budesonide… because my relative tells me it's going to give me cancer. (40–50 years old/Chinese/teacher/uncontrolled asthma)

There were misconceptions about what good control could be and some described adapting to and living with symptoms and were unaware that they could prevent or relieve them.

We feel sometimes when there is wheeze sound, it is normal. No need to use inhaler also OK. (40–50 years old/Malay/Tailor/partly controlled asthma)

Only six of the participants were familiar with asthma action plans. Most, even when shown an action plan, had very limited understanding of how it could help them manage their asthma. Some participants regarded asthma action plans as a 'meal plan' with advice on foods to avoid because they triggered asthma symptoms. Others could not recall the details in the asthma action plan and the actions that they should take when experiencing changes in their asthma symptoms. Several people identified barriers to action plan use in terms of both the content and practicalities.

From what I understand, this plan is for asthma prevention lah (a suffix used to emphasise the previous words) … . (40–50 years old/Malay/teacher/well-controlled asthma)

The red area (information in a traffic-light-coded action plan) *was good. But doesn't tell you that should you use or continue using your normal medication or not*. (40–50 years old/Chinese/teacher/uncontrolled asthma)

No, I am illiterate, how to read? (60–70 years old/Chinese/housewife/uncontrolled asthma)

Variable support for self-management by healthcare practitioners

Some healthcare practitioners considered the beliefs and views of patients with asthma while providing asthma education and advice on asthma self-management, but more often, participants reported variable advice. Examples included a 31-year-old, Indian, factory worker who was advised to stop jogging and dancing because she had asthma, and a 41-year-old housewife who was told to ensure that she avoided getting wet when doing chores to prevent attacks.

Poor communication and ineffective doctor–patient partnerships impeded knowledge transfer and sometimes resulted in people seeking alternative care.

Because we can't express (our thoughts)… (and the doctor said) *'Are you the doctor, or I am the doctor?'… Sometimes we want to tell but they straight away stop us… Why did we want to go there* (traditional practitioner) *to get asthma medications? Because doctors here, not all but some of them, do not communicate with patients*
. (30–40 years old/Indian/housewife/uncontrolled asthma)

For me, everything I did is wrong, if the doctor really advised me the ways for daily living …from now on lah… maybe I will follow lah, because I also want to follow lah…. (30–40 years old/Chinese/police/partly controlled asthma)

I asked for the doctor's advice…'can I buy the nebulizer machine?' Doctor told me… 'We need to monitor you', 'you cannot use it yourself every time when you have an asthma attack, only neb neb neb… cannot lah…. (40–50 years old/Indian/housewife/uncontrolled asthma)

Social influences on asthma self-management

Family and friends influenced participants' self-management of asthma, in particular, the nonpharmacological approach, the usage of complementary and alternative medications and over-the-counter purchase of medications from community pharmacies.

She (my neighbour) *came to my house. She asked why (are you wheezing) sister?*

Go and take this medication (prednisolone, that can be purchased over the counter from the community pharmacy), try and see… she (my neighbour) *says…*. (40–50 years old/Malay/housewife/uncontrolled asthma)

My children ask me to walk…my neighbour also walked… I walk lah… if diabetes is able to disappear, asthma can also disappear …. (60–70 years old/Malay/retiree/partly controlled asthma)

There was perceived social stigma with the use of inhalers as a self-management strategy. One participant felt embarrassed to use an inhaler in public and resorted to smoking for symptom relief during an exacerbation.

Because my job involves the public right, so if I want to use it (the inhaler)*, I don't use in front of the public as they will see, hide yourself, in the car or something*.

If I have difficulty breathing, I will use this method that makes the mouth small (pursed lip breathing) *…If it doesn't go away, I smoke one cigarette, I will tell my subordinate, one cigarette…smoke only*. (30–40 years old/Chinese/police/partly controlled asthma)

DISCUSSIONPrincipal findings

Our participants had learnt over time to self-manage their asthma in the context of the healthcare norms of Malaysian society. The 'hot and cold' concept is widely accepted by all the cultural groups in Malaysia and many of the misconceptions about asthma were based on this. Medications were used experimentally, and self-management was based on personal beliefs, perceptions, past experience and information obtained from family, friends and healthcare practitioners. This resulted in patients developing their own self-management plan rather than following the plans recommended by asthma guidelines. Furthermore, stigma attached to inhaler use further reduced compliance and use of action plans.

Strengths and limitations

A strength of our study is that we explored understanding of asthma self-management in a multiethnic and culturally diverse setting by conducting interviews in three languages, followed by analysis to ensure that we did not miss cultural nuances. Although our participants came from a range of socioeconomic backgrounds, one limitation is that we only recruited participants from the public health clinic and our findings do not reflect the views of patients from the private healthcare sector. We reached data saturation with respect to the opinions of the three major ethnic groups, but did not recruit natives, foreigners or migrant workers living in Malaysia, so we cannot comment on their cultural perspectives and whether they conform to the cultural norms that we observed.

This study focused on the perspectives of people living with asthma, but exploration of asthma self-management from the healthcare provider point of view could further enhance understanding of asthma self-management among patients with asthma. The researcher who undertook the interviews and analysed the data is a primary care physician, but we were aware of reflexivity and the emerging findings were discussed within a multidisciplinary team to ensure a balanced interpretation.

Interpretation of findings

The ‘hot and cold’ concept of health and illness appears in many geographically separated areas of the world. The origins of this concept are debated, with European accounts tracing the origin to Hippocrates and Galen, which influenced the physicians of medieval Islam and later spread to America. Similar traditions, however, were seen in early Chinese and Indian cultures.[27] Although varying in detail, the common concept is that health can be lost or restored as a result of the effect of ‘hot’ and ‘cold’ elements on the human body.[28] These elements do not refer to the actual temperature or taste but rather the internal properties of the foods or herbs as well as the state of the illness. Based on this concept, health practices were targeted at the ‘avoidance of extreme conditions’ or consumption of food items to restore the balance between the opposing forces of ‘hot and cold’. In the Asian context, the ‘hot and cold’ health belief stemmed from traditional ancient Chinese medicine that viewed Yin and Yang as the symbolic power of hot and cold that appeared to be concurrently dependent on and in opposition to each other.[29] A person is said to have perfect health if he or she has an unopposed flowing chi with well-balanced Yin–Yang forces. This balance can be restored by dietary changes or the use of traditional medications and herbs to compensate the effect of excess ‘hot’ or ‘cold’ elements. Similarly, in Indian culture, the ‘hot and cold’ concept had long been practiced by the people in Sri Lanka, using food to achieve balance between the ‘hot’ and ‘cold’ elements based on Ayurvedic medicine in disease prevention and treatment.[30]

The ‘hot and cold’ health belief is an accepted cultural norm in Malaysia, and is practised across all major ethnic groups (Malay, Chinese, Indian) as a result of cultural assimilation.[31] A qualitative study conducted among carers and children with asthma in Malaysia showed that some carers used certain ‘hot’ complementary and alternative medicines to counteract asthma, which is believed to be ‘cold’.[16] Healthcare practitioners need to acknowledge these cultural beliefs so that asthma self-management can be discussed in terms that patients can understand. Whilst of obvious importance in an explicitly multiethnic country (such as Malaysia), globalization means that cultural diversity is now the norm in almost all societies and an understanding of a widely held belief (such as ‘hot/cold’ concepts) is of relevance universally.

Culturally targeted or tailored asthma self-management interventions could potentially enhance acceptance of the intervention, reducing unscheduled visits and improving asthma control and confidence in self-managing asthma.[18] On a practical level, tailoring asthma education materials by appropriate use of ‘hot and cold’ colours and colour-coded inhalers with ‘hot’ colour tones would resonate with these widely held ‘hot and cold’ cultural beliefs.[32]

Few of our participants had an action plan, suggesting underprovision by the healthcare practitioners. One reason may be concerns about poor health literacy; indeed, many older Malaysians (including one of our participants) are illiterate.[33] To assist patients with low health literacy levels, a pictorial action plan for patients may need to be considered.[34] In addition, healthcare practitioners, nurses and pharmacists need to be trained to educate people with asthma irrespective of their level of literacy.[35,36]

Key barriers to provision of supported asthma self-management are poor communication between the doctor and the patient and the lack of continuity of care, which frustrated and confused our participants. Similar findings were also noted in a systematic review and thematic synthesis focusing on barriers and facilitators of effective self-management in asthma.[37] These barriers might further be due to the lack of time, organizational barriers and the need for further training in professional skills development.[38] Good doctor–patient partnership, communication and continuity of care are central to effective supported asthma self-management.[10,29] This could be enhanced by patient-centred consultation skills and shared decision-making, providing opportunities for patients to voice their expectations and concerns and to cocreate their own asthma management plan.[7,39]

Stigma led to at least one of our participants preferring to smoke rather than using an inhaler during an attack. This has been described before and attributed to the fact that smoking is accepted or seen as a social norm in Malaysia and Thailand and widely accepted among young adult males.[40] In Australia, studies have shown that close to half of adult patients felt embarrassed to use inhalers in public as it revealed the diagnosis of asthma.[41] This stigma hinders adherence to long-term management as well as everyday life and ability to socialize,[42] and is associated with increased morbidity.[43] Whilst patients could be imparted skills to overcome the stigma they face, it is important to educate the public and community about asthma and its treatment to reduce the stigma of inhaler use among the public and patients. A whole-system approach is required to achieve sustained improvements in clinical asthma outcomes.[44]

Implications for clinical practice

Supported self-management in asthma has gained recognition over the years based on extensive evidence of its effectiveness in reducing asthma morbidity and mortality.[6–9] Supported asthma self-management includes a written asthma action plan, self-monitoring and regular review by a knowledgeable healthcare provider.[10] Our findings highlight some of the challenges faced by primary care providers in a multicultural country such as Malaysia. Personalization of an asthma action plan involves not only incorporation of individual patients' preferences but also tailoring to the embedded cultural practices and concerns. This can be achieved by better collaboration between healthcare practitioners and patients, and developing the skills of shared decision-making, acknowledging cultural norms whilst empowering patients with the confidence, skills and knowledge that they need to adopt evidence-based self-management on a regular basis. Accurate and easy to understand information on asthma, potentially delivered through pictorial representation, should be made widely available in clinics and pharmacies, and community awareness programmes may be helpful. Patient peer support groups, family and friends may reach out to communities where health literacy is low.

CONCLUSIONS

Asthma self-management practices were learnt experientially from personal experiences and beliefs that are culturally ingrained among patients with asthma in Malaysia, influenced by healthcare practitioners, family and friends. Effective self-management needs to be tailored to the communities' cultural norms (especially the ‘hot and cold’ beliefs), personalized to the individuals' preferences and clinical needs, adapted to their level of health literacy and underpinned by robust patient–practitioner partnerships.

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CONFLICT OF INTERESTS

E. M. K. reports grants from the National Institute for Health Research (NIHR) Global Health Research Unit on Respiratory Health (RESPIRE) and Seqirus UK; personal fees from AstraZeneca and GlaxoSmithKline; and is board director of the International Primary Care Respiratory Group.

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All other authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Aziz Sheikh was PI of RESPIRE contributing to the conception, design and oversight of this study and contributed to interpretation and editing of the study manuscript. All authors contributed to the conception of this study; W. M. K., E. M. K. and A. I. A. B. performed the data collection, coding and data analysis. W. M. K. drafted the manuscript, and all authors provided recommendations to the editing and revision of the manuscript. All authors approved the final version.

ETHICS APPROVAL

Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia (MOH): NMRR-18-1087-40634 and sponsorship approval from the Academic and Clinical Central Office for Research &Development (ACCORD) at the University of Edinburgh (AC19040).

DATA AVAILABILITY STATEMENT

Data of relevant findings are shared as deidentified quotes in the paper. Other data are available on request from the authors.

DETAILS

Subject:	Language; Asthma; Health beliefs; Health literacy; Body temperature; Constitutions; Health care; Ambient temperature; Sociocultural factors; Codes; Norms; Ethnicity; Cultural factors; Primary care; Professional ethics; Interviews; Inhalers; Embarrassment; Minority &ethnic groups; Multiculturalism &pluralism; Adults; Individualized; Medical personnel; Patients; Management; Partnerships; Past experiences; Qualitative research; Friendship
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Location:	United Kingdom--UK; Malaysia
Company / organization:	Name: Global Initiative for Asthma; NAICS: 813212
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Advancing understanding of influences on cervical screening (non)-participation among younger and older women: A qualitative study using the theoretical domains framework and the COM-B model

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ProQuest document link

ABSTRACT (ENGLISH)

Background

Effective screening can prevent cervical cancer, but many women choose not to attend their screening tests.

Objective

This study aimed to investigate behavioural influences on cervical screening participation using the Theoretical Domains Framework (TDF) and COM-B models of behaviour change.

Design

A qualitative study and semistructured phone interviews were conducted with women invited for routine screening tests within the national cervical screening programme in Ireland.

Setting and Participants

Forty-eight women aged 25–65 years were recruited from the national screening register.

Results

Seven core themes were identified that mapped to three COM-B components and 11 TDF domains: (1) knowledge of cervical cancer and screening, (2) coping with smear tests, (3) competing motivational processes—automatic and reflective, (4) cognitive resources, (5) role of social support, (6) environmental influences and (7) perceputal and practical influences. A range of knowledge about screening, perceived risk of cervical cancer and human papillomavirus infection was evident. Factors that influenced screening behaviours may be hierarchical—some were assigned greater importance than others. Positive screening behaviours were linked to autonomous motivation. Deficits in physical and psychological capability (inadequate coping skills) were barriers to screening, while physical and social opportunity (e.g. healthcare professional 'champions') could facilitate participation. Older women raised age-related issues (e.g. screening no longer necessary) and had more negative attitudes to screening, while younger women identified practical barriers.

Conclusions

This study provides insight into screening participation and will aid development of theoretically informed interventions to increase uptake.

Patient or Public Contribution

Women invited for screening tests through the national screening programme were interviewed. A Public &Patient Involvement (PPI) Panel, established to provide input into all CERVIVA research projects, advised the research team on recruitment materials and were given the opportunity to review and comment on the interview topic guide. This panel is made up of six women with various cervical screening histories and experiences.

FULL TEXT

INTRODUCTION

Cervical cancer is a global public health issue with an estimated worldwide incidence of approximately 570,000 new cases in 2018, of which over 116,000 occurred in Europe.[1] Cervical screening programmes operate in many countries and are effective in reducing the incidence of and mortality due to cervical cancer.[2] However, data from the screening registers of 19 European states indicates that screening coverage can vary considerably: from 10% to 79%.[3] Over the past decade, a pattern of falling uptake has been reported in several countries. Initially, there were concerns in some developed countries about uptake in younger women;[4] however, in recent years, a new pattern of lower uptake in older women has emerged in England and Ireland (https://www.cancerresearchuk.org/health-professional/cervical-cancer-screening-and-diagnosis-statistics#heading-Five).[5]

It is important to encourage older women to attend screening as the incidence of and mortality due to cervical cancer remain high in this age group.[2] Screening older women can reduce their cancer risk—women who are screened in their early 50s have a 75% lower risk of developing cervical cancer between 55 and 59 years.[6] Considerable research has investigated the factors that are associated with women's screening participation. Demographic factors such as ethnicity[7,8]; practical and environmental factors such as accessible appointments and female smear takers [6,9,10]; and psychosocial influences such as trust,[10,11] embarrassment, anxiety[7,12,13] and concerns about pain/discomfort [6,13] have been identified as being related to screening participation. Age differences also exist, with younger women reporting practical barriers, embarrassment and the perception that they are at low risk of developing cancer.[9,10,12,13] In contrast, older women may make active decisions not to participate; in one study, older women reported low levels of worry about cervical cancer and also perceived themselves to be at low risk of developing cancer.[13] However, the research that has generated these findings has frequently lacked a theoretical grounding. Assessments of the strategies and interventions that have been tested to increase cervical screening uptake have found mixed evidence of increased participation.[14–16] In part, this may be because intervention development has not always been informed by key requirements, that is, empirical data linked to an appropriate theoretical underpinning.[17]

The Theoretical Domains Framework (TDF) is a comprehensive integrated theoretical framework—synthesized from 128 theoretical constructs from 33 theories—that can guide the identification of theoretical constructs that influence behaviour.[18,19] The TDF model can be condensed into an overarching behavioural model—the COM-B model—with three central components, capability, opportunity and motivation, that interact in behavioural processes.[18] The TDF and COM-B models have been used to inform intervention design in various healthcare settings,[20–22] but have not previously been used to examine influences on cervical screening behaviours.

In the current study, we aimed to identify factors that influence women's decisions on cervical screening (non)-participation using the TDF and COM-B models, with a secondary objective of comparing and contrasting factors relevant for younger and older women.

METHODSDesign and setting

This study took place in Ireland. In-depth semistructured telephone interviews were conducted among women who had been invited to attend for routine/follow-up cervical screening tests. The study was carried out as a partnership between CERVIVA (the Irish Cervical Cancer Screening Consortium) and CervicalCheck, Ireland's national cervical screening programme. This programme offers free screening tests to women in Ireland aged 25–65 years. Invitation letters are issued, to women on their register, to remind them when their next screening test is due. Women can book their test at any CervicalCheck registered GP or clinic. Under human papillomavirus (HPV) primary screening protocols, women aged 25–29 years are screened every 3 years, while those aged 30–65 years are screened every 5 years. Ethical approval was obtained from the Royal College of Physicians of Ireland (RCPI RECSAF 74). While this study was being conducted, a high-profile controversy developed in CervicalCheck when the Health Service Executive confirmed that an audit had revealed that over 200 women who developed cancer had not been told of earlier smear tests that were misdiagnosed. A scoping inquiry into issues relating to CervicalCheck and a review of the screening histories of all women who had developed cervical cancer by the Royal College of Obstetricians and Gynaecologists (RCOG) took place in 2018 and 2019, respectively.[23,24]

Sampling and recruitment

The CervicalCheck register of women in Ireland aged 25–65 years is compiled, and maintained, using numerous data sources including the Department of Social Protection and self-registration by women. A purposive sample of women who had been invited to attend for routine or follow-up (i.e., following a borderline cytology result in a routine test) screening tests was selected from this register. Purposive sampling strata were as follows: (1) age group: younger (younger than 50 years) or older (50 years or older) and (2) screening history: adequate history (attended all routine screening tests that they had been invited to since 2008) or inadequate history (attended some or no screening tests that they had been invited to since 2008), resulting in four study groups. Women undergoing colposcopy clinic surveillance (for abnormal cytology), with cervical cancer or awaiting smear test results were not eligible. Data were extracted and quality-checked by CervicalCheck staff in April 2018. CervicalCheck invited 600 women to be interviewed in two recruitment cycles. Each invitation included an information sheet, a reply slip, a consent form and a prepaid envelope. One reminder letter was sent to nonresponders. Recruitment ended when saturation was achieved.[25]

Interviews

A semistructured topic guide (Appendix A) was developed from literature review and informed by the TDF model. The original 12-domain version of the TDF model (v1) was selected as a comprehensive tool that would identify a broader spectrum of potential influences on screening behaviours.[26] Signed consent forms were returned by all participants before interviews. Interviews were conducted by a CERVIVA researcher between August and December 2019 and lasted 45–75 min (mean 60 min). Verbal consent to record the interviews was obtained, and recordings were transcribed verbatim and anonymized. A ‘One4All’ gift voucher (€25) was sent to participants once the interviews were completed to thank them for their time. All personal data were handled in accordance with the General Data Protection Regulation (GDPR), 2018.

Coding and analysis

Transcripts were imported into NVivo 10 and an iterative analysis was performed concurrently with data collection. A combination of inductive thematic and deductive framework analyses using the TDF model was conducted. The transcripts were reviewed through familiarization, construction of a thematic framework (TDF domains), indexing, sorting of data and interpretation.[27] Salient text blocks referring to barriers and facilitators were inductively identified and coded. Two researchers (B. O'D., B. R.) independently read and coded 10 transcripts; recurrent themes and coding were compared and discussed, with differences resolved by consensus. Coding was finalized, and the remaining interviews were coded by one researcher (B. O'D.); in separate steps, each theme was deductively mapped to the TDF domains and then to the COM-B model. Other members of the research team were consulted as and when needed. Analysis identified the similarities and differences across age and screening histories. Themes were deductively mapped to the three COM-B components and their subdivisions: Capability (psychological, physical), Motivation (automative, reflective) and Opportunity (social, physical), and 12 TDF domains (*Knowledge, Skills, Social/professional role and identity, Beliefs about capabilities, Beliefs about consequences, Motivation and goals, Memory, attention and decision processes, Environmental context and resources, Social influences, Emotion, Behavioural regulation* and *Nature of the behaviours*).

Where appropriate, illustrative anonymized quotes from the study participants are included in Section 3.

RESULTSCharacteristics of the study participants

Interviews were conducted with 48 women—34 were adequately screened (AS) and 14 women were inadequately screened (IS); 17 women were younger than 50 years of age, while 31 women were 50 years of age or older. Detailed information about the participants is shown in Table 1.

Table 1 Characteristics of the study participants (*n* = 48)

Demographics	Number (*n*)
Age at interview (years)	
Below 40	9
41–50	11
51–60	24
61–70	4

Screening history	
Adequatea	34
Inadequateb	14
Relationship status	
Married/cohabiting	36
Separated	5
Divorced	3
Single	4
Education	
Tertiary levelc	22
Diploma/certificate	15
Leaving certificated	11
Employment	
Employed/self-employed	38
Retired	3
Unemployed	2
Other	5
Previous abnormal cytology result(s)	
Yese’f	34
No	14
Ethnicity	
White Irish	44
White English/Other	3

Mixed	1

a

Self-reported had attended all routine CervicalCheck screening tests.

b

Attended some (*n* = 9) or no CervicalCheck screening tests (*n* = 5).

c

Post-secondary education, for example, university and/or higher education institutions.

d

School-leaving qualification.

e

Self-reported had an abnormal smear at some time in the past, either through CervicalCheck or private cytology tests.

f

Of these, 30 had an adequate screening history and 4 had an inadequate screening history.

Summary of core themes, TDF domains and COM-B constructs

Seven core themes were identified in relation to women's cervical screening participation: (1) Knowledge of cervical cancer and cervical screening; (2) Coping with smear tests; (3) Competing motivational processes—automatic and reflective; (4) Cognitive resources; (5) Role of social support; (6) Environmental influences; and (7) Perceptual and practical influences. Table 2 presents the subthemes and themes that emerged during analysis. Results are presented according to each of the core themes and relevant COM-B construct and TDF domain(s) with illustrative quotes; example quotes are included in the main body of the paper. Additional quotes linked to TDF domains and COM-B constructs are presented in Table S3 in the Supporting information.

Table 2 Subthemes and themes linking to relevant TDF domains and COM-B constructs

Abbreviations: HPV, human papillomavirus; TDF, Theoretical Domains Framework.

Thematic resultsKnowledge of cervical cancer and screening (COM-B construct—psychological capability; TDF domain—knowledge)

Knowledge of cervical cancer mapped onto the COM-B component of psychological capability and the TDF knowledge domain. Factors related to psychological capability included procedural knowledge; knowledge about cervical cancer, HPV infection and the risk factors for cervical cancer; and women's perception of their own risk of developing cervical cancer.

Most interviewees felt that they had a good level of knowledge about screening. However, some older women—both AS and IS—were confused about screening processes. This confusion centred on poor system knowledge about eligibility criteria, frequency of invitation letters and how samples are processed. These knowledge deficits also emerged in relation to knowledge about HPV—many older women demonstrated limited/no HPV knowledge compared to younger women. Poor procedural knowledge often meant that women were surprised by their invitation, questioned its timing or their eligibility and therefore did not make arrangements to attend:

I wasn't sure if it [invitation letter] was real, or what it was, [laughing] whether it was one of those things you get in the post.

(DS300025, IS, 43 years)

Many interviewees felt that they were informed about cervical cancer and regarded it as a ‘serious’ disease. On the other hand, some interviewees demonstrated poor levels of knowledge about which women are at the highest risk of developing cervical cancer:

I don't know I'm not sure if it's a certain age group that's more susceptible or not

(DS30032, AS, 42 years)

Some differences emerged; more knowledge deficits about higher risk groups were evident among IS women compared to AS women, with limited/no knowledge particularly evident among younger IS women.

Women's perceptions of their own risk of developing cervical cancer varied. AS women, regardless of their age, stated that they considered themselves above medium risk or high risk for developing cervical cancer. They linked this perception to previous abnormal results or their general concerns about all cancers. In contrast, IS women perceived themselves to be at low risk of developing cervical cancer.

Coping with smear tests (COM-B construct—physical capability; TDF domain—skills)

The theme of coping with smear tests mapped to the COM-B component of physical capability and the TDF skills domain. One factor that emerged in relation to physical capability was women's intrinsic coping skills. Both IS and AS women (in both age groups) spoke about finding smear tests uncomfortable and stressful. However, AS women, both younger and older, while acknowledging the negative aspects of smear tests, were confident in their personal ability to cope and maintain their patterns of attendance. This self-efficacy was often linked to their use of coping techniques such as deep breathing and distraction as well as their accumulated experience of screening. Many older women, both AS and IS, spoke about how they felt less embarrassment attending for screening as they aged. They linked this change in attitude to their increasing maturity, experiences of childbirth and their coping skills. In contrast, some AS older women felt increased anxiety that they linked to embarrassment about changes to their bodies as they aged:

I think seeing your body ageing, you get a bit shy about it. More shy.

(DS300011, AS, 50 years)

Competing motivational processes—automatic processes (COM-B construct—automatic motivation; TDF domain—emotion)

The theme of competing motivations—automatic processes maps to the COM-B construct of automatic motivation and the TDF domain of emotion. Automatic motivation involves instinctive and affective processes that can stimulate or inhibit women's positive screening behaviours. These included inhibiting factors: women's feelings of embarrassment/anxiety about smear tests; the mediating effects that competent smear takers could have on negative emotions; and potentially ‘triggering’ effects of previous adverse experiences of smear tests or a history of sexual assault.

Many women across all four groups highlighted the embarrassment that they felt during their smear tests as well as the invasiveness of the procedure. However, many women spoke about the benefits of competent and experienced smear takers in reducing women's anxiety:

You need to have somebody that's fairly confident that can do it quite quickly, quite promptly, and that's very experienced. That probably works best with your more anxious lady.

(DS300014, AS, 53 years)

Both AS and IS women reported difficult smear tests in the past; however, IS women often described lasting anxiety/fear because of these negative experiences, for example, incompetent smear takers. They spoke about their instinctive desire to avoid smear tests:

I do remember the one [smear test] I had when [name] was born and it wouldn't have been a great experience and I kind of said to myself ‘Oh no I don't want to go back through this’

(DS3006, IS, 60 years)

Some women also highlighted that competently trained smear takers were essential as the procedure could be significantly more difficult for women who have experienced sexual assault and could trigger extreme distress/trauma.

In contrast, some AS women described screening attendance as a habitual behaviour that began with a postpartum test and was maintained:

I suppose it's [screening] routine, isn't it? I had to get one [smear test] done after [my child] was born, but even though I have been delayed sometimes in getting them and booking them, I have stayed up to date, I have got all the tests done after that I should have done

(DM550492, AS, 34 years)

Competing motivational processes—reflective processes (COM-B construct—reflective motivation; TDF

domains—beliefs about consequences, beliefs about capabilities, motivation and goals, knowledge)

Reflective motivational processes map to the COM-B construct of reflective motivation and the following TDF domains: beliefs about consequences, beliefs about capabilities, motivation and goals and knowledge. Reflective motivation involves conscious thought processes that can activate or discourage women's screening attendance. These processes included: evaluation of screening; autonomous/self-determined motivation; and controlled/external motivation.

Women across the two groups (AI and IS) reported perceiving similar advantages and disadvantages to screening. The positive aspects included the following: it being a free service; providing peace of mind; being potentially lifesaving; and providing early detection of problems. Most AS women, regardless of age, acknowledged the negative aspects of the procedure (such as discomfort, intrusiveness, pain), but were more focused on the health benefits of screening. Some AS and IS women, irrespective of age, reported significant concerns about delays in getting results and the accuracy of the results:

Whereas now I'm like even if I go and have it [smear test], I could have it [cervical cancer] and they still won't find it

(DM550499, IS, 56 years)

Older and younger IS women differed in their evaluations of screening. Older women often felt that screening was no longer necessary for them, as they were older and/or were not sexually active. Despite this viewpoint, they mostly had positive perceptions of cervical screening and felt that it had significant benefits and relevance for younger women. In contrast, IS younger women described problems: the invasiveness of the procedure itself; lack of information when abnormal results were received; extended waiting times for results; and anxiety related to further testing/repeat smears:

In terms of negatives, for some people it could cause a lot of anxiety because they might need repeat smears when there's nothing wrong

(DM550498, IS, 32 years)

Generally, AS women displayed stable intentions to participate; older women in this group usually arranged their screening appointment promptly, while younger women spoke about how they were frequently delayed in making appointments. However, these delays were usually unintended and their intrinsic/self-determined goal was to keep up to date with their screening. In contrast, IS women, both older and younger, were not similarly motivated and often spoke about having conflicting priorities. For some women, this was because they did not have concerning symptoms:

I don't feel I have any symptoms, or any pain or discharge, or any reason to have it [smear test] done.

(DS3008, IS, 62 years)

A few IS women had attended for some smear tests in the past because of external or controlled reasons. These included recent health concerns in the family or to gain the approval of family/friends. However, women who felt pressured to participate for these external reasons often did not persist with screening:

So, I did go back then four or maybe five years ago, and of course it was no problem, so it's not that there was a problem, it's just I was going on holidays whenever it came up, and then I let it lapse and I haven't gone.

(DS3006, IS, 60 years)

Cognitive resources (COM-B construct— psychological capability; TDF domain—memory, attention and decision processes)

In terms of cognitive resources, factors related to psychological capability (which mapped to the TDF domain of memory, attention and decision processes) included memory lapses; memory aids/prompts; and past salient events. Most women, regardless of age or screening history, could not recall how many screening invitations they had received. They reported that they often put invitations in ‘safe places’ and then forgot about them. Reminder letters were considered useful and prompted many women across the groups to make appointments:

I'm happy to get the prompting letters…I wouldn't see it as an annoyance…We have such busy lives we have to be reminded.

(DM550494, IS, 50 years)

When cued by their invitation letter, many AS younger women considered salient events (such as past abnormal results, family history of cancer) and allocated attentional priority to screening.

Role of social support (COM-B construct—social opportunity; TDF domain—social influences)

The theme of social support maps to the COM-B construct of social opportunity and the TDF social influences domain. Factors related to social opportunity included: social influences such as social/family support; creating group norms; and health professional 'champions'.

Generally, women made decisions about attendance themselves and did not seek advice from others, regardless of their screening histories. Some AS women talked to their family/friends about upcoming screening tests, indicating that attending for cervical screening was an established behaviour in their social group that could be discussed without embarrassment.

There was a pattern of advocacy among the older women; many AS and some IS women encouraged their family/friends/work colleagues to participate in screening. Some older IS women had recently decided to participate in screening when personally encouraged by their health professionals to attend. These health professional 'champions' had engaged with the individual woman about screening during a routine medical appointment:

It was really the nurse in the practice who… I think I was getting stitches out or something, or having some test or other done, and it was she who highlighted it and she got me put on the register.

(DM550496, IS, 57 years)

In contrast, younger IS women reported that family support had been a critical factor in their recent decisions to attend. This support often originated from partners who had read the CervicalCheck information sheets and urged the women to prioritize their health and find time to attend.

Environmental influences (COM-B construct—physical opportunity; TDF domain—environmental context and resources)

Environmental influences mapped to the COM-B construct of physical opportunity and the environmental context and resources TDF domain. The factors that linked to physical opportunity included: smear takers; HPV self-sampling kits; and use of information sources.

Irrespective of age or screening histories, women expressed their preference for female and/or experienced smear takers. Some younger IS women described problems with their local smear takers that inhibited their attendance, but they had not made any plans to access different GPs:

If there were a clinic or a different patient section in a hospital or whatever, I would have no problems, but it was just the nursing staff at my GP's that I don't like

(DM550495, IS, 41 years)

Most of the IS women, younger and older, reported that they would use HPV self-sampling kits if they received one in the post. They felt that kits would be useful and more convenient for them, but highlighted the importance of clear, 'step-by-step' instructions. In contrast, many AS older women said that they would not as they lacked confidence that they would do it correctly.

Similar information sources—such as healthcare professionals, family/friends and the internet—were available to most of the women. AS women spoke about using these resources in the past—often prompted by their CervicalCheck invitations—to find out about cervical cancer and/or screening. IS women did not generally research these topics, but indicated that they would use similar sources if such information was required. GPs were reported as the most trusted source of health information, but younger women—both AS and IS—often accessed multiple information sources:

It wouldn't be just one step. I wouldn't take the doctor's word for it; I would want my own research done. Because not one person knows everything. You can't say that everything on the internet is true.

(DM550495, IS, 41 years)

While specific information sources were not linked to screening participation, several women who were IS highlighted the merits of health websites with supportive components such as patient forums and webchats.

Perceptual and practical influences (COM-B construct—psychological capability; TDF domain—behavioural

regulation)

Perceptual and practical influences mapped to the COM-B construct of psychological capability and the TDF behavioural regulation domain. Women's ability to regulate screening behaviours often linked to perceptual and practical factors—both inhibitory and stimulating—and their prioritization of screening.

There were distinct age differences in reported barriers to screening. Many older IS women felt that screening was no longer necessary because of their age/lifestyle:

A few years ago, when I was younger, I did attend some of them. But. With my age…and I'm not sexually active. I just didn't think it was necessary

(DS30008, IS, 62 years)

This contrasted with the health beliefs of many older AS women who felt that screening was an essential part of their healthcare, with benefits that outweigh the inconvenience.

In contrast, most younger women—both AS and IS—highlighted practical barriers to screening such as time pressures, difficulties with childcare and accessing appointments. Many younger women also considered screening a low priority in their lives because as mothers, they often had competing demands on their time, were not worried about cervical cancer, were in a monogamous relationship or displayed no symptoms.

Although AS women felt that screening was necessary for maintaining good health, many AS older women described age-related barriers—increasing difficulties with procedure as they got older, due to postmenopausal changes—psychological (e.g., increased anxiety) or physical (e.g., vaginal dryness):

I just hate getting them done. I find that, maybe as I'm getting older, I don't know, I find it very uncomfortable and very painful. Maybe because I am a bit tense, or something, about it as well. I just find it, and I know it has to be done, and so forth, but I just found the last couple of ones were very uncomfortable

(DS30016, AS, 55 years)

Both AS and IS women described factors that could potentially encourage screening attendance such as flexible screening appointments/access to GP practices or practical tips such as pelvic tilts during the procedure or taking painkillers before the smear test.

DISCUSSION

This is the first study to use the combination of TDF and COM-B models to identify influences on cervical screening behaviours. We identified seven themes: (1) knowledge of cervical cancer and cervical screening; (2) coping with smear tests; (3) competing motivational processes—automatic and reflective processes; (4) cognitive resources; (5) environmental influences; (6) role of social support; and (7) perceptual and practical influences. These were linked to six COM-B elements and 11 TDF domains. The COM-B and TDF models provide a framework to systematically identify the influences on screening behaviours and, hence, targets for strategies to increase screening participation. The use of the combination of the COM-B and TDF models had additional benefits helping to highlight the underlying influences that both inhibit and promote screening. This links from the TDF domains to the associated Behavioural Change Wheel (BCW),[19] meaning that relevant intervention functions and supporting policies that could facilitate behaviour change/increase screening attendance can be identified. Moreover, further links to the Behavioural Change Taxonomy[28] can provide suggestions as to possible behavioural change techniques for consideration in intervention development. This study therefore provides a direct springboard for the development of evidence-based and theoretically informed interventions to improve screening uptake.

Consistent with previous research,[12,13,29] many IS women reported limited knowledge about cervical cancer risk factors and believed that they were at low risk of developing it. In contrast, many older women who considered screening unnecessary because of their age or current sexual activity positively assessed cervical screening. These findings suggest that a hierarchy of influences could exist in determining screening behaviours among older women—the perceived personal relevance of screening was more important than their knowledge of its overall health benefits. Improving knowledge of cervical cancer and screening alone is likely to be insufficient for effective behavioural change strategies.[30] This suggests that modelling and environmental restructuring interventions that increase psychological capability would be useful. Strategies tailored for older women that target their beliefs about salience of screening, which can change over time as they age, would be worth testing. Relevant advertising campaigns with high-profile ‘older’ women modelling positive screening behaviours or on-screen prompts for GPs to ask older women about screening could also prove effective.

Women highlighted the invasiveness of undergoing a screening test and, as with other studies, described high levels of stress and anxiety before their appointments.[12,13] AS women were confident in their abilities to cope with negative aspects of screening such as finding the test intrusive. Coping strategies such as breathing techniques were commonly used, suggesting that prescreening information that offered women tips and advice on such coping strategies could be useful. As with previous research, many older women reported increasing problems with the smear test procedure—linked to menopausal changes—as they aged.[13] These findings highlight the necessity of supporting older AS women and building physical capability to maintain their adherence. This can be achieved with physical skill development through training or enabling interventions.[20] Practical advice on lubrication or pain medication in information leaflets or as part of standard verbal instructions from smear takers could increase individuals’ skills and be beneficial for these older women. The current study also found that promoting physical opportunity with HPV self-sampling kits could prove effective as older women who were IS indicated that they would use HPV kits if given the opportunity to do so. Such kits could be enabling interventions, provided they were accompancied with additional support to develop women's confidence. This additional support could include online video tutorials of self-sampling; information sheets with step-by-step instructions (both clear explanatory text and a visual guide); or ‘practise’ sessions across healthcare settings, where women are supported by experienced smear takers, receiving guidance from HCPs during their self-collection/while using the kits themselves.

A key finding of this study was that both motivational processes, automatic and reflective, were important in influencing screening behaviours. In contrast to IS women, those who were AS were autonomously motivated to attend screening—salient events such as previous abnormal results played a role in their prioritization of screening. The self-determination theory (SDT) on health behaviours suggests that intrinsic motivation will increase when psychological needs of autonomy, competence and relatedness are satisfied.[31,32] Potential strategies to increase intrinsic motivation, which support autonomy, relatedness and encourage identification with the value of screening, could include motivational interviewing, peer support and relevant information with meaningful rationales for behaviour change.[32,33] These approaches would augment automatic motivation and could prove beneficial in increasing uptake in IS women. Application of the BCW suggests that changes to service provision that focus on training and enablement interventions could help establish and maintain screening attendance over time.

Social support was a significant influence, further highlighting the role of relatedness in reinforcing women's attendance by creating group norms of positive screening behaviours within families/friendship groups.[32–34] It should be noted that the CervicalCheck controversy was part of the social environmental context at this time. The high-profile events that were occurring may have impacted on women's views on screening and our findings. However, additional aspects of social support emerged in this study among IS women. Younger women in this group identified the impact of family support in encouraging them to attend, while IS older women reported the positive effects of a personal interaction with their health professionals on their screening behaviours. While previous research has identified the central role of healthcare providers in supporting screening,[35–37] the current study offers information specific to older women. The theory of planned behaviour model identifies a gap between intention and behaviour.[38] Our findings suggest that family support may act as a moderating factor on this gap for younger IS women, while health professional ‘champions’ who encourage women to attend screening may possibly have a similar moderating effect for older women who are IS. However, it should be noted that controlled motivation may not be a reliable influence on screening behaviours over time.[39] SDT suggests that women who are motivated to attend screening for controlled reasons—perceived approval of others—feel a sense of obligation and will only persist if the external pressure is maintained.[33,39] Our findings suggest that persuasion and education interventions that link to environmental/social planning and communication/marketing policies could prove effective in maximizing the positive effects of social opportunity on screening behaviours.

Psychological capability was found to be influential in screening behaviours; as with previous research, practical barriers were commonly reported by younger women (for example, lack of time, arranging childcare and time off work), while older women cited issues such as perceived irrelevance of screening for them and concerns associated with postmenopausal changes/ageing bodies.[8,13] Psychological capability can be augmented with modelling and environmental restructuring interventions.[20] This suggests that system changes that increase convenience and provide prompts such as drop-in clinics, evening/weekend appointments and text reminders could improve uptake in younger women. Different approaches are required for older women such as targeted information campaigns with relevant data such as latency periods from HPV exposure, high-risk groups and the possibility of HPV reactivation around menopause. In this context, policy changes in communication/marketing with campaigns across multiple media platforms and guidelines (such as establishing age-specific HPV infection communication documents within the screening programme) would also be valuable.

Strengths and limitations

A major strength of the current study is the use of the COM-B and TDF models in examining influences on screening behaviours. The COM-B and TDF models provided a framework to explore and identify the complex factors that influence these behaviours. A comprehensive behavioural analysis of influential factors could be undertaken, which is an essential step in developing theoretically informed interventions.[40] The links between the TDF and COM-B models to the BCW provide a systematic process to fully understand the nature of screening participation, characterize interventions and link these to specific policy categories. The TDF model also informed the topic guide, which enabled information to be gathered on women's typical screening behaviours. Another strength is the inclusion of women with a range of screening histories. This proved insight into an understudied cohort—those who do not (consistently) engage with screening. We also distinguished younger and older women, which is important, given the indications here of how influences on behaviour may differ in these groups. However, as in any qualitative study, women who were interviewed (both AS and IS) were motivated to participate and may have distinctive views/opinions about screening. Moreover, it is worth remembering that the interviews took place against the background of a high-profile controversy around CervicalCheck. It is possible that this may have impacted on women's views on screening and, hence, on our findings.

CONCLUSION

This study has identified that women's screening decisions were influenced by a variety of factors, some of which can evolve over time. Establishing positive screening behaviours that persist will require tailored strategies that support autonomous motivational processes and increase capability (physical and psychological) and opportunity (physical and social). The study findings can be mapped to specific intervention functions, thereby taking a step towards the development of evidence-based and theoretically informed interventions to improve screening uptake.

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CONFLICT OF INTERESTS

The authors declare that there are no conflicts of interest.

AUTHOR CONTRIBUTIONS

M. O'Connor, C. Martin and L. Sharp conceived and designed the study. M. O'Connor, L. Sharp, C. Martin, T. Mooney, P. Fitzpatrick, G. Flannelly and B. O'Donovan developed the study methods. M. O'Connor, T. Mooney, L. Doherty and B. O'Donovan assisted in acquiring data. C. Martin and M. O'Connor managed the project. B. Rimmer, L. Sharp, M. O'Connor and B. O'Donovan contributed to the analysis and interpretation of data; all authors critically reviewed the manuscript and approved the final version.

DATA AVAILABILITY STATEMENT

Data are available on request from the corresponding author, but not publicly available due to privacy or ethical restrictions.

AAPPENDIXTOPIC GUIDEIntroduction

‘Hello…it's XX from xx, we spoke last week and arranged to talk about your views on smear tests and cervical screening. Is it still a good time for you?’

Verbal consent

‘Just to remind you…’

Start recording

‘I'll start the tape now…’

Assure of confidentiality

‘Please be assured that everything you say’.

Summarize purpose and structure again

‘Before we start I'ld just like to tell you a bit about the study. We are exploring womens' views of smear tests and cervical screening and what influences their decisions to attend for screening tests. We want to hear the views of a variety of women—so women who attend regularly, those who attend sometimes and those who never attend. We also want to find out what women think would improve screening/smear tests’.

'So how does that sound? Do you have any questions before we begin?'

Background (demographic information)

‘So to start off can you tell me a bit about yourself?' (raised questioning tone &pause)

- Cervical screening history

‘Have you ever received an invitation to take part in CervicalCheck?'

If not

‘Has your doctor/nurse at your GPs surgery ever mentioned having smear tests?'

‘What were your first thoughts when you got your first invitation letter from CervicalCheck?'

‘Did these thoughts/your thinking change when you got your second invitation?…Did you make arrangements to have a smear test?…Was it long after getting your invitation?'

‘Why did you decide to have your screening test?'

‘What did you consider when you were making your decision?'

‘Did you talk to anyone about it?'

If not

‘Why did you decide not to have your CervicalCheck screening test?'

‘What did you consider when you were making your decision?'

‘Did you talk to anyone about it?'

‘Did you know about/were you aware of cervical screening before you got the CervicalCheck invitations?'

‘Have you participated in other screening programmes e.g. BreastCheck, Diabetic RetinsScreen?…Can you tell me about that?'

Undergoing the screening test

‘So just to return to your most recent screening test. Can you tell me about it?'

‘What do you think would make undergoing the screening test easier?'

‘Was there anything particularily difficult about undergoing the test?' [Physical/Psychological elements]

‘What might make you more likely to participate in screening?…There is a screening tool that you could use yourself at home called HPV self-sampling. Have you heard of it?'

If not

‘So I know you decided not to have your CervicalCheck smear test but I'ld like to ask you some general questions about screening. What do you think would make undergoing the screening test easier?'

‘What might make you more likely to participate in screening?…There is a screening tool that you could use yourself at home called HPV self-sampling. Have you heard of it?'

- Information-seeking and social support

‘If you were looking for trustworthy/reliable information on cervical screening what would you do?…Would you use any other sources of information e.g. friends/medical book/Internet?'

- HPV

‘Have you heard about HPV?'
‘What can you tell me about it?'
‘Have you heard of HPV testing/a HPV test?'
'CervicalCheck may soon be changing their screening test from the current test, which looks for abnormal cells in the cervix to a test that looks for the presence or absence of HPV infection. Physically, it will feel the same as having smear tests. The changes, if implemented, will mean that all women (aged 25–60 years) will attend for screening every 5 years. This will be different from current screening protocols, where women aged 24–44 years attend for screening every 3 years.'
‘Do you have any thoughts on the proposed changes?'
‘Do you think you will be more or less likely to participate in cervical screening in the future if these changes are made?'

- Future improvements to cervical screening

‘Looking back what would you have liked to know before you went for your smear test?'
‘What would you want a family member/friend who was invited for a smear test to know?'
‘What would you want a family member/friend who was going for a smear test to know beforehand?'
‘What would you want her to know afterwards?…How do you think she should get this information?'
‘Any suggestions on how the screening test experience could be improved for other women?'
If not
‘So I know you decided not to have your CervicalCheck smear test but I'd like to ask you some general questions about improving screening…Looking back to when you were invited for a smear test (pause) was there anything/any information you would have liked to know?'
‘What would you want a family member/friend who was invited for a smear test to know?'
‘What would you want a family member/friend who was going for a smear test to know beforehand?'
‘What would you want her to know afterwards?…How do you think she should get this information?'
‘Any suggestions on how the screening test experience could be improved for other women?'

- Close

DETAILS

Subject:	Motivation; Womens health; Cervix; Automatic processes; Environmental aspects; Coping skills; Ethnicity; Teams; Cervical cancer; Capabilities; Domains; Consent; Social support; Human papillomavirus; Cellular biology; Health care; Risk perception; Recruitment; Interviews; Participation; Cancer; Older women; Young women; Negative attitudes; Uptake; Patient participation; Age groups; Medical personnel; Social interactions; Cognitive ability; Patients; Medical screening; Education; Research projects; Health risks; Qualitative research; Behavior change
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Perceptions of recurrence risk and behavioural changes among first-ever and recurrent stroke survivors: A qualitative analysis

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ABSTRACT (ENGLISH)

Background

Among stroke survivors, the risk of stroke recurrence is high, and stroke survivors' perception of the risk of recurrence is crucial to promote healthy behaviours.

Objectives

This study aimed to explore the perceptions of stroke survivors about their risk of recurrence and healthy behavioural modifications.

Design

A qualitative interview study was carried out.

Results

We interviewed 19 stroke survivors from 3 hospitals. Thematic analysis showed that the perceptions of recurrence risk and healthy behavioural changes differed between first-ever and recurrent stroke survivors. Three themes were generated from the data of first-ever stroke survivors: indifference to and unawareness of the risk of stroke recurrence, the need for professional information support and different awareness of the importance of different healthy behaviours. For first-relapse stroke patients: worry but feel powerlessness towards recurrent event, accurate information is still warranted, regret of unhealthy behaviour patterns. For the survivors suffered two or more times recurrences: perceived severity of recurrences, increased psychological care need, incorrect perceptions of healthy behaviour.

Discussion and Conclusion

Stroke survivors with or without recurrence hold different perceptions towards the risk of recurrence and behavioural changes. The need for information related to warning signs, recurrence risk and risk factors remained consistently unmet. The benefits of healthy behaviours could be a double-edged sword for the prevention of stroke recurrence if the survivors fail to understand these accurately. It is strongly recommended that a specific recurrence risk communication tool and related health education plan be explored on the basis of the number of times patients have experienced stroke recurrence to inform secondary prevention of stroke in the future.

Patient/Public Contribution

The patients were involved in the formulation of interview questions and conduct of this study. No public was involved in this study.

FULL TEXT

INTRODUCTION

Despite many advances in stroke prevention and treatment, stroke is still the leading cause of death and disability worldwide.[1] Also, patients who survive after an initial stroke are known to be at a significantly increased risk for stroke in the future.[2] The risk of recurrence of stroke is 11.1%, 26.4%, 39.2% and 39.7% at 1, 5, 10 and 12 years, respectively,[3,4] and a significant proportion of all hospitalized stroke cases are due to recurrence.[5] Fortunately, 80% of recurrent strokes can be prevented by addressing the modifiable risk factors; therefore, secondary prevention after the first stroke is very important.[6] For secondary prevention of stroke, an understanding of the risk factors for recurrent stroke and the appropriate lifestyle modifications necessary to minimize risk is essential among stroke survivors.[7] According to the health behaviour theory,[8] accurate perceptions of risks to one's own health are critical to adopt changes in health-relevant behaviours. A study conducted in the United Kingdom showed that stroke survivors who were aware of the risks to their health made significant lifestyle modifications after stroke, that is, decreased consumption of salt and increased consumption of vegetables or fruits.[9] However, most stroke survivors do not have an accurate understanding of the risk of recurrence of stroke.[10–12] Boden-Albala et al.[12] reported that only 20% of stroke survivors had an accurate understanding of their risk for a recurrent stroke; 10% of the survivors underestimated their risk and 70% significantly overestimated their risk. Another study conducted in Thailand revealed that most survivors wrongly estimated their risk of further stroke; 43.6% of survivors underestimated their risk and nearly one-fifth (17.1%) overestimated their risk.[10] In summary, quantitative evidence shows that overestimation or underestimation of recurrence risk is not unusual among stroke survivors.

Although a large number of qualitative studies focusing on patients with stroke have been conducted,[13–15] very few quantitative studies have focused on the perception of recurrence risk among stroke survivors.[10–12] Additionally, Hiraga[7] reported that both knowledge and perception of recurrent stroke risk were crucial for secondary prevention of stroke; he also claimed that the perception of risk and overestimation may gradually decrease with time, and underestimation might increase after the first stroke. Wondergem et al.[16] pointed out a significant difference in disease cognition, coping attitudes and behaviour adjustment in stroke survivors with first-onset and recurrent events. Other scholars followed stroke survivors for 3 years and conducted in-depth interviews to explore their life experience after stroke, and found that life after stroke always involved a continuous adjustment and adaptation process.[17] Thus, this may raise the research question of whether individuals with new-onset and recurrent stroke have different perceptions of their susceptibility to and risk of recurrent stroke. However, to date, this issue remains unclear.

Risk perception is an individual's capability to acknowledge the presence of a certain degree of risk; it refers to people's subjective judgements about the likelihood of negative occurrences such as injury, illness, disease and death.[18] An understanding of patients' awareness of the risk of recurrent stroke is important and essential for translating the perception and knowledge of recurrent stroke risk and individual risk factors into appropriate behavioural changes.[7] Ignoring the risk of recurrence may affect stroke survivors' attitude towards prognosis and response to secondary prevention. However, misperceptions of the risk of chronic diseases are common among the public, and the relationships between these beliefs and consequences are also complex.[19] Therefore, using a qualitative research approach, this study aimed to provide insights into the perceptions of recurrence risk and healthy behavioural modifications among stroke survivors who experienced first-ever and recurrent stroke. The results will then inform the development of interventions based on frequency of relapse to promote effective health education and stroke secondary prevention strategies.

METHODSSetting and sample

This qualitative analysis forms the basis of an intervention study, which has been approved by the Chinese Clinical Trial Registry, that aims to provide a basic understanding of stroke survivors' perceptions of recurrence risk and behavioural modifications. Stroke survivors with first-onset or recurrent events were recruited from two city-level hospitals (city H) and one county-level hospital across two cities in Henan, China (Zhengzhou city and Anyang city). The inclusion criteria were as follows: survivors of various types of stroke[20] with communication ability (Token test ≥17 points)[21] and self-care capability (activities of daily living ≥40)[22] and individuals without cognitive dysfunction (mini mental state examination ≥17 points).[23]

Data collection

The demographic information of the stroke survivors was collected using a short questionnaire. The preliminary interview guide was formulated based on explorative interviews and extensive literature reviews. A discussion within the research group was held, and three relevant experts in stroke care research, psychological care and behaviour management were identified and consulted to formulate the interview guide. The focus was on first-ever and recurrent stroke survivors, including six questions related to their experience of stroke onset and opinions about the risk of recurrence (Supporting Information Appendix).

The interview was conducted from April 2019 to April 2020. The interviews were conducted in a quiet consultation room in hospitals by two researchers using a semi-structured interview guide and audio recordings. The survivors were informed of the purpose and significance of the research, the possible interview duration and the recording methods. The interview was started after written consent was obtained from the survivors. A relaxed atmosphere was maintained, and interview techniques such as questioning, listening, response, follow-up and repetition were used to encourage the interviewees to express their true views and feelings. Field notes were written immediately during or after the interview and included observations, reflections and nonverbal behaviours, such as tone, expression, eye contact and subtle body language of the interviewees. When no new topics emerged, a group discussion on data saturation was held to achieve consistency. In addition, the Essen stroke risk score was used in this study to estimate the stroke survivors' risk of recurrence[24]; the Barthel index was scored and the self-care level of the interviewees was determined.[22] During the data collection process, if the interviewees exhibited sadness, we discontinued the interview and comforted the participants until they felt better.

Data analysis

The recording was transcribed. After transcription, 4 out of 19 sets of verbatim responses were randomly selected for checking to ensure accuracy. The data were analysed inductively using thematic analysis strategies.[25,26] The analysis steps were as follows: (1) the interview transcripts were read and reread by two researchers to familiarize themselves with the data as a whole, and to make sense of the data, preliminary ideas were captured in interpretive notes and discussed in an interpretive team meeting; (2) the sentences and paragraphs were inductively analysed by one researcher to generate initial codes; (3) the codes were collected and categorized into potential themes, and all data relevant to each potential theme were collated and gathered; (4) the emerging themes were reviewed by another researcher who was not familiar with the transcripts to work in relation to the coded extracts and the entire data set; (5) interpretive writing on the ascertained themes was displayed; (6) clear definitions and names for each theme were analysed; and (7) report was produced.

Rigour

To establish reliability, several strategies were used according to relevant criteria,[27] including credibility, dependability and transferability. Credibility was achieved by interviewing survivors of both sexes and across different age groups and areas of residence; in addition, the primary researcher performed the coding, categorisation and analysis to select the most suitable meaning unit. Dependability was achieved by peer evaluation of transcripts and group discussion to ensure that a consistent decision was made. Transferability was established by extensive clear and distinct descriptions of the culture and context, selection process and characteristics of the participants, data collection and the process of analysis. Meanwhile, we report the findings based on the COREQ checklist to ensure transferability.[28]

RESULTSDemographic information

A total of 19 survivors with stroke were interviewed in this study, but none of them had taken part in the previous explorative interviews. The respondents' ages ranged from 42 to 89 years; 42.11% were female. Of these, 7 had a low risk of recurrent stroke and 12 had an intermediate risk of recurrent stroke. The duration of the interview ranged from 19 to 42 min, and a total of 94,000 words were transcribed. The characteristics of the participants are summarized in Table 1.

Table 1 Demographic characteristics (*N* = 19)

No.	Gender	Age (years)	Educational level	Diagnosis	NSE	ADL	Occupation	ESRS
S1	Female	60	Illiterate	IS &HS	1	Totally independent	Clean worker	0
S2	Male	66	Primary school	IS	1	Totally independent	Farmer	3
S3	Male	89	Primary school	IS	1	Totally independent	Worker	3
S4	Male	52	College	IS	1	Totally independent	Officer	1
S5	Female	73	College	IS	1	Totally independent	Farmer	3
S6	Male	66	High school	IS	1	Minimally dependent	Worker	5
S7	Male	53	Middle school	IS	2	Totally independent	Driver	2
S8	Female	72	Illiterate	HS	2	Minimally dependent	Farmer	3
S9	Male	78	College	IS	2	Minimally dependent	Worker	2
S10	Male	72	High school	IS	2	Minimally dependent	Teacher	3
S11	Female	58	Illiterate	IS	2	Partially dependent	Farmer	3

S12	Male	55	High school	IS	2	Partially dependent	Security	2
S13	Female	53	Illiterate	IS	3	Minimally dependent	Farmer	2
S14	Male	71	Middle school	IS	3	Partially dependent	Worker	4
S15	Male	72	High school	IS &HS	3	Partially dependent	Manager	4
S16	Male	66	Primary school	IS	4	Minimally dependent	Security	4
S17	Female	74	Illiterate	IS	4	Partially dependent	Farmer	4
S18	Female	42	Illiterate	IS	5	Minimally dependent	Farmer	2
S19	Female	67	Illiterate	IS &HS	7	Partially dependent	Farmer	3

Note: The ESRS is used to predict the risk of stroke recurrence; higher scores indicate higher recurrence risk. The risk is defined as low at 0–2, intermediate at 3–6 and high at 7–9. The Barthel index is used to assess stroke survivors' activities of daily living (ADL); 80–100 indicates total independence, 60–79 indicates minimal dependence, 40–59 indicates partial dependence and less than 40 indicates very high dependence on others.

Abbreviations: ESRS, Essen stroke risk score; HS, haemorrhage stroke; IS, ischaemic stroke; NSE, number of stroke events.

Perceptions of recurrence risk and behavioural changes

Nine major themes emerged, the themes with illustrative quotes are listed below, and examples of the illustrating coding tree are presented in the Supporting Information Appendix.

First-ever stroke survivorsIndifference to and unawareness of stroke recurrence risk

The first-ever stroke survivors who had experienced mild stroke generally had complete confidence in their stroke prognosis and had no awareness of recurrence risk. A participant with a college degree stated, ‘I have been here (hospital) two days, and I am very well, I don't think it (recurrence) will happen’ (S4). However, he was at low risk of stroke recurrence, according to ESER, and we found that he was reluctant to talk about the possibility of a relapse. Regardless of the educational background, an illiterate participant explained, ‘I got an (unclear) injection, and everything is ok now; it's ok’ (S1). An older man (S2) with primary school education also said, ‘This was just a minor cerebral infarction; it was nothing at all. My son has cerebral infarction too, and he is well now’. In terms of recurrence risk, some of the survivors had no idea of and never considered their risk of recurrence; as one participant asked, ‘what is recurrence and why? I am fine now’ (S1). Some survivors had complete confidence in their ability to prevent recurrence: ‘I have a good mentality and a high-level adherence so it (recurrence accident) won't happen’ (S5); however, her Essen score was 3, indicating that she had an intermediate risk of stroke recurrence. Therefore, some survivors lacked knowledge of recurrence, some underestimated their susceptibility to and severity of stroke recurrence and some were unable or unwilling to make a connection between their disease and the possibility of recurrence (S3 and S4 avoided discussion of the topic of recurrence).

Need for professional support for information

Most first-ever stroke survivors broadly mentioned warning signs when asked to recall the onset of stroke. Three survivors reported that they were able to identify anomalies quickly, but lacked accurate knowledge about the warning signs of stroke (S1, S2, S4). As S1 noted, ‘I do not know what happened, but I can feel that one of my legs is weak’.‘I felt weakness suddenly, I did not know exactly what happened, my son took me to the hospital’ (S2). However, there were patients who ignored the significance of emergency care because they were unaware of the symptoms; one patient who experienced a TIA before stroke did not know about the TIA at all: ‘I did not know what happened at that time. I couldn't remember the falling accident, so I did not tell them (his wife and daughter)’ (S6). Although two interviewees had a positive learning attitude and they could recognize stroke once they were aware that they suffered a stroke, they gained related knowledge from others, the TV or books, rather than from medical staff, as one older man noted, ‘I always saw some people with hemiplegic paralysis walked around in the garden. I asked them, and then I knew some warning signs of stroke’ (S3). Another patient mentioned, ‘I like to read books and watch TV. So, I know some; that is why I was able to visit the hospital in time’ (S5, she laughed and was proud). Both participants mentioned knowing ‘some…’; this might indicate the fact that they still need professional support to obtain information.

Different awareness of the importance of different healthy behaviours

Participants' treatment-seeking behaviour was relatively active; they knew that it was necessary to visit the hospital if they experienced any symptoms. As some participants highlighted, *‘*At nine o'clock pm, I felt uncomfortable and could not move my leg, I did not know what happened… I told my son, he called 120 (emergency hotline) and sent me to this hospital immediately’ (S1). However, when talking about secondary prevention behaviour, most of them were aware of the importance of medication intake, but some of them were not aware of the importance of lifestyle modifications, as emphasized by S3, ‘It is critical to adhere to physicians' advice to take medication’. On probing patients' perceptions, most participants reported feeling guilty about their previous self-medication behaviour; ‘I threw away the medicines after being diagnosed with atrial fibrillation, it was boring, I won't do again…’ said S1 with regret. In terms of lifestyle modifications, many showed an indifferent attitude, as S2 claimed: ‘Many people around me suffered stroke, but they still had to work (earn money), who care about anything else? I have to earn money; I am fine now…’ Moreover, some patients who lived in an extended family set-up had limited freedom to choose what to eat ‘I cannot, they (son or daughter-in-law) cooks and I eat, we have no awareness of “healthy food”’ (S1).

Survivors with a second strokeWorry, but feel powerlessness towards recurrent event

We found that all the participants expressed different degrees of worry or fear about their prognosis. Patient S7, a middle-aged male driver, explained, ‘I am afraid; although I'm afraid, I do not know what to do at all…’. A female stroke patient (S8) also noted, ‘I'm afraid. I'm afraid to come back here (hospital) again’. The decline in self-care ability caused by the disease also directly led to a sense of powerlessness, as some of them explained: ‘Another cerebral infarction, what is a big deal? What else can you do? What can you do (nothing…)?’ (S7). Patient S9 reported, ‘You cannot do anything at home. I am getting old. I have no thoughts of future’. One of the participants wanted to find a job and return to work, but he was rejected: ‘I tried to find a job, but they finally sent me back to home, I felt weak, and I could not walk a long distance’ (S10). The occurrence of recurrence events, worsening of symptoms after recurrence, lack of knowledge about the prognosis of recurrent events and sense of powerlessness may be the reasons that led to the interviewees' negative emotional responses.

Support in terms of obtaining accurate information is still warranted

The lack of accurate information about stroke was still an unresolved concern among recurrent survivors. As one middle-aged patient (S7) explained, ‘I felt uncomfortable and dizzy; I thought it might be another stroke’. S8 stated, ‘I never thought that it was a recurrent stroke; I thought I might have caught a cold, but it progressed quickly’. S11 claimed, with a smile, ‘I thought the doctor scared me when he told me the recurrence risk; I did not take it seriously’. Receipt of inadequate or insufficient information led to lack of confidence among the survivors. One patient described his feelings regarding his second stroke as follows: ‘I do not know what happened, this makes me unhappy and confused’ (S10). When the participants were asked how stroke can be prevented, most of them still could not answer correctly. Even though some of the participants quit smoking after their first stroke, they did not know why they had to change their behaviour; ‘they (doctor or nurse) always gave me some suggestions in a hurry, but I could not understand very well, and I didn't know why. They are so busy…, I don't know how to ask…' S7 said and scratched his head. Thus, it can be seen that accurate and sufficient information is still needed. A middle-aged male survivor (S12) stated that 'Even though there are lots of health education flysheets in the hospital, but I never read them, I have no patience to read them…'.

Regret of unhealthy behaviour patterns

A recurrent event is possibly a triggering factor that could increase survivors' motivation to change unhealthy behaviours. Some of the participants expressed regret and described why they felt self-reproach. One participant (S7) explained, 'I did not think of it here; I did not take it seriously. I must be wrong'.'I did not want to take medicine; I thought I was well, but now I'm in trouble (scratch head, sigh, etc)'. Poor adherence to medication was considered to be the main reason for recurrence, as illustrated by the following statement: 'I did not take the medication according to the prescription, but I should do' (S8). In addition to medication adherence, poor compliance with functional exercises was mentioned as a barrier; a middle-aged man (S10) noted: 'No one told me how to exercise after discharge, and I failed to do rehabilitation exercises every day'. Some survivors also regretted losing their temper: 'you cannot get angry, this time, I was angry with my children, so it happened again…, I knew I shouldn't, but I couldn't control myself…' (S9). 'The impact of getting sick was great, and people who have not had it do not know this kind of pain; I cannot bear the burden of my thoughts anymore' (S10). While making this statement, it was observed that the interviewee was trying to control his emotions. Most participants had some degree of regret of incompliance or unhealthy behaviours.

Survivors with multiple recurrencesPerceived severity of recurrences

All participants reported that they perceived the severity of the stroke, and they noted participation limitations caused by frequent stroke events. As one participant explained, 'The first time, I was young, and I did not pay attention to it. The second time, I could not speak very clearly, but I recovered within two weeks. This time, I cannot do housework; I think it must be much worse…' (S13). 'The first time was just a case; the second time, it had a relatively mild impact on my life. However, this time it was too heavy, eh!' (stated by S14). 'I was able to go out and go around before, but I have urinary incontinence this time; I will not do anything outside, as I am a little ashamed and it is inconvenient', as stated by S16, who used to be a security guard. 'I cannot do anything, I liked square dancing, but now, it's impossible…' claimed by S18. Limitation in terms of social participation is a common problem among stroke survivors with severe physical disabilities or communication disorders.

Need for increased psychological care

A belief in fatalism was expressed and seemed to affect stroke survivors' attitudes towards their disease.[29] Some participants held ambivalent attitudes; on the one hand, they thought that the disease was a natural process, there was nothing they can do to prevent or stop it (recurrence) from happening and people will get sick and die anyway: 'Death. Nothing can be done to prevent death. I won't hide, and I know I cannot change the process; each person will die' (S13). On the other hand, they showed a significantly passive attitude towards stroke recurrence; four participants recognized their stroke recurrence as uncontrollable and unpreventable; a strong sense of failure and powerlessness was evident from their words: 'When I met some old friends in the garden, I smiled, and we did not talk with each other as we know what will happen next' (S15). 'I cannot get around, and I don't like to do things; I just want to sit here and wait' (S17). 'I do not want to do anything; whatever, it (recurrence) will occur' (S18), and 'It is impossible to worry, and I never think about it' (S19). An older man said, 'someone told me I would die at 70, and now I only have four years left. I want to do what I like (drinking and eating my favourite food)' (S16). We could observe that it was difficult for the participants who had lost confidence in terms of control over their life to talk about this topic, which indicates that they might need more psychological care.

Incorrect perceptions of healthy behaviours

Perceived benefit is a critical motivator for chronic disease survivors to change their behaviour.[29,30] Behavioural change is beneficial only when the survivors know what healthy behaviour is and what benefits they can gain. However, no perceived visible benefit is a barrier in this study. As one male stroke patient with a moderate level of dependence in terms of daily activities said, 'I am doing exercise every day, but I am sick again; It may be too much exercise, who knows why it happened again and again?' (S14). One patient (S16) mistakenly thought that alcohol could reduce blood sugar levels; he explained, 'I think alcohol cessation was good for controlling blood sugar. However, it seemed that drinking some alcohol effectively reduced my blood sugar level; who knows why. Whatever; I started to drink again'. A female patient (S17) with self-perceived high-level adherence suffered stroke four times. She expressed doubts about the effects of treatment and healthy behaviours: 'I never forgot to take my medication, and I paid attention to diet, exercise, etc., but it occurred again. What is going on?' (The interviewee showed irritability and had a helpless smile). Another patient who exercised every day noted, 'I do not know how to exercise; I just do as much exercise as I can, if I have time' (S14). Another patient with 'high-level' adherence changed her medication because it was too expensive (S17).

DISCUSSION

In extending previous quantitative evidence on this topic, this study provides additional insight into participants' feelings and attitudes towards recurrence risk and behavioural changes. This analysis uncovered nine major themes regarding first-ever or recurrent stroke survivors' experiences and feelings. Participants with first-ever stroke tended to ignore or are unaware of recurrence risk, while recurrent events led to awareness of the severity of recurrence, but made them feel powerless. Moreover, survivors with multiple relapses showed a triple attitude toward recurrence risk, e.g., negative acceptance, positive acceptance, or both, which indicate an increased psychological care need. Also, their attitudes toward behavioural changes were influenced by the number of relapses as well, in terms of the decision made to make changes in their life, regret for nonadherence to medication and questioning the benefits of behavioural changes.

As Hiraga[7] commented, knowledge and perception of recurrent stroke risks and risk factors are very important from the points of view of education and secondary prevention strategies. However, in these interviews, it was found that almost all survivors had only recently heard of the risk of recurrence and had limited knowledge about the likelihood of recurrence. Still, they rarely considered the possibility of susceptibility to recurrence; this result could be related to the Chinese cultural context, as people prefer to adopt an optimistic attitude and discuss positive outcomes.[31] Although the findings of this study were based on interviews with only a few individuals, previous studies in different countries and regions have reported similar results.[10,12,32,33] Boden et al.[12] investigated the perception and awareness of recurrence risk in survivors with ischaemic stroke and transient ischaemic attack. The results revealed that only 20% accurately perceived the risk of recurrence; 10% of these patients underestimated the risk of recurrence and 70% of the survivors overestimated the risk. Another study conducted by Croquelois and Bogousslavsky[11] reported the perceived risk of recurrence among survivors with first stroke after 3 months; 65.2% of survivors claimed that they did not consider the risk of recurrence (e.g., recurrence should not happen to me). Similarly, a study conducted in a developing country determined and compared the self-perceived risk of recurrence and the actual risk of recurrence in survivors with transient cerebral ischaemia and found that most survivors did not accurately perceive their risk of recurrent stroke; 43.6% of the survivors underestimated the risk and 17.1% of the survivors overestimated the risk.[10] It can be seen that poor perception of recurrence risk is a global problem, and an individual's perception of recurrence risk is likely to have a strong impact on their prognosis and long-term outcomes.

We also found that the unmet need for medical information was a general problem among most participants in this study, especially in terms of warning signs and the treatment time window. Even in the case of a patient with a high level of education, when we asked him about the best treatment administration time, he claimed that it was within 12 h after onset (S6, Manager); furthermore, most of the remaining survivors could not accurately specify the proper treatment time. Previous studies have shown that only very few stroke victims (16.9%) recognize the initial signs of stroke; not only stroke survivors but also their family members need support in terms of receiving information on stroke.[34] Even in developed countries, the most common (73.8%) unmet need of stroke survivors in the acute stage is stroke education.[35] In addition to the survivors with first-ever stroke, the survivors with multiple recurrences had no confidence in their ability to identify or recognize the initial signs of stroke accurately. Thus, they were able to recognize slight abnormalities and seek medical treatment as soon as possible. However, in most cases, it is not the patients, but their children or spouses who called the ambulance service. In addition, when survivors with stroke lack sufficient information, they may lose confidence and motivation to make behavioural changes in response to recurrences and engage in rehabilitation.[36,37] Lack of knowledge can become an obstacle to behavioural changes if survivors cannot perceive the benefits as well, as described by some interviewees. Survivors were willing to make additional changes if the changes were perceived to be beneficial to their health.[38] Therefore, despite extensive efforts, further dissemination of information of and education about the benefits of lifestyle modifications are still needed worldwide.

Additionally, our findings suggested that participants with or without recurrence have different attitudes towards behavioural changes. We found that almost all the participants were prompt in quickly going to the hospital following the onset of symptoms, even though most of them failed to precisely describe the warning signs or the time window for the treatment of stroke. For the first-ever stroke survivors, this was due largely to their family members in this study, as S1/S2/S3 mentioned, which was consistent with the literature that having a knowledgeable bystander was associated with appropriate help-seeking behaviour and shorter prehospital delay.[39] Although previous studies have shown that inability to accurately identify the symptoms of stroke and failure to treat stroke as an emergency can result in longer prehospital delay,[40] awareness of the severity can also promote appropriate help-seeking and early arrival at a stroke centre.[39] For the participants with recurrent stroke, it has been argued that perception of severity of and susceptibility to stroke may be trigger factors for behavioural modifications.[8,39] However, in terms of self-perception of the risk of disease, underestimation of risk or ‘optimism’ may be a barrier to the adoption of preventive health behaviours as well.[41] We found that patients with a second incidence of stroke adopted healthy behaviours but they also complained about lack of knowledge and feeling powerless. Also, some patients blamed their recurrence on fate, as an excuse of his/her maladaptive process[29]; this is also in agreement with our findings among patients with multiple recurrent events. We found that patients with multiple recurrences were sceptical about healthy behaviours, and they were more inclined to indulge themselves rather than strictly manage their behaviour. This may be primarily because patients cannot perceive any benefits from changing their behaviour in the short term, which is particularly important, as considerable effort is involved in changing these behaviours. Indeed, the benefits of behavioural changes are complex, dynamic and could be cumulative.[42,43]

These findings provide us with a better understanding that accurate information and education about perceived benefits are necessary to promote active responses among survivors of stroke and facilitate healthy behaviours.[7] Accurate information about warning signs, onset of symptoms and other disease-related information should be provided, and proper education to raise awareness of the benefits of healthy behaviours to prevent stroke recurrence may be more appealing and acceptable to stroke survivors with multiple recurrences. Considering misperceptions of disease risk are common among public,[19] strengthened education on recurrence risk communication could be a possible alternative to resolve this problem.[44,45] It can help stroke survivors realize that they are a high-risk group for recurrence, and they need to use proactive strategies to prevent it.[40] The most common risk communication programmes among stroke survivors mainly focus on treatment decisions for intravenous thrombolysis or other medical treatments.[40,46] However, few studies have focused on the effect of recurrence risk assessment and standardized risk communication tools among stroke survivors. Therefore, relevant risk communication education should be provided to improve stroke survivors' perception of recurrence risk. Additionally, the findings of this study also highlighted that professionals should explore more targeted interventions in the future based on the number of relapses that patients experience.

Strengths and limitations

This study delineates typical perceptions according to the number of recurrences of stroke. However, this study is not without its limitations. First, the participants with first-ever or recurrent stroke in this study were mildly or moderately dependent on others for daily activities, and we mainly included low- and intermediate-risk survivors, and although the generalisability of these study findings was limited, their perceptions of recurrence risk were suboptimal, and these outcomes were similar. Second, we only recruited stroke survivors without problems in communication to obtain more useful information; the perception of recurrence risk among a broader study population needs to be explored for the development of tailored interventions. Furthermore, we attempted to discuss the changes in recurrence risk perception among stroke survivors with different recurrence times, and it would be better to conduct a longitudinal qualitative study on a fixed sample to explore the complex and dynamic nature of recurrence risk perception over time.

CONCLUSIONS

This study found that even survivors with multiple incidences of stroke do not have a good understanding of the risk of recurrence. The lack of awareness of the risk of recurrence after the first attack, the worry caused by the first recurrence and the inability to cope with the recurrence and positive or negative acceptance of multiple recurrences provide further evidence of the need for support in terms of information provision. It is necessary to develop a risk communication education plan during hospitalisation for stroke survivors who have experienced multiple incidences of stroke and to highlight the importance of the required information according to the needs of the survivors as much as possible. This approach could improve information acceptance, understanding and mastery among stroke survivors and their families and could ultimately promote health-promoting behaviours and long-term recovery.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Bei-lei Lin conceptualized the study. Bei-lei Lin and Yun-fei Guo developed the interview guide, and Zhen-xiang Zhang approved the guideline. Bei-lei Lin and Yun-fei Guo collected the data, supported by Yong-xia Mei and Wen-na Wang. Bei-lei Lin, Yun-fei Guo and Wen-na Wang transcribed the interviews and analysed and interpreted the data. Bei-lei Lin wrote the first draft of the manuscript. Yong-xia Mei and Yao Tong verified the initial translation of code. Daphne Cheung, Nazia Shuaib and Shan-shan Wang reviewed the translation. Zhen-xiang Zhang and Daphne Cheung performed the quality control of this study, and Daphne Cheung revised the manuscript critically for important intellectual content. All authors have read and approved the final manuscript.

ETHICS STATEMENT

Ethical approval was obtained from the Ethics Committee (ZZURIB2019-005), and approval for data collection was obtained from the Science and Research Department of the three hospitals.

DATA AVAILABILITY STATEMENT

The data sets analysed during the current study are available from the corresponding author on reasonable request.

DETAILS

Subject:	Behavior; Risk behavior; Information needs; Relapse; Secondary prevention; Risk factors; Survival; Design modifications; Activities of daily living; Survivor; Prevention; Risk analysis; Recurrent; Interviews; Risk communication; Qualitative analysis; Qualitative research; Hospitals; Risk taking; Stroke; Risk perception; Perceptions; Regret; Worry; Change agents; Health education; Data collection; Recurrence; Patients; Health information; Health risks; Behavior modification; Behavior change
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Experiences of healthcare for people living with multiple sclerosis and their healthcare professionals

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ABSTRACT (ENGLISH)

Background
Multiple sclerosis (MS) is a chronic inflammatory and neurodegenerative condition of the central nervous system that commonly strikes in young adulthood and has no cure. Many people living with MS (PwMS) will have significant contact with a range of healthcare professionals (HCPs). To achieve optimal health outcomes in MS, it is important to understand factors that contribute to positive or negative healthcare experiences. Previous studies have shown that PwMS want clear communication and in-depth relationships with their HCPs. However, many studies have lacked qualitative feedback from HCPs.

Objective
This study aimed to investigate healthcare experiences of PwMS and HCPs and identify areas that are working well and areas that could be improved.

Methods
Semistructured interviews with 15 PwMS and 11 HCPs (seven neurologists, four MS nurses) from across Australia were conducted. Interviews were transcribed verbatim and analysed thematically.

Results
Both PwMS and HCPs valued clear communication, recognized uncertainties associated with MS and highlighted the importance of rapport. PwMS focused on decision-making, understanding roles and expectations, self-directed management and their needs for support. HCPs discussed issues related to medical management, providing hope and reassurance, barriers to healthcare and multidisciplinary care.

Conclusion
Greater transparency and communication, particularly around the approach to care and the roles played by HCPs, is likely to enhance healthcare experiences and contribute to better health outcomes for PwMS.

Public Contribution
PwMS and HCPs volunteered to be interviewed, and PwMS assisted with the development of interview content and structure.

FULL TEXT

INTRODUCTION

Multiple sclerosis (MS) is a chronic neurodegenerative condition involving demyelination in the central nervous system that impacts over 25,000 Australians.[1,2] The experience of MS is unique to each person living with this condition; however, it typically involves impairment in cognitive, motor and sensory functioning. In Australia, the typical healthcare journey begins with consultation with a primary care physician following the onset of symptoms. For some people who will go on to develop MS, these initial symptoms can be vague, and there will be recurrent visits to the primary care physician before referral for specialist care and investigation. For others, symptom onset will be dramatic, for example loss of vision in one eye, leading to an initial contact with the healthcare system through the emergency department, followed by rapid referral to a specialist neurologist. The latter initiates care, further detailed investigations, for example MRI, and typically maintains the ongoing neurological care of the patient, with variable involvement of the primary care physician. In Australia, subsidized drug treatment can only be provided to people living with MS (PwMS) once the diagnosis of MS is confirmed, typically following a second bout of neurological symptoms. Specialist MS nurses are available in some major cities to provide support to neurologists and PwMS.

There are many factors that contribute to improved outcomes in healthcare including patient education and partnership between a physician and a patient.[3] As MS is a chronic condition that requires ongoing interaction with the healthcare system, it is particularly important to understand the factors that contribute to optimal health outcomes. For example, recent evidence indicates that, for PwMS, previous healthcare experiences heavily influence future decisions to seek care for MS-related matters.[4] Further, although previous studies highlight an overall level of satisfaction with care, they reveal a greater need for informative communication during the early stages of diagnosis and management, as well as greater input from the PwMS in decision-making.[5,6]

It is not uncommon in MS to have a significant delay between the onset of symptoms and diagnosis of MS, and inadequate provision of support and information during this time is reported.[7] While treatment and understanding of MS have improved over the past few decades, it is unclear whether this has led to objective improvements in the diagnostic experience for PwMS.[7,8] A recent meta-synthesis of qualitative research into the overall experiences of PwMS showed that many individuals described lack of information and personalized advice at the time of diagnosis.[9] These previous studies have heavily focused on the experiences of PwMS.

There is limited literature outlining the experiences of healthcare professionals (HCPs) in MS healthcare, with these studies highlighting more clinical concerns, such as treatment choices, management of side effects and alignment of care with the personal goals and preferences of PwMS.[10,11] However, concern has been raised regarding discrepancies between PwMS and HCPs in expectations of care.[12] A systematic review of studies into HCP–PwMS interactions found that PwMS often felt uninformed following appointments, and felt a lack of depth in the relationship with their HCPs.[13] However, input from HCPs was underrepresented in this study. It is noteworthy that most previous studies have been quantitative; however, qualitative research may be particularly suited to gaining a deeper understanding of healthcare experiences from different perspectives.

Evaluation of healthcare for PwMS in Australia should be informed by qualitative research that includes the experiences of both PwMS and HCPs, to assess what is currently working well and to identify what needs to be addressed. This qualitative study aims to examine the following research questions:

- 1. What is the experience of MS healthcare for both PwMS and their HCPs?
- 2. For PwMS and their HCPs, what works well and are there any areas in healthcare that could be changed?

METHODSStudy design

This was an explorative qualitative study using purposive sampling to interview 15 PwMS and 11 HCPs specializing in MS.

Interviews

We recruited participants from among those who had been previously involved in research with the research team, using personal invitations and circulation of study flyers. This study was approved by the researchers' university Human Research Ethics Committee, and written consent was obtained from all participants. To be eligible for the study, PwMS had to be over 18 years of age with a diagnosis of MS. HCPs who had extensive experience working with PwMS were invited to participate in the study, including neurologists and MS nurses. It was expected that saturation (i.e., no new insights obtained in the interviews) would be reached within 10–12 interviews if the purposive samples were relatively homogeneous.[14]

Before the interview, PwMS completed a 10-min online questionnaire using Qualtrics[15] to collect demographic and clinical characteristics.

The first four interviews were conducted face to face and the remainder by telephone due to local Government regulations during the SARS-CoV-2 pandemic. The interview questions were based on a top-down (theoretical) approach using findings from current research literature and a bottom-up (inductive) approach consulting with PwMS regarding their experiences of healthcare to correspond with the thematic analysis methodology.[16] The research team's consumer reference group of PwMS was consulted during the design of interview questions and provided feedback on the consistent use of sensitive and inclusive language, and whether the questions were relevant and appropriate in the context of modern MS healthcare in Australia, such as the frequency and type of routine investigations and appointments with HCPs. For PwMS, the interview was divided into four broad areas: (1) Personal experience with MS, (2) Experience of diagnosis, (3) Experience of follow-up appointments and (4) Experience with allied-HCPs. For HCPs, the interview was divided into two broad areas: (1) Approach to diagnosis and (2) Approach to follow-up appointments.

Analysis

Online questionnaires were downloaded into Microsoft Excel; we used descriptive statistics to describe the participant populations. Interviews were audio-recorded, transcribed verbatim and analysed to identify themes. Analysis involved three coders from diverse backgrounds, including personal experience with MS, experience as an HCP and experience in coding qualitative data. Interviews were independently coded, with each coder identifying, analysing and interpreting the patterned response or themes and meaning in the data,[16] with any coding discrepancies resolved via consensus. One coder used NVivo 12 software[17] to collate the data and a second coder cross-checked this coding.

RESULTSInterview results

Fifteen PwMS (Table 1) and 11 HCPs (seven neurologists and four MS nurses) were interviewed. PwMS were located in the Australian Capital Territory (ACT) and Victoria, and the HCPs were from the ACT, New South Wales, Victoria and Western Australia.

Table 1 Demographics of PwMS, their clinical characteristics and healthcare teams

PwMS characteristics	*(n = 15)*
Mean age (years) (SD)	55.0 (11.1)
Mean age at diagnosis (years) (SD)	40.2 (7.9)

Gender [*n* (%)]	
Female	11 (73)
Male	4 (27)
Current MS classification [*n* (%)]	
Relapsing remitting	7 (47)
Secondary progressive	3 (20)
Primary progressive	2 (13)
Progressive relapsing	2 (13)
Unknown	1 (7)
Mean number of HCPs in the MS Care Team [*n* (SD)]	3.3 (1.9)
Types of HCPs from whom PwMS receive MS carea [*n* (%)]	
Neurologist	12 (80)
GP	11 (73)
MS nurse	3 (20)
Allied-healthcare professional	10 (67)
Types of allied-HCPs from whom PwMS receive MS carea [*n* (%)]	
Physiotherapist	4 (27)
Exercise physiologist	5 (33)
Massage therapist	2 (13)
Psychologist	1 (7)
Occupational therapist	1 (7)
Other	8 (53)

Abbreviations: GP, general practitioner; HCPs, healthcare professionals; MS, multiple sclerosis; PwMS, people living with MS.

a

Participants listed multiple HCPs in their healthcare team and many were seeing more than one allied-HCP; therefore, percentages are greater than 100.

Following coding, three themes were common to both PwMS and HCPs: communication, uncertainty and relationship and rapport. Four unique themes were described by PwMS: decision-making, roles and expectations, self-directed management and support, and four unique themes were described by HCPs: medical management, multidisciplinary approach, barriers and access and hope and reassurance (Table 2).

Table 2 Identified themes for PwMS and HCPs

Shared themes for PwMS and HCPs	PwMS	HCPs
Communication	Decision-making	Medical management
Uncertainty	Roles and expectations	Multidisciplinary approach
Relationship and rapport	Self-directed management	Barriers and access
	Support	Hope and reassurance

Abbreviations: HCPs, healthcare professionals; PwMS, people living with MS.

Common themes for PwMS and HCPsCommunication

Communication was a salient theme across all interviews. Both PwMS and HCPs stated that effective communication involved being clear and direct when delivering the diagnosis and discussing ongoing management.

He didn't beat around the bush [got straight to the point], he was very clear what was going on …he got across the message very quickly that what you want to do is get on some kind of immunomodulatory therapy as soon as you can. (PwMS02)

Demonstrate your findings to make it really clear that this is all based on objective findings and trying to use clear language, don't beat around the bush [get straight to the point] with the description or the language, if it's MS you need to say MS because that is what people are expecting to hear. (HCP04)

PwMS liked when their neurologist explained an examination or investigation to them, rather than just giving them the final diagnostic decision, with some PwMS expressing that they would like more of this practice.

He actually shows me the images as well, which is really great. (PwMS02)

I think if you've done a test, it's good to give the results and talk through them …that could definitely be done, and just a little more explaining and not assuming. (PwMS14)

For some PwMS, one of the most important aspects of clear, effective communication involved the use of simple language without using complex medical terminology. PwMS also stated that they would like clearer explanations and no assumption of prior knowledge, particularly during diagnosis.

The extremely good thing about the neurologist is that he will speak English and answer questions …not just instruct and speak jargon. (PwMS13)

He knew exactly what he was talking about and I didn't …it would have been great if he assumed I knew nothing. (PwMS14)

Several HCPs mentioned the importance of addressing any preconceived ideas of MS. These HCPs reported that most of their consultation time with a PwMS, both at the time of diagnosis and during follow-up appointments, is spent providing education and correcting any misinformation.

Typically, in the modern world, they may access various information resources, many of which are misleading or, quite frankly, totally incorrect. That is quite common. I do give them what I believe are appropriate links to resources with authoritative and objective information, but not infrequently they still access, not incorrect but sometimes dangerous information. (HCP02)

One PwMS stated that they would like greater transparency when it comes to communicating the side effects of disease-modifying therapies (DMTs).

You're told about the relapse reduction and all these great new drugs but you're not told of the side effects. (PwMS01)

Several HCPs noted that they generally do not discuss DMTs in the very early stages of diagnosis, explaining that they use a staged approach when communicating the diagnosis and management options, in an attempt to prevent overwhelming the PwMS with too much information.

We don't really even tend to touch on therapies in that really early diagnostic point. We let them know that there's therapies there, but we kind of save that for that second appointment, or for those that are still coming to terms with their diagnosis, that's in the third appointment …we're trying not to overload them with too much information all at once. (HCP05)

Uncertainty

Uncertainty associated with MS was discussed in multiple interviews by both PwMS and HCPs. Three PwMS listed uncertainty as one of their three biggest concerns surrounding MS, either relating to the future of their progression or whether they were on a suitable treatment option.

The uncertainty of the future, you just don't know what's going to happen tomorrow, even if you're stable today. (PwMS15)

PwMS also said that they did not like it when their disease trajectory was framed as unpredictable or uncertain.

The overwhelming impression I got from him most of the time was that everything was completely unpredictable, so… take it one day at a time, and that wasn't as helpful. (PwMS02)

This notion of uncertainty was identified as a significant challenge for HCPs. Several neurologists said that the lack of definitive diagnostic tests for MS creates a level of uncertainty that can create difficulty in communicating an MS diagnosis.

I think it is important to discuss differential diagnosis …I never tell someone that it is one hundred percent certain that it is MS, because there is no absolute definitive pre-mortem diagnosis apart from brain biopsy. (HCP04)

Adequate exploration of various differential diagnoses was highlighted by several HCPs as a way to mitigate this uncertainty. Uncertainty in disease trajectory also made it difficult for HCPs to provide reassurance or give an accurate prognosis when asked.

Very often people that are very, very emotional and distressed, it's a very difficult conversation to have and often people are just stressed because it's a fear of the unknown and they want someone to tell them that it's going to be okay and you can't do that. (HCP10)

Relationship and rapport

The importance of developing rapport was a prominent theme discussed by both PwMS and HCPs. PwMS frequently reported that they liked it when their neurologist was engaged and showed an interest in them.

He was very sympathetic and he listened to what I had to say. (PwMS09)

Similarly, HCPs highlighted that building rapport included listening to the patient and directing care based upon their preferences and needs.

This is a good diagnosis in neurology because we've got lots of good treatment …so I start focussing on what's important to them so they know that the diagnosis is not the primary feature of their life …That's my approach to treating MS. (HCP06)

Whilst PwMS and HCPs shared the same belief in the importance of building rapport, relationship building was revealed to have multiple purposes for HCPs, which included building therapeutic alliances to facilitate treatment engagement.

So if you've commenced early and established effectively and the patient is tolerating and trusts you, trusts your judgement and your decision and is happy with the choice, then that's a big determinant of success. (HCP04)

Some PwMS said that they were not satisfied with their current relationship with their neurologist, with some describing disappointment as a result of poor rapport at the time of diagnosis.

There's a lot sort of lacking in the depth of the relationship… given that this is a life-long thing, and it just always stays at that very superficial level. (PwMS01) They don't realise that this is now my whole world and to them, I'm just like a folder and they just open it, have a quick check, then close it. So, I felt very invalidated. (PwMS03)

Themes unique to PwMS

Decision-making

PwMS discussed that they would have liked greater guidance when it came to selecting a DMT and felt overwhelmed with the responsibility.

You're often just handed all this information and you've just received this huge life-changing diagnosis and it's like ‘oh, you choose’, and that's quite overwhelming. (PwMS01)

Two PwMS also expressed the belief that they initially made the wrong DMT choice, and that this could have potentially been avoided if they had received more guidance from their neurologist.

I think I probably could have had eight months of my life back with much better quality, if I had just gone straight on Copaxone and if that had been adequately explained. (PwMS02)

He wasn't pushing it, he said it was really up to me and at the time, I really didn't want to do injections so I chose not to …and in retrospect it would have been good to go on them earlier. (PwMS11)

One PwMS outlined a positive decision-making experience with his neurologist, where he felt that he had received sufficient information and guidance.

They were very good at talking about what treatment options there were, and what was better about each one and which would be the most preferable for me at the time. (PwMS13)

Roles and expectations

PwMS reported a range of beliefs about the roles and expectations of their HCPs. Nine PwMS listed their neurologist as one of the most important members of their treatment team.

He has the ‘big guns’, because with the MS, he's the one who gives me the medication. (PwMS05)

Additionally, one person with primary progressive MS felt as though their neurologist could not offer them much in terms of management.

There's not much that he can do for me. We're just going to follow-up every 12 months. (PwMS07)

Another PwMS explained that they had to change their expectations regarding their neurologist.

Once I noticed that my expectations were not being met, and that my expectations were probably very high and were probably never going to be met …as soon as I've dropped all of that I've been a lot happier. (PwMS01)

Some PwMS were uncertain as to what GPs could offer in terms of MS support and management.

I don't see what GPs can really do, it's a bit beyond them in that it's sort of specialised. (PwMS01)

However, GPs often played a more central role for PwMS in rural areas.

The GP can't initiate management when I've got an acute attack, I've got to see my neurologist who then has to arrange it, but my GP has been really good at triaging it so that I can actually have it done locally, because we're rural. (PwMS08)

Self-directed management

Multiple PwMS said that much of their disease and symptom management is instigated and directed by them. Some PwMS did not mind directing their own management and were happy to share the responsibility with their HCPs.

He said this is to the best of his knowledge what is available and if I felt that I was interested in anything else that I could research and I could discuss it with him if I wanted to. (PwMS10)

However, some PwMS were more averse to self-directed management.

He didn't give me any information, I had to go and find it myself. (PwMS14)

Support

Many PwMS reported inadequate emotional support from their HCPs at the time of diagnosis.

No one said to me, ‘I'm really sorry, this is what you've got’ …it's a very funny, lonely moment. (PwMS03)

The value of introducing access to support services early, including those provided by MS Australia and MS Limited, was discussed in numerous interviews.

I would have liked him to have referred me to the MS Society in the most strongest terms and say that they will help you with your immunotherapy, and don't attempt this without speaking to them. (PwMS02)

One participant expressed concern at a lack of government support towards MS.

I was knocked back by the NDIS and now I have to apply again …there is not enough government force and not enough support government wise. You are pretty much left on your own to struggle and it's on a daily basis. That's what they don't realise. You go home and live with it every day. (PwMS03)

Themes unique to HCPs

Medical management

Optimal medical management of MS was discussed across all HCP interviews. HCPs discussed their approaches towards diagnosis, treatment, monitoring and ongoing care. When discussing diagnosis, many HCPs explained that they do not find classifying MS into specific phenotypes useful when communicating with PwMS, and prefer describing MS as active or nonactive.[12]

I think it is far more important now to call a patient active or non-active, and that's the Lublin criteria which I think is much more helpful than the CIS, relapsing-remitting, secondary progressive, primary progressive classification. (HCP01)

Some HCPs said they only consider these classical MS phenotypes as a requirement when prescribing medication from the Australian Pharmaceutical Benefits Scheme.

Additionally, HCPs highlighted the need for a personalized approach in MS that balances the factors and preferences of each individual, with the best available evidence, which is based on group outcomes.

There's no one size fits all, you really need to take a few things into account. (HCP02)

There are lots of options and they've all got a proven efficacy profile so they clearly all work for some people but you can't guarantee that they are all going to work for everyone so there is no absolute means of determining which is going to be the best tolerated treatment …it might depend on whether they are in the childbearing years and actively thinking about having a family in the near future or maybe you can already see that they're medication adverse and so you might move away from frequently administered treatments. (HCP04)

Multidisciplinary approach

All HCPs described the importance of a multidisciplinary approach for MS healthcare. Some neurologists highlighted that neurology is becoming increasingly specialized.

Medicine is becoming more and more complicated, all of us only know a little slice of it, but we know that slice really well, and we're incredibly interested in optimising the outcomes for that slice. (HCP03)

Neurologists were described as playing a central and unique role within the multidisciplinary team, typically with a greater focus on the treatment and prevention of relapses (due to their ability to prescribe DMTs), while nurses and other allied-health professionals were often more focused on everyday functioning and quality of life. It was also stated that as the severity of MS increases, the engagement of a comprehensive multidisciplinary team becomes more important.

The people with advanced MS are better managed by a multidisciplinary team, because their management is dominated by their physical demands …They should, however, still have some contact with a neurologist, to cope with neurology-specific things. (HCP02)

Multiple neurologists also explained the usefulness of having an MS nurse to assist in the management of their patients.

Having a nurse there is essential. (HCP01)

Barriers and access

Many barriers and issues in access to healthcare were identified by HCPs. One commonly identified barrier for neurologists was time constraints and availability of appointments, particularly in the public system.

Time constraints …twenty minutes is often not ideal and in private practice people might be able to offer more than what we can in the public sector, and again the ability to see people quickly. (HCP07)

Reduced access to MS specialists (both nurses and neurologists) in rural areas was identified as a barrier to care.

For some patients, access to neurologists is very difficult …Our average waiting time is six months, so I'm trying to get these patients in early if they get referred to me, but others might wait six months. (HCP01)

A lack of funding was discussed by several HCPs.

I don't think the health system in Australia recognises and funds that clinical nursing consultant role the way it should, particularly in chronic disease …MS is a great example of a chronic disease where the input of a nurse can be really critical. (HCP04)

The government is not funding enough specialised clinics. (HCP01)

Hope and reassurance

Hope and reassurance was identified as a theme, often discussed in the context of communication. Many HCPs said that they focus on delivering hope to their patients, often through highlighting advances in MS therapies, and how a diagnosis of MS today carries a much more positive prognosis than it did in the past.

I point out in the last five years we've had more advances than in the last twenty. So, I stress the positive aspect, and I also stress that science has the explanation. I point out that the majority of new lesions do not produce any symptoms. (HCP02)

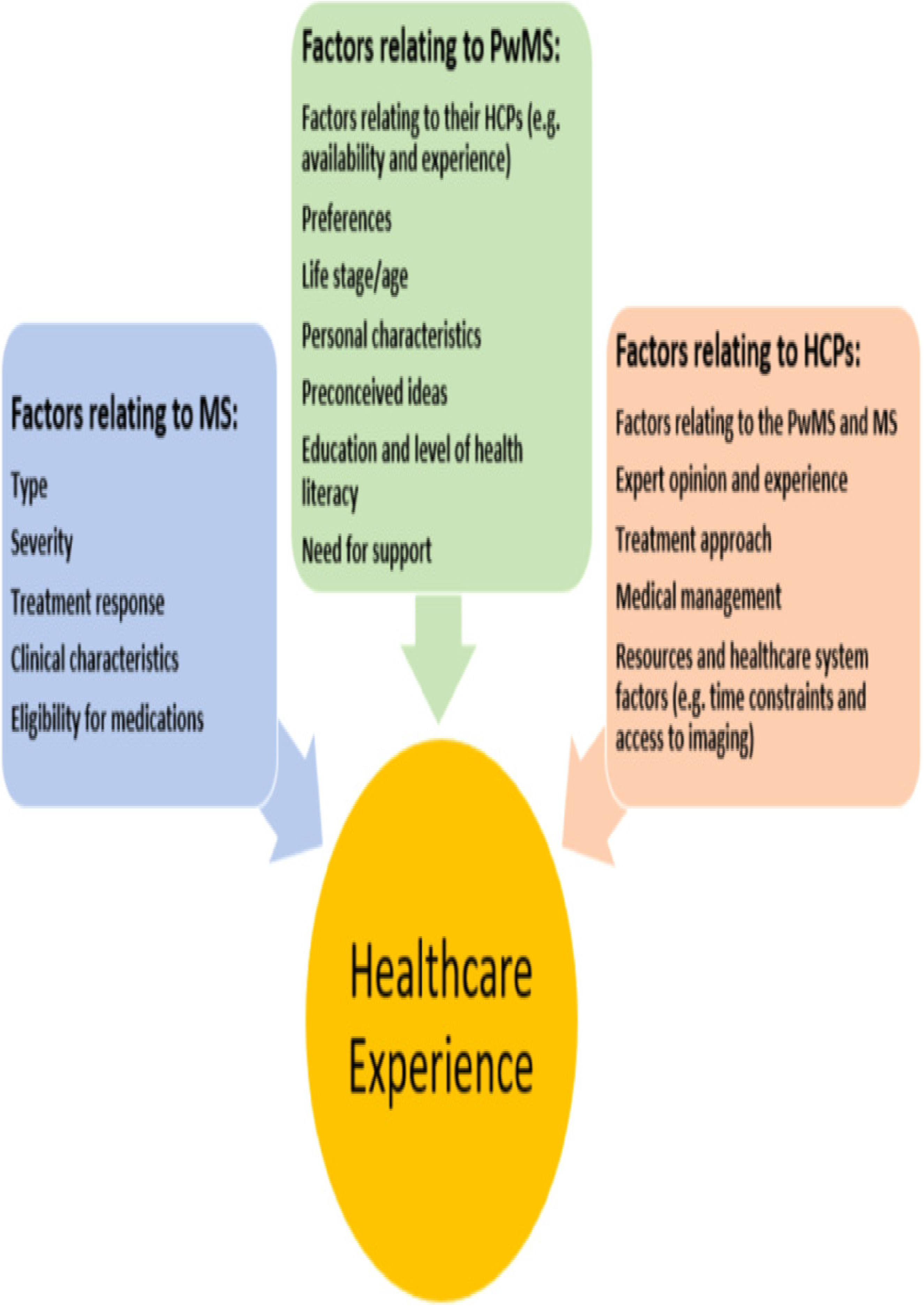
I think its positivity and a plan are the two most important things. I think being realistic is important too. But I think in this day and age reality and optimism go together because we've got options. You can be realistic and optimistic. (HCP06)

DISCUSSION

In this study, we found similarities and differences in the experiences of healthcare for PwMS and their HCPs. Both groups valued clear communication, recognized the uncertainties associated with MS diagnosis, treatment and progression and highlighted the importance of developing rapport in this dyadic relationship. These common themes are interrelated, with both groups recognizing that effective communication is integral in developing rapport, and that uncertainty can present as a barrier in this process. However, the purpose of developing rapport was multifaceted and not necessarily consistent between the two groups. For example, some PwMS wanted to be supported through a sense of connection with their HCPs. This was also valued by some HCPs; however, HCPs also recognized the importance of relationship and rapport in developing therapeutic alliance, trust and treatment adherence. A recent literature review supports this rationale held by HCPs, that effective communication can enhance the healthcare experience for PwMS, improve treatment adherence and lead to better patient outcomes.[18]

In this study, communication was the salient theme across all interviews with both PwMS and HCPs and is clearly a strong determinant of the healthcare experience. Many of the issues identified by PwMS were associated with a lack of open and empathetic communication with their HCPs. Overall, PwMS wanted support and assistance with their decision-making from their HCPs. PwMS often undergo substantial self-directed efforts to receive enough information to meet their needs.[9] In this study, the level of need for self-directed management was variable across PwMS and was often linked to their understanding of the roles and their expectations of the HCPs. To overcome this, some PwMS said they changed their expectations and sought support elsewhere, whilst others said that they felt disappointed when their HCPs did not meet their expectations and needs.

Modern management of MS presents many challenges for HCPs and demands consideration of many factors, as indicated in Figure 1. Treating neurologists need to consider uncertain drug efficacy and disease trajectory,[10] as well as potential side effects and financial impact,[11] and this is often in the context of time constraints and limited resources. This study highlighted that HCPs' perspectives and experiences of healthcare were guided by factors that were often not transparent to PwMS. HCPs aimed to provide hope and reassurance whilst focusing on delivering healthcare that is both evidence-based and individualized, to achieve optimal health outcomes. Neurologists also considered factors associated with a complex health system (e.g., barriers and access) whilst often leading a multidisciplinary team of HCPs. The lack of transparency to PwMS of the multiple factors considered by HCPs may be contributing to the experiences of PwMS of poor communication, confusion around the roles and expectations of HCPs, experiences of a superficial relationship with their HCPs and low support with decision-making.



Enlarge this image.

Discrepancies between PwMS and HCPs in perspectives and expectations of care have been documented previously.[6,12] The need for improved communication is consistent with the existing literature,[13] as well as the need for adequate empathy, support and person-centred care.[19] Therefore, clear communication of factors that impact the healthcare experience in MS, as shown in Figure 1, may provide a more positive experience for both PwMS and HCPs and contribute to optimal health outcomes. Figure 1 outlines that the healthcare experience is guided by multiple factors that relate to the MS presentation, the PwMS and the HCP. Whilst both groups recognize factors associated with the PwMS (preferences, age), MS presentation (type, severity, symptoms) and the HCP (preferences, treatment approach, experience), the HCP is also considering additional factors that can influence and complicate management (optimal medical management, barriers, resources) and these may not be clearly communicated to the PwMS. This may explain why some PwMS feel as though their concerns have not been received by their HCPs when they are presented with management options that do not align with their preferences. It is known that alignment of appropriate management with personal preferences and goals of the PwMS can present as a challenge for neurologists.[11] It can be difficult for neurologists to elicit PwMS' preferences and goals amidst the stress surrounding diagnosis.[20] Some studies have shown that patient decision aids can help to share the decision-making process and ensure that PwMS' preferences are met during DMT selection.[20,21]

When communicating with PwMS, HCPs reported that they focus on addressing misinformation and then temporally staging their discussion of diagnosis and treatment across multiple consultations to prevent overwhelming the PwMS with too much information at an emotionally distressing time. However, this staged approach to communication was at times interpreted by PwMS as the HCP not providing adequate assistance with decision-making and a lack of empathy that impacted rapport development. It may be useful for HCPs to comprehensively explain the rationale for their staged-communication approach to provide reassurance and support with decision-making to PwMS, which may build trust and therapeutic alliance.

Strengths and limitations

One major strength of the study was the semi-structured interview format, allowing PwMS to openly share their diverse perspectives and experiences of healthcare. Participants were from various regions across Australia, providing greater generalizability. However, not all regions were included, and differences between urban and rural areas could be examined further. The study was limited by a small sample size and thus findings were not stratified according to demographic data. Additionally, the perceptions of PwMS who have minimal interaction with HCPs may not have been captured comprehensively in this study. It should be noted that healthcare experiences of PwMS may vary greatly depending on the year in which they were diagnosed with MS, and the study population was fairly heterogeneous regarding time of diagnosis. In the past 10 years, there has been a significant increase in the number of DMTs available. Therefore, it is possible that PwMS who were diagnosed more recently were more hopeful and had a less negative experience than those diagnosed before this time.

CONCLUSION

Many factors are considered by PwMS and HCPs during their interactions. However, the multiple factors considered by HCPs that guide their decisions are not always transparent to PwMS and could be better communicated. During interactions with PwMS and HCPs, PwMS often focus on their unique personal factors and factors relating to their MS. In the same consultation, HCPs consider those factors as well as factors associated with optimal medical management, the health system and working in a multidisciplinary team, which is not always transparent or communicated clearly to the PwMS. Many of the issues with MS healthcare identified by PwMS, such as lack of support and assistance with decision-making, could be resolved by more open and empathetic communication with their HCPs. HCPs could also explain the rationale for taking a staged approach when communicating the diagnosis and management of MS, which may improve therapeutic alliance and provide reassurance for PwMS about this approach. To give PwMS realistic expectations of what their HCPs can provide, HCPs should clearly outline the role that they will play in MS management, as well as the roles that can be played by other allied-HCPs and MS support organizations. These interactions may improve healthcare experiences of both PwMS and HCPs, leading to better engagement with treatment and better overall health outcomes.

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CONFLICT OF INTERESTS

The authors declare that there are no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data will be made available from the corresponding author upon reasonable request.

DETAILS

Subject:	Transparency; Reassurance; Severe acute respiratory syndrome coronavirus 2; Communication; Health care; Health status; Disease management; Nurses; Central nervous system; Multiple sclerosis; Cure; Interviews; Inflammation; Young adults; Clinical outcomes; Medical personnel; Neurologists; Medical referrals; Decision making; Nervous system; Primary care; Strikes; Professionals; Family physicians; Qualitative research
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The CORE study—An adapted mental health experience codesign intervention to improve

psychosocial recovery for people with severe mental illness: A stepped wedge cluster randomized-controlled trial

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ABSTRACT (ENGLISH)

Background

Mental health policies outline the need for codesign of services and quality improvement in partnership with service users and staff (and sometimes carers), and yet, evidence of systematic implementation and the impacts on healthcare outcomes is limited.

Objective

The aim of this study was to test whether an adapted mental health experience codesign intervention to improve recovery-orientation of services led to greater psychosocial recovery outcomes for service users.

Design

A stepped wedge cluster randomized-controlled trial was conducted.

Setting and Participants

Four Mental Health Community Support Services providers, 287 people living with severe mental illnesses, 61 carers and 120 staff were recruited across Victoria, Australia.

Main Outcome Measures

The 24-item Revised Recovery Assessment Scale (RAS-R) measured individual psychosocial recovery.

Results

A total of 841 observations were completed with 287 service users. The intention-to-treat analysis found RAS-R scores to be similar between the intervention (mean = 84.7, SD = 15.6) and control (mean = 86.5, SD = 15.3) phases; the adjusted estimated difference in the mean RAS-R score was −1.70 (95% confidence interval: −3.81 to 0.40; *p* = .11).

Discussion

This first trial of an adapted mental health experience codesign intervention for psychosocial recovery outcomes found no difference between the intervention and control arms.

Conclusions

More attention to the conditions that are required for eight essential mechanisms of change to support codesign processes and implementation is needed.

Patient and Public Involvement

The State consumer (Victorian Mental Illness Awareness Council) and carer peak bodies (Tandem representing mental health carers) codeveloped the intervention. The adapted intervention was facilitated by coinvestigators with lived-experiences who were coauthors for the trial and process evaluation protocols, the engagement model and explanatory model of change for the trial.

FULL TEXT

INTRODUCTION

Internationally, mental healthcare policies are replete with references to embed coproduction and codesign with service users in the design, planning and delivery of programmes.[1–9] The 2017 United Nations Special Report identified coproduction as fundamental to mental health service participation to reach the highest attainment of physical and mental health.[10] This is coupled with consensus for recovery-oriented mental health services that consistently facilitate psychosocial recovery as a subjective, ongoing process that encompasses spiritual, social, psychological and cultural dimensions for individuals.[11–13] Engaging mental health service users is central to the enactment of recovery-oriented systems and to ensure that participation in service design, planning and delivery holds personal and social meaning for individuals. Despite a growing evidence base that supports an association between engagement leading to improved patient experience, clinical effectiveness and patient safety,[14] a more recent review of service user participation in mental healthcare planning and programmes to improve experience and service effectiveness found that exclusion continued to be the norm rather than the exception.[15] There is also cautiousness emerging about engagement as the next big blockbuster drug for healthcare and the driver for improved health outcomes, quality and safety and reduced healthcare costs.[16,17]

In the attempts to implement systematic approaches to engage people who access mental healthcare services and to ensure that the engagement methods do foster shared power and decision-making, interest has grown exponentially in participatory methods such as codesign and coproduction. In the last decade, a rapid evolution of studies labelled as codesign, coproduction, coinnovation and cocreation has occurred in healthcare quality improvement. This evolution has contributed to what has been called a Participatory Zeitgeist, where participation using codesign and coproduction has become the spirit of our contemporary times, but not without conceptual and definitional challenges and a need for robust evaluation.[18] For example, the extent to which engagement using codesign leads to recovery-oriented service delivery, individual empowerment or improved health outcomes in mental health services is yet to be determined.

One quality improvement, participatory method to engage service users, carers and staff in service design where experience is central is experience-based codesign (EBCD). EBCD aims to improve experiences of services by working in partnership with staff, service users and carers on areas for change.[19,20] EBCD has been implemented to improve service experiences and outcomes in head, neck, breast and lung cancer services, gynaecology and colorectal settings, stroke and rehabilitation, emergency, to end of life and intensive care units and to a much lesser extent in mental health.[21] While organisational improvements such as operational efficiencies, interpersonal dynamics of care, increased communication, team relationships, patients feeling listened to and reduced complaints have been documented,[22,23] no studies have examined the impact of codesigned improvements on systems or service levels or on individual health outcomes. No randomized-controlled trial (RCT) study designs have been used to date to test this.

To address this gap and to identify the benefits or otherwise of an adapted EBCD method for recovery-oriented mental health services and improved psychosocial recovery of service users, the CORE study tested the effectiveness of mental health experience codesign (MH ECO). A stepped wedged cluster randomized-controlled trial (SW-CRT) was conducted in nonclinical (psychosocial recovery-oriented) Mental Health Community Support Services (MHCSS) in Australia. CONSORT guidance for reporting SW-CRT was followed.[24] Our primary participants were people living with severe mental illness (SMI was defined as including psychosis, schizophrenia, bipolar disorder, major depression and other disorders such as personality and eating disorders), with carers who had a family member engaged in services and staff.[25] The secondary outcomes were improved quality of life for people living with SMI and carers, and changes to recovery attitudes from staff and the recovery-orientation of services. This paper reports on the trial outcomes for people with SMI only; carer and staff outcomes are reported separately.[26]

METHODSTrial design

A SW-CRT was conducted between 2013 and 2017 using an open cohort design (meaning both cross-sectional and longitudinal data were included).[27] Trial registration was completed with ANZCTR (No. 12614000457640) before recruitment commenced; the study protocol and a statistical analysis plan were published (2015; May 2017) before the final follow-up period of data collection was completed.[28] The intervention, MH ECO (explained below), was directed at the service level for improvements, so a cluster design was determined to be the most appropriate. Four large mental health organisations (two nongovernment providers and two community health centres) were partners in the trial and the intervention was delivered to nine teams across these four organisations in metropolitan, outer metropolitan and regional locations. Teams were randomly allocated (three at a time) to different start dates 9 months apart (see Table 1).

Table 1 Schematic of stepped wedge cluster randomized trial for the CORE study

	Follow-up time			
Arms	Wave 0	Wave 1	Wave 2	Wave 3
	Baseline	9 months	18 months	27 months
1	0	9 months	18 months	27 months
2	0	0	9 months	18 months
3	0	0	0	9 months

Note: 0 = control phase; 9, 18, 27 months = intervention phases (indicates the length of time since the start of the intervention).

Arm is the allocation of group of clusters/individuals. Three clusters were randomized to each arm.

PARTICIPANTSSettings

Nine teams delivering psychosocial recovery programmes as part of commissioned MHCSS were recruited across four large service providers in Victoria, Australia. Organisations had delivered services to approximately 14,000 people in any given year at the time of recruitment in 2013. Support included daily living skills development, recovery planning and facilitation of social and community participation to people living with SMI in community settings. At the time of trial commencement, an outreach model of individual support was implemented shifting away from on-site, group models of service. The goal of MHCSS programmes is to support psychosocial recovery and deliver recovery-oriented mental healthcare.

The most available data on MHCSS service recipients showed people lived with between one and four complex factors, which included social isolation, activities of daily living, issues related to unresolved trauma, treatment-resistant symptoms, extensive time to maintain levels of functionality with little improvement in functionality over time, chronic physical health problems, difficulty maintaining medications, problems with intellectual disability/cognition, alcohol use and drug use. MHCSS staff were not responsible for clinical assessments, though they engaged with clinical care providers for updates and information sharing.

Service recipients

Eligibility for people living with SMI to be recruited to the study followed service eligibility criteria set by the government funder. MHCSS service users were characterized as having enduring psychosocial disabilities and long-term impairments from mental illnesses that range from diagnostic names such as bipolar disorder, schizophrenia, psychosis, chronic depression and anxiety to obsessive compulsive disorders and other personality disorders. Inclusion criteria to services were as follows: aged between 16 and 75 years and a psychiatric condition (bipolar disorder, schizophrenia, psychosis, major depression, severe anxiety, personality disorder, posttraumatic stress) that results in persistent impairment and substantial reduction in psychosocial functioning for communication, social interaction, learning, self-care and self-management affecting social and economic participation. Carers were eligible for recruitment to the study if they were a family member, friend or in a caring relationship with the person living with SMI; carers did not need to be matched. People with SMI and carers were not recruited if they could not understand spoken English and were unable to complete the two-stage consent process (outlined in the published protocol) or were not in receipt of services from a participating team. The rationale for exclusion of people who could not understand spoken English was due to the primary and secondary outcome measures not being appropriately translated for the cultural communities in question, interpreter availability and the challenges presented by multiple languages with an interpreter within the face-to-face codesign sessions.

Intervention

The adapted MH ECO intervention[18,28] is described in the published trial and nested process evaluation protocols.[28] The MH ECO model was codeveloped by the state consumer (Victorian Mental Illness Awareness Council) and state carer (Tandem representing Victorian Mental Health Carers) peak agencies in Victoria, Australia, in partnership with the Victorian State Government. The model was piloted and evaluated in Psychiatric Disability and Rehabilitation Support Services (now called MHCSS) before this trial and a short explanatory video was produced. Two lived-experience coinvestigators (a consumer and a carer) participated in intervention adaptations, and delivered training for codesign preparation and all codesign meetings. Figure 1 illustrates the adapted MH ECO intervention for the trial in two stages: information gathering (Stage 1) and codesign (Stage 2).

Figure 1. Adapted mental health experience codesign intervention

To implement Stage 1, positive and negative touch points were identified per cluster (e.g., per individual service teams) over 6 weeks. University-based telephone interviewers received training from each lived-experience coinvestigator about working with people living with SMI and carers. Service users and carers were asked to share stories about: ‘a time when something went well’; ‘a time when something could have gone better’ and ‘the things that stood out about those experiences’; and ‘how ideal care might look’ (this included prompts about involvement in decision-making and being informed about services). The above three open-ended interview questions were used instead of the longer survey version originally planned as the team sought to maintain the narrative and qualitative focus underpinning EBCD. The film component usually employed within EBCD to share experiences with staff was not used as the service partners indicated that this was not a preferred option for people from their previous experience.

Responses to telephone interview questions were analysed by group using the Leximancer software analytics programme. Leximancer organizes prominent concepts discussed in text within themes into a thematic map.[29] Thematic maps were reviewed to identify the most commonly shared negative touch points per group and textual responses examined to understand nuanced meanings. These touch points were then explored in focus groups with service users, carers and staff (held separately) as neutral statements to develop a deeper understanding of people's experiences. Emotion mapping was completed using brighter colour post-it notes to represent strong feelings and pale colours to represent less strong/mild feelings (the written feedback that participants provided could be either positively or negatively framed; the focus was on emotional connection to the touch point).

Emotion mapping and how this was used to identify shared patterns across groups is presented in Supporting Information Appendix 1. Once the shared touch points for improvement areas were determined in a cluster, a summary of the service stories was provided to the Collaboration Group (detailed in Figure 2) as a short report for development of the codesign objective.

Figure 2. Illustration of emotion mapping and synthesis of service stories for presentation to collaboration groups to formulate codesign objectives

All participants received training before codesign meetings (6 h over 2 half days). Training included activities to explore previous experiences of working in groups and with staff and ways to determine power dynamics; it encouraged people to be open, to listen together, to foster comfort in meeting with others, build confidence and set the parameters for respectful ways of working. The short video from the pilot was played for participants to share the MH ECO approach and the experiences that other participants had shared. Staff joined training after the service user and carers completed their sessions. This was to ensure adequate time to explore any negative experiences of previous group work and to address concerns around power dynamics in working with staff.

Codesign groups worked with the codesign improvement objectives set out by the collaboration group over three facilitated meetings (2 h each). They codesigned (a) a process map in relation to the codesign objective. The process map led to the identification of sticking points related to the area for improvement and this supported narrowing the focus of what might need to be codesigned for changes to be implemented. (b) They brainstormed improvements to implement. The research team provided a brief evidence synthesis of any initiatives related to a codesign objective to inform the codesign of improvements. (c) Solutions were formulated for implementation and these were presented in an action plan. The final part of Stage 2 involved the collaboration group reviewing the action plan and cocreating an implementation plan for the service. A research team member completed implementation check-ins with staff to collect data on the barriers and enablers in services for implementation of the codesigned improvements. Clusters that were in the control phase received a questionnaire to check on staff numbers to ensure balance across groups and reduce the possibility of contamination. The implementation check-ins will be reported separately in the nested process evaluation paper for the trial. All participants were invited to complete an open-ended feedback form for training and codesign sessions. A summary of the feedback from all participant groups can be found in Supporting Information Appendix 2.

Outcomes

Trained telephone interviewers collected data at the cluster and individual levels at baseline (October 2014–July 2015) before randomisation and subsequently at 9 (January–February 2016), 18 (October–November 2016) and 27 (June–July 2017) months postrandomisation. The trial was approved by the University research ethics committee, registered with ANZCTR (No. 12614000457640) and conducted in accordance with the published trial protocol with only changes to the telephone interview.

Participants were asked to complete a structured questionnaire that included the 24-item Revised Recovery Assessment Scale (RAS-R) as the primary outcome measure.[30] The measure for psychosocial recovery for service users was identified in a small pilot completed with 40 people who were recruited from the partner agency VMIAC. Service users completed combinations of either the 24-item RAS-R (N = 20), the 26-item Maryland Assessment of Recovery in People With Serious Mental Illness (N = 17) or the RAS-R and person in recovery version of the 36-item Recovery Self-Assessment Scale (N = 13). Measures were completed in written form and/or over the telephone by different groups for acceptability and feasibility. There was overwhelming positive feedback for the RAS-R.

The RAS-R uses a 5-point Likert rating scale for each item, from 1 = ‘Strongly Disagree’ to 5 = ‘Strongly Agree’; scores range from 24 to 120, and higher scores indicate greater recovery. There are five RAS-R subdomains: (i) personal confidence and hope (nine items; range: 9–45), (ii) willingness to ask for help (three items; range: 3–15), (iii) goal and success orientation (five items; range: 5–25), (iv) reliance on others (four items; range: 4–20) and (v) no domination by symptoms (three items; range: 3–15). Higher ratings within domains indicate greater recovery.[30] The secondary outcome quality of life was measured using the shortened eight-item version of the World Health Organisation Quality of Life Scale (EUROHIS-QoL eight-item index).[31] EUROHIS-QOL measures personal satisfaction on eight different aspects of life: overall quality of life, general health, energy, daily life activities, self-esteem, relationships, finances and home. Each item is scored on a five-point Likert scale ranging from 1 = ‘Not at all’ to 5 = ‘Completely’; score range is between 8 and 40, and higher scores indicate better quality of life. EUROHIS-

QOL was selected because recovery-oriented mental health services ideally should improve general health, daily life activities, self-esteem, relationships, financial and home life.

Participants were asked additional questions about previous hospitalisations, any previous involvement in service improvement activities with service providers, physical health conditions in the last 12 months, physical activities and perceived challenges that individuals felt they faced in the next 12 months. A subsample of participants consented to qualitative data collection that included sharing a timeline of times of being well or unwell, a week-in-the-life diary and a social network map. In addition to evaluation feedback at the end of every collaboration or codesign meeting, a subsample of participants (service users, carers and staff) was interviewed for the nested process evaluation. These interviews were conducted face-to-face and/or by phone; the analysis of these data will be presented separately in the nested process evaluation for the trial.

Sample size

Sample size was powered for at least 80% to detect a standardized effect size of 0.35 for psychosocial recovery RAS-R (primary outcome) between the intervention and control phases for a fixed cluster size of 30 people with SMI from nine clusters at each of the four follow-up times (see Table 2 in the full published study protocol).[28] Power was determined in a simulation study that assumed an intracluster correlation of 0.1, a 5% alpha level for a two-sided test, different probabilities that each individual would remain in the cluster at each follow-up time point (0, 20% and 60%) and within-individual correlations of 0.2 and 0.7 for service users that contributed observations to two or more consecutive follow-up time points (reported in the published study protocol). Interim analyses and stopping rules were not required.

Table 2 Trial participant flow

[IMAGE OMITTED. SEE PDF.]

Note: At baseline, 1334 invitation letters were delivered to the service organisations for each of the nine clusters. Thirty-seven were returned to the sender. It was not possible to track whether services sent all the letters or whether all letters reached intended recipients due to ethics requirements.

Randomisation

A computer-generated random allocation sequence stratified by the MHCSS organisation was generated by the statistician blinded to cluster identity and not involved in assessment or intervention delivery. The trial coordinator received the order for delivering the intervention. Study participants, facilitators, telephone researchers and staff assisting at intervention meetings were blinded to the allocation sequence during recruitment and baseline data collection. All participants provided audio-recorded consent. Once assigned to the intervention, participants could no longer be blinded to their status due to the face-to-face components of the intervention. Participants in the control phases at Wave 1 were blinded to whether they would receive the intervention during the second or third wave. Clusters allocated to the Wave 1 intervention phase were notified after baseline data were completed. Participants in Waves 2 and 3 were informed of intervention commencement at the start of their allocated waves. Research interviewers collecting outcome data remained blinded to the intervention status of the participants.

Statistical methods

Descriptive statistics were used to summarize the characteristics of people living with SMI on first entry to the open cohort (either at baseline, 9, 18 or 27 months) by arm and for the entire sample. A linear mixed-effects model compared the intervention and control phases for each continuous outcome. Each outcome measured at each follow-up time was arranged into a single variable, and a second variable was created that identified the time point at which the data were collected. The model included indicator variables for the study arm (0 = control phase, 1 = intervention phase) and the follow-up time (1 = baseline, 2 = 9 months, 3 = 18 months, 4 = 27 months) as fixed effects. The intercept was constrained to be equal during the control phases because we expected no intervention effect. Cluster and individuals were treated as random effects to account for the correlation of outcomes of individuals who belonged to the same cluster (within-cluster correlation) and repeated measures on the same individual over time (within-individual correlation).[32] Estimates of the intervention effect were reported as a difference in the mean outcome between the intervention and control phases, with respective 95% confidence intervals (CIs) and *p* values. For these analyses, the underlying assumption was that treatment effect was constant across the different individuals (both cross-sectional and longitudinally) and at the different time points, regardless of length and level of exposure to the intervention phase. In a prespecified secondary analysis, the estimates of the intervention effect were adjusted for education level, employment status and quality of life measured at baseline.[31] Analyses were conducted using Stata statistical software 13.1.[33]

An intention-to-treat approach analysed all study participants according to the arm that the cluster was assigned to at each time point.[34] People who refused or were unable to complete follow-up questionnaires were asked to complete the primary outcome measure to minimize missing outcome data. Up to five attempts were made over the 2-month data collection period for outcome measures. This included contacting trusted proxies who were provided by individuals at enrolment. The reasons for why individuals were lost to follow-up were recorded. Under the mixed-effects models used for the analysis, data were implicitly assumed to be missing at random.[34]

In a planned secondary analysis, direct effects of the length of time for which the participants were in the intervention phase (namely, 0, 9, 18 and 27 months) at each follow-up time were estimated using a linear mixed-effects model, where the length of time exposed to the intervention was treated as a fixed effect and adjusted for follow-up time. Estimates were reported as the mean outcome difference when exposed to the intervention for 9, 18 or 27 months compared to ‘0 months’, the time when individuals were in the control phase and not exposed to the intervention. The log-likelihood ratio test was used to assess whether to treat the length of time in the intervention phase as a continuous rather than a categorical variable in the regression model. Treating exposure time to the intervention as continuous assumed that the increase in the intervention effect was linear with the length of time in the intervention phase. In sensitivity analyses, long-term intervention exposure was investigated using the same methods as above, but restricted to participants recruited at baseline only.

RESULTS

Table 2 shows the participant flow of people with SMI in each arm at each follow-up time. In total, 287 people with SMI (91 in Arm 1, 106 in Arm 2 and 90 in Arm 3) enroled in the study and contributed to at least one follow-up time point. Of these, 235 (81.9%) were recruited at baseline, 37 (12.9%) at 9 months, 13 (4.5%) at 18 months and 2 (0.7%) at 27 months. Of the 52 recruited at subsequent time points, 31 people with SMI (59.6%) were from clusters that had not yet received the intervention.

A total of 841 observations were completed with 287 participants (an average of 2.9 observations for each participant) recruited from within the nine clusters (average 93.4 observations per cluster, with a range between 52 and 123). More than half of the participants who enroled at baseline contributed observations to four-time points (130/235, 55%), 14% (34/235) to three-time points, 16% (37/235) to two-time points and the remaining 15% (34/235) to baseline only (see Supporting Information Appendix 3).

The mean of the RAS-R scores was similar between the intervention (mean = 84.7, SD= 15.6) and control (mean = 86.5, SD= 15.3) phases. This was observed in the RAS-R subdomains and the EUROHIS-QOL index (see Supporting Information Appendix 4). Estimated within-cluster and within-individual correlations for the total RAS-R score were 0.02 and 0.73, respectively. Supporting Information Appendix 5 provides a table that shows the within-cluster and within-individual correlations for the primary and secondary outcomes, estimated using the linear mixed-effects model in the primary analyses.

Of the 37 new people with SMI enroled at 9 months, 22 (59%) contributed outcome data to all three subsequent time points, 6 (16%) to two-time points and the remaining 9 (24%) completed only one survey. Nine (69%) of the 13 individuals recruited at 18 months contributed data at 27 months. Overall, 83% (238/287) of the people with SMI contributed at least two observations. Twenty-four percent (70/287) were lost to follow-up: 27% (25/91) in Arm 1; 27% (29/106) in Arm 2; and 18% (16/90) in Arm 3. Acute illness and no further interest in taking part were the two most common reasons cited for withdrawal.

Table 3 summarizes the demographic, clinical characteristics and carer relationships at baseline for people living with SMI. Overall, the characteristics of the individuals enroled at the baseline were balanced between the three study arms. The characteristics of the 52 individuals who enroled in the trial after baseline were also similar across the three arms (results not shown), although they tended to be slightly younger on average than the people with lived-experiences of SMI recruited at baseline and they had a shorter duration of psychiatric illness. This may reflect that individuals recruited at baseline before randomisation included people who had been with the service for a longer period. They might have been older compared to those who were enroled at subsequent time points or for those who may have been new to the services.

Table 3 Characteristics of people with SMI enroled at baseline and postbaseline (9, 18 and 27 months) (*N* = 287)

		People with SMI enroled at baseline (*N* = 235)			
	People with SMI enroled postbaseline (*N* = 52)		**Total** (*n* = 235), mean (SD)	**Arm 1** (*n* = 74), mean (SD)	**Arm 2** (*n* = 88), mean (SD)
Arm 3, (*n* = 73) mean (SD)	**Total** (*n* = 52), mean (SD)	Age (years)	50.5 (12.7)	48.1 (14.0)	52.0 (12.2)
50.9 (11.7)	44.7 (12.5)	RAS-R score (range: 24–120)	87.1 (15.3)	84.6 (17.0)	89.7 (15.3)
86.5 (13.1)	–	EUROHIS-8 QoL index (range: 8–40)	25.6 (6.6)	24.0 (6.7)	27.3 (6.5)
25.1 (6.3)	–	Duration of longest-standing mental health condition (years)a	18.1 (12.7)	17.6 (14.0)	17.0 (11.7)
19.9 (12.6)	14.6 (13.1)	Age at first hospital admission (years)b	32.3 (13.1)	34.6 (14.1)	33.5 (13.1)
28.7 (11.5)	31.9 (12.6)	Duration of the caring relationship (years)c	11.6 (13.9)	9.9 (12.9)	9.8 (12.3)
14.9 (15.9)	10.9 (15.2)		***n* (%)**	***n* (%)**	***n* (%)**
***n* (%)**	***n* (%)**	Femaled	155 (67)	52 (71)	61 (69)
42 (58)	20 (58)	Born in Australia	199 (85)	67 (91)	73 (83)

59 (81)	41 (80)	English is the first language	222 (95)	72 (97)	83 (95)
67 (92)	48 (96)	Education (highest level)			
		Left school before completing Year 10	43 (18)	13 (18)	18 (20)
12 (16)	8 (16)	Completed Year 10 or equivalent	62 (16)	21 (28)	26 (30)
15 (21)	15 (29)	Completed Year 12 or equivalent	28 (12)	13 (18)	9 (10)
6 (8)	9 (18)	Certificate or diploma	67 (29)	16 (22)	24 (27)
27 (37)	14 (27)	Bachelor degree or higher	35 (15)	11 (15)	11 (13)
13 (18)	5 (10)	Currently workinge	48 (20)	17 (23)	19 (22)
12 (16)	10 (19)	Pension/benefit is the main source incomee	213 (91)	66 (89)	77 (88)
70 (96)	46 (88)	Self-reported physical health is a problemf	169 (76)	50 (77)	62 (72)
57 (80)	43 (83)	Number of self-reported mental health conditionsg			
None reported	12 (5)	3 (4)	7 (8)	2 (3)	1 (2)
1	62 (27)	18 (24)	21 (24)	23 (32)	16 (34)
2	71 (30)	21 (28)	28 (32)	22 (31)	15 (32)
3 or more	88 (38)	32 (43)	32 (36)	24 (34)	15 (32)
Self-reported mental health conditionsg,h					
Major depression	121 (52)	39 (53)	47 (53)	35 (49)	25 (53)

Anxiety disorders (excluding posttraumatic stress disorder)	97 (42)	35 (47)	36 (41)	26 (37)	19 (40)
Schizophrenia and other psychotic disorders	85 (36)	27 (36)	28 (32)	30 (42)	12 (26)
Bipolar disorder	70 (30)	20 (27)	25 (28)	25 (35)	11 (23)
Personality disorders	39 (17)	19 (26)	12 (14)	8 (11)	9 (19)
Posttraumatic stress disorder	29 (12)	13 (18)	10 (11)	6 (8)	10 (21)
Substance use disorder	10 (4)	4 (5)	4 (5)	2 (3)	2 (14)
Eating disorders	6 (3)	3 (4)	3 (3)	0 (0)	1 (2)
Admitted to hospital for mental health	183 (78)	64 (86)	63 (72)	56 (77)	33 (63)
Has a carer	124 (53)	40 (54)	40 (45)	44 (60)	25 (48)
Currently living with carerc	63 (51)	16 (40)	25 (63)	22 (50)	11 (44)
Relationship to carerc					
Partner	24 (19)	7 (18)	7 (18)	10 (23)	6 (24)
Family member	71 (57)	26 (65)	23 (57)	22 (50)	14 (56)
Friend	13 (10)	3 (8)	4 (10)	6 (14)	2 (8)
Other	16 (13)	4 (10)	6 (15)	6 (14)	3 (12)

Note: Discrepancies in totals due to missing responses.

Abbreviation: RAS-R, 24-item Revised Recovery Assessment Scale; SD, standard deviation; SMI, severe mental illness.

a

Duration of any longest-standing mental health condition self-reported by participants. *N* = 206 at baseline (66 in Arm 1, 75 in Arm 2 and 65 in Arm 3) and 42 postbaseline participants.

b

Based on responses to the question, ‘How old were you the first time you were admitted to hospital to get help for your mental health?’ 216 service users (75%) who reported a hospital admission related to mental health were asked this question.

c

n = 149 (52%) participants who reported having a carer at the time of entry into the study.

d

One respondent in Arm 1 and one in Arm 3 selected ‘Rather not say’. They have been coded as missing for the analysis.

e

Based on responses (yes/no) to the questions, ‘Do you work?’ and ‘Is a pension or benefit your main source of income?’ at entry into the study.

f

Based on responses to the question, ‘In the past 12 months, have you had any problems with your physical health?’

g

Based on participant responses to the question, ‘Have you ever been given a name for your condition? If yes, what is the name?’. All mental health conditions reported were included in the total.

h

Self-reported health conditions are not mutually exclusive. Eight self-reported mental health conditions were selected and grouped into the ICD-10 Classification for Mental and Behavioural Disorders Diagnostic Criteria for Research established by the World Health Organisation 1993.

Table 4 presents the negative touch points identified to inform service improvements and codesigned objectives across the nine clusters.

Table 4 Touch point category, themes for improvement and the implemented codesigned solutions from a mental health experience codesign intervention

Touch point broad service area of connection	All themes related to touch points for people living with severe mental illness and carers on what could be better	Codesigned solutions that were implemented within the funded period of the triala
Continuity of care: Holistic care	Facilitate connection between services Provide colocated medical and nonmedical services Integrated support for people with multiple and complex needs Consistency of support workers, staff rescheduling of appointments Service user-driven care Knowing a story and what is happening in someone's care—relating to someone as a person	Designed and implemented a secondary worker process for when staff were on leave

Social connection (groups)	Providing a variety of groups, flexible drop-in options to connect with other people Localized group with common needs, geographically local groups Worker presence in social activities Shared life experiences with group members not just membership based on illness	Newsletter options developed to share information Designed and implemented calendar of events to distribute via email and or web Provided WiFi access to service users to increase internet use for information finding Developed a Facebook page for organisation and service user contact
Communication	Better communication between outreach visits Communication about service changes and models of case management and progress made Follow up with someone when they try to connect to a service	Technical change to the voicemail system and answer machine messages updated Outreach policies updated at service Websites reviewed and updated in some services
Service engagement	Opportunity to give feedback and be updated on feedback Feeling heard Feeling needs are heard by the organisation	Designed and implemented a feedback system in conjunction with the distribution of calendar of events Implemented feedback box near reception
Physical infrastructure	Feeling welcome at service	Redesigned receptionist space for more of a welcoming experience on arrival and waiting
Public and private information	Public: Information about what groups exist at a service Private: Access to private information and treatment records	More information provided on websites

Carers	Informing and involving carers with updates about services provided to a person they care for Communication with and involvement of carers in care planning and outcomes Support options to carers for when they are unwell themselves Communication about support groups for carers directly Time to process information when first engaging at a service	Implemented carer peer support workers within service delivery Provided information to staff on the role of carer workers Designed new brochure and website updated (involved carers in the design of these) Increased activities for carers and options for access to self-care programmes

a

Not all touch points for improvement were addressed within the codesign stage of the intervention due to trial limitations to focus on one area.

Table 5 shows the estimated intervention effect comparing the intervention and control phases (primary analysis) and the direct effects of the length of exposure (duration) to the intervention, adjusted for the time point the outcome was measured. The adjusted estimated difference in the mean RAS-R score between the intervention and control phases was −1.70 (95% CI: −3.81 to 0.40; *p* value = .11), with the CI excluding the minimum hypothesized difference of 5.4, given a standard deviation of 15.3 at baseline. There was no evidence to support time-specific intervention effects. The results did not change after adjustment for confounders or when analyses were repeated for only the 235 participants enroled at the baseline cohort only (results not shown). Similarly, there was no evidence to support improvements in the RAS-R subdomains of personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others, no domination by symptoms or in the EUROHIS-QOL index between the intervention and control phases, or time-specific intervention effects (Table 3). No significant harms or unintended effects were reported.

Table 5 Estimated intervention effect for the primary and secondary outcomes for people with SMI (*N* = 287,841 observations)

Abbreviations: CI, confidence interval; RAS-R, 24-item Revised Recovery Assessment Scale; SMI, severe mental illness.

a

Mean difference in outcome between the intervention and control phases (reference)

b

Mean difference in outcome between the length of time exposed to the intervention and being in the control phase (zero months is the reference).

CI, confidence interval

DISCUSSION

This is the first SW-CRT designed trial to investigate whether a MH ECO intervention to increase recovery-orientation of services would lead to increased psychosocial recovery outcomes and improved quality of life for people living with SMI. The primary outcome measure of psychosocial recovery was selected because the MH ECO pilot data had identified experiences of hope and empowerment and meaningful participation aligned with personal recovery definitions.[35] These findings are also consistent with published qualitative evaluations of EBCD improvement projects. In those studies, participant involvement in EBCD has been described positively and there has been an emphasis on sharing stories as a practice in meaning-making and participation in codesigned improvements as equal partners as generating hope.[21]

Many of the service improvements that resulted from the adapted MH ECO intervention centred on communication and information flow to and from services, the involvement of service users in programme design and delivery, and information about local activities and readiness to participate in groups. Service users also highlighted a desire to be able to meet people from similar life backgrounds, but not solely because they shared a diagnosis of a mental illness. Service users also described re-design needs for physical spaces in services, and feeling unwelcome because of unfriendly or distant voicemail messages at services. In relation to this, service users wanted to see an increased use of SMS to receive appointment reminders, make changes to their own appointments or to receive information about staff absences.

These improvement areas can be understood within four categories that were initially identified in the seminal head and neck cancer centre EBCD projects conducted in the United Kingdom.[22] The four categories were quick fixes—improvements that involved little or no change in everyday working practices (e.g., revising information, updating brochures); process redesigns—improvements where new in-service procedures for consent or access to services were developed; cross-service or interdisciplinary redesign—improvements involving process or structural redesign across different services to improve responses to an issue; and organisational change—improvements addressing organisational issues such as delayed receipt of results of a procedure or appointment wait times. Two further categories were added from this trial: Technological fixes—improvements to technological components of services such as websites, internet access, social media and app provision, phone and voicemails or SMS use, and physical infrastructure—improvements where there were changes to the physical environments of services.

Overall, the most prominent codesigned improvements implemented in the trial were related to quick fixes and process redesigns. New information and welcome packs were cocreated with service users, or information about social groups was gathered and presented on websites. A commonly reported barrier for uptake of the local information, though, was that service users tended to have limited use of emails and did not read the websites or typically use social media. The lessons here might be most relevant to future digital mental health transformation and the implementation of technology-based interventions where purposive methods for engaging people will be needed.

In one or two services, attempts were made for organisational change and physical infrastructure improvements. Organisational changes that were implemented led to a coproduced camp by and for service users in one service, and in another service, a carer peer worker was arranged as a response to specific carer engagement needs. The implementation check-ins conducted by the research team found that the carer peer worker role was not sustained, which does echo the published literature on recovery models, which suggests that the mere addition of peer workers within services and teams in isolation of changes to other parts of the service culture may be inadequate to foster recovery-oriented services.[25] In terms of physical infrastructure, one service redesigned a reception area to create a more welcoming environment and to display information brochures more prominently. Other codesigned improvements that resulted from the adapted MH ECO intervention included extra feedback mechanisms, the provision of internet access for service users and a coaching model to support readiness for community group participation.

Overall, we successfully implemented the MH ECO intervention and engaged people living with SMI who may typically be framed within literature as harder to reach with 80% follow-up. The SW-CRT design ensured that the intervention was delivered to all service teams, service users and carers and enabled a rigorous evaluation of impacts. Despite clear codesign objectives and evidence that improvements were further codesigned and implemented, there was still a null effect. On the one hand, this may reinforce current debates about the challenges of codesigned service improvements being measured at an individual level.[20] On the other hand, it might be that the codesigned improvements did not target core components of recovery-oriented care and therefore could not improve psychosocial recovery. It is possible that the reported 18-year average of living with SMI played a role. Additionally, it is plausible that the codesign processes played a role in the outcomes; however, the qualitative evaluation feedback gathered from all postgroup meetings suggested that participants found value in feeling heard, being involved in decisions about improvements and working together. Where improvements were noted for codesign, it related to increased representation in codesign groups, for example, where carer numbers were lower and time.

The strengths of this study included that the adapted MH ECO intervention was codeveloped by the state consumer and the carer peak agencies, it was piloted before this trial and delivered by lived-experience coinvestigators in real-world settings of MHCSS. This demonstrates the feasibility of delivering a structured codesign model such as the adapted MH ECO model for quality improvement within mental health services with multiple groups and to scale. However, if this intervention were to be adopted for service design and quality improvement in the future, it would be essential to retain the training delivered before codesign due to the inherent need for power discussions and agreements on shared decision-making approaches in the mental health context. Additionally, the adapted MH ECO model could benefit further from the design-thinking elements of EBCD being more closely in the foreground. A further limitation of the MH ECO model as implemented may be that the adapted method did not use the film components that the broader EBCD model supports.

A weakness could be that the codesigned improvements did remain mostly quick fixes and process-oriented. Recent work that has examined the experiences that people might draw from their service encounters is important to consider here as it might point to a need to widen the lens of service users engaged in sharing their stories and to identify further who is taking part in codesign.[36] There may be a need in EBCD to establish the backgrounds of service users and carers for participation in codesign, so that multiple service encounters or engagement with specific therapeutic models are explicitly sampled for more tangible effects to be realized and sustained. Despite this possible need, the trial did adopt multiple recruitment strategies to enhance representativeness by passive mail-outs, staff providing a bespoke study postcard to return and express interest and the provision of on-site recruitment days where people with lived-experience of mental illness who had been trained in the Stand Up for Mental Health programme delivered by Canadian David Granirer delivered comedy to break-down silos, address stigma and reduce the burden of participating in formalized research.

In addition to sampling for different service stories, our previously published work outlining an explanatory theoretical model of change for codesign and coproduction in healthcare improvement is highly relevant. In that explanatory model, we noted eight mechanisms of change that are essential for the relational work of EBCD. These mechanisms include recognition (of the importance of experiential evidence and narrative identities), dialogue (to share stories and give equal weight to what is shared and to ensure that conversations do not close off others), cooperation (agreeing to work together in the context of polyphony where there is unlikely to be 100% agreement all of the time), accountability (a shared responsibility for change), mobilisation (generating the movement for change to happen), enactment (making change happen), creativity (using creative approaches and design thinking intentionally for transformation) and attainment (making implementation visible and experiencing those benefits). These mechanisms, we argued, interact with ideal relational transitions that may be observed through codesign processes where individuals transform a position held on issues and experiences in services, and with the people they might be codesigning with. In this ideal, people might be said to move along a relational continuum of being solo and disconnected I's (here, others are typically viewed separately to 'them') and through codesign processes, people begin to see others and their vulnerabilities through shared understanding of 'You' that forms. This process continues and, longer term, may enable 'Us' to form in a way where 'We' emerges to enact and attain change. It is possible to suggest, given the null effect that greater attention to the eight mechanisms of change might have fostered relational conditions that could bolster psychosocial recovery. An analysis of this aspect of trial data is currently underway for the process evaluation.

CONCLUSIONS

There have been more than 60 noncontrolled evaluations of EBCD quality improvement projects[37] where patient experience and transformations to healthcare workforce, culture, values and behaviours have been documented to improve.[22] As mental health policy increasingly advocates for coproduction and codesign approaches[37,38] to facilitate better services, improved experiences and outcomes, there is a need for controlled studies to measure impacts. Using more rigorous SW-CRT design could assist in this. The broader implications of these findings might best be reflected by consideration of the main action areas identified by people living with SMI and their carers that highlighted the central concerns of better communication, the importance of involvement in decision-making and the provision of opportunities for being with other people with similar life experiences not solely because of having a diagnosis of mental illnesses. Service providers are challenged daily to truly listen to what people are saying that they want and need and to reflect on their own part and role in providing services that can facilitate hope, meaning and empowerment. The results of this trial confirm the importance of person-centred care and recovery-oriented mental health systems, but they show that codesign on its own is inadequate.[39] The results of this trial may indicate, then, that health policy is to some degree ahead of practice particularly in terms of what we might be able to expect of codesign. Coproduction and codesign in healthcare improvement are essential to the future of mental healthcare reforms, but it is essential that these methods demonstrate how power dynamics and shared decision-making are attended to.[18] The critical message for healthcare policy-makers, service delivery providers and service reformers in this current era of participation in service design and quality improvement is to ask the difficult questions about what outcomes we should expect of coproduction and codesign. We might also require research efforts to elicit what people engaged in codesign expect from it and what kinds of methods and approaches work best for whom, when and under what circumstances. This will require multiple study designs and trials to compare quality improvement methods and, moreover, it is dependent on the engagement of people with lived-experience of mental illnesses on setting out the expectations of codesign to be able to better determine the effects on service experiences and individual outcomes.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Victoria J. Palmer and Jane M. Gunn substantially contributed to the study conception, and all the authors contributed to the design. Kali Godbee and Konstancja Densley contributed to the acquisition of data and analysis, and Victoria J. Palmer, Jane M. Gunn, Helen Herrman, John Furler, David Pierce, Patty Chondros and Kali Godbee all contributed to the interpretation of data for the research findings. All authors reviewed drafts of the manuscript and contributed to revised content for publication. All authors accept accountability and responsibility for the content in this publication.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

DETAILS

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Evaluation of Japanese people's perception of risk information for making decisions to receive influenza and rubella vaccinations

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ProQuest document link

ABSTRACT (ENGLISH)

Background

Generally, vaccination uptake in Japan lags behind World Health Organization targets.

Objective

This study aimed to understand how risk information and advice affect intention to receive vaccinations.

Methods

This study had a within-subjects design. An online survey based on the Health Belief Model was sent to 2501 Japanese individuals (≧20 years) to assess the intention to be vaccinated for influenza and rubella after receiving minor and severe risk information and hypothetical advice about each vaccine. Regression analysis was used to measure changes in intentions to receive each vaccination after being provided with (1) risk information about each vaccine and (2) hypothetical encouragement and discouragement to be vaccinated.

Main Outcomes

The main outcomes included changes in vaccination intentions from baseline.

Results

Forty-one percent (N= 1030) of those sent the survey completed it. At baseline, 43% and 65% of the respondents intended to have influenza and rubella vaccinations, respectively. Being provided with information about severe risks and susceptibility increased the intention to have the influenza vaccination among females in their 40s. Receiving inaccurate and discouraging information from one's mother significantly decreased the intention to have the rubella vaccination. Women 50 and older were more likely to intend not to have vaccination for rubella. Severe risk information decreased rubella vaccination intention in all age groups, except women in their 30s and 40s (p<.05).

Conclusion

For both vaccinations, older individuals demonstrated vaccine hesitancy. This group requires tailored messaging to help them understand their vulnerability (to influenza) and their role in transmission (for rubella) to encourage uptake of essential vaccinations.

Patient or Public Contribution

Members of the Japanese public responded to our online questionnaire on vaccination risk.

FULL TEXT

INTRODUCTION

In Japan, influenza vaccination rates among different age groups of adults older than 20 years ranged between 40% and 50% during the 2017/2018 influenza season; rubella vaccination coverage among different age groups ranged between 29% and 90% in 2018.[1,2] Both rubella and influenza vaccinations are recommended by the Japanese government, but vaccination decisions are voluntary. Although several previous reports describe factors that might increase Japanese people's vaccination intentions, they focused primarily on sociodemographic factors, understanding of vaccination benefits, physician recommendations and concerns about side effects.[3–5] Forces that shape risk perceptions and methods that effectively promote vaccination uptake are not well understood in Japan. Multiple studies have identified that concerns about the risks of receiving vaccinations, including side effects, pose a barrier to vaccination.[6–10] Even if due to incorrect information, mistrust or misunderstanding, vaccine hesitancy dampens immunisation uptake.[9–11] Documented primarily in the United States and Europe,[10,12] vaccine hesitancy appears to be multifactorial, attributable to underestimation of susceptibility, excessive anxiety about vaccine side effects and misinformation.[10–12] Recent studies indicate that vaccine hesitancy is also operative in Japan,[11] shaped by an anti-vaccination movement that undermines confidence in vaccines and weakens government recommendations, a preference for treating diseases rather than preventing them,[13] the costs of vaccination[3] and insufficient information from healthcare services.[4,5]

Risk perception is considered to be a combination of probability and subjective judgement shaped by an individual's unique psychological, social, cultural and even political context.[14,15] Matsui et al.[4] found that accurate information and understanding of individual susceptibility, vaccination and severity of seasonal influenza infection were associated with increased vaccination uptake. However, even when respondents feel sufficiently informed to decide whether to be vaccinated, concerns about safety may shape risk perceptions and uptake, as demonstrated by a study by Walter et al.[16] of a vaccination developed to combat the influenza A(H1N1)pdm09 pandemic. Social influences and access to services may also shape vaccination uptake.[4,17] However, how Japanese people perceive the risks of vaccination and how information and advice shape their intentions are still unknown.

For rubella, one would expect higher vaccination intentions among women of childbearing age. In Japan, rubella vaccination was mandatory for junior high students from 1977 to 1989, after which it became voluntary and vaccine coverage rates decreased, leading to rubella epidemics in the early 2000s. Since 2006, rubella vaccination guidelines recommend two childhood vaccinations: At 12 months of age and immediately before entering elementary school. The Ministry of Health, Labour and Welfare (MHLW) recommends rubella vaccination for adults, including healthcare workers who have not had a rubella vaccination in many years, those who are unsure whether they been previously infected with or vaccinated against rubella and those who plan to travel overseas.[18] The Japanese government recommends that those who live with or have frequent contact with women of childbearing age be vaccinated for rubella because epidemics of rubella have occurred since 2002.[18,19]

The aims of this study were to discover how exposure to different risk messages and social cues affect intentions to be vaccinated for influenza and rubella in Japan. Identification of differences in vaccination intentions between influenza and rubella could reveal how Japanese people appraise the risks of side effects alongside the benefits of being vaccinated. We designed risk messages around likely concerns about vaccination, including adverse reactions, consequences of remaining unvaccinated and social cues to action.[6,8,10,14,15]

METHODSResearch design

We designed an online survey administered by Macromill Inc. in Japan from 11 to 31 March 2014. Macromill Inc. is a private marketing research company that maintains a database of layperson registrants in Japan interested in participating in different research surveys. We selected Macromill Inc. to distribute the questionnaire and collect responses; their national reach of participants, experience with online survey research and their ability to build in cut-off criteria suited our study design. The survey was designed to solicit intentions around receiving two elective vaccinations: seasonal influenza and rubella vaccinations. Both are voluntary in Japan; however, Japanese immunisation law states that influenza vaccines be generally obtained at individual expense, preferably annually and timed appropriately to provide immunity during the peak influenza season, while the rubella vaccination is strongly recommended and provided free, with resultant immunity persisting for many years.

To minimize bias in respondent risk perception about influenza and rubella, we avoided the peak influenza season. A within-subjects design was used for the analyses; individuals under 20 years of age and medical professionals were excluded from the study. Variables included (1) demographics, (2) information-seeking behaviours regarding healthcare- and vaccination-related risks and (3) responses after receiving different risk information. Demographic questions included gender, age and education level to assess how these strata interpret the risks of vaccination. We also included having/not having a child or children under 20 years of age, based on evidence that having children affects influenza vaccination uptake.[3]

We developed risk statements around influenza and rubella vaccinations for the survey guided by the Health Belief Model (HBM).[20] In the HBM, core constructs of perceived susceptibility to and severity of an adverse outcome, perceived benefits of and barriers to adopting a preventive action, cues to action and self-efficacy all shape intentions. If perceived benefits of a preventive action exceed perceived barriers, and if individuals perceive that they are susceptible to an adverse outcome, they are more likely to adopt a recommended preventive health action. In this study, we defined the adverse outcome as side effects of having vaccination, because several articles reported that concerns about side effects of having vaccination would lead to a lack of confidence or negative attitude towards vaccination.[6,8–10] We defined ‘severity’ as the severity of the side effect, ‘susceptibility’ as the risk of experiencing infections and ‘barrier’ to adopt a preventive action as a barrier to having vaccination. If respondents saw vaccination as beneficial after being made aware of minor and severe risks and susceptibility, their intention to receive a vaccination would subsequently increase. Cues to action, such as messages in mass media campaigns, doctors' recommendations and advice from others, can also promote or discourage vaccination intentions. Self-efficacy is the level of a person's confidence in his or her ability to take action[21] and is associated with increased information-seeking behaviours as well as integration and more effective use of information.[22]

Survey design

First, respondents were asked about their intentions to receive influenza and rubella vaccinations, when provided no information about either vaccination. Then, respondents were asked about their intentions to receive each vaccination after being provided different levels and types of information: Description of the risk of a minor adverse reaction, description of the risk of a severe adverse reaction and an adverse health risk faced by unvaccinated persons (susceptibility). Self-efficacy was assessed through questions inquiring about other health information-seeking behaviours. For cues to action, we asked respondents to consider two hypothetical nonmedical advice statements: (1) being discouraged by one's mother from getting the vaccine and (2) being encouraged to get the vaccine by a friend. These scenarios were selected based on studies showing that parental advice (especially from one's mother) and peer influences have a strong influence on preventive health behaviours and vaccination uptake among young adults of childbearing age.[23–26] Peers have been shown to influence decision-making by parents about immunisations for their children.[24,26] It is unclear whether and how maternal influence over health decision-making wanes over the life course in Japan; our study attempted to address this literature gap by exploring whether and how maternal and peer advice influenced adult intentions.

Minor and severe risk explanations were designed by the authors based on information published on the home page of the MHLW, including the National Institute of Infectious Diseases (Table 1). The information on the MHLW website is based on medical evidence, but worded for laypersons, with some probabilities presented as percentages, while others are qualitative, using phrases such as ‘in quite rare cases’. Conveying vaccination risk information in this way seems to be common practice internationally, exemplified by information issued by the Centres for Disease Control and Prevention (CDC) in the United States.

Table 1 Risk information in the online survey

	Influenza vaccination	Rubella vaccination
Minor risk	10%–20% of people receiving the influenza vaccination will experience eczema at the injection site. 5%–10% will have eczema all over the body, but it will resolve in 2–3 days	One in several thousand people (0.05%) receiving the rubella vaccination will experience severe headache with cramping at the back of the neck, fever, nausea and/or vomiting (aseptic meningitis). For comparison, the all-cause rate of aseptic meningitis among those not vaccinated for rubella is 2 in 100 (2%)
Severe risk	In rare cases, fever, headache, spasms, disturbance of motility and/or consciousness, shock, hives and difficulty breathing may occur several days to 2 weeks after having the influenza vaccination. These side effects may be serious and possibly life-threatening	In rare cases, idiopathic thrombocytopenic purpura may develop, which poses a risk of mild to excessive bruising and bleeding. This condition is associated with an unusually low level of platelets, which aid blood clot. Extremely rarely, platelet levels may fall so low that dangerous internal bleeding occurs, though effective treatments are available

Susceptibility	Very rarely, unvaccinated individuals may develop bronchitis, pneumonia and/or encephalitis. Cardiac arrest may occur; the risk is higher among seniors and those with chronic conditions	If pregnant women who are not immune to rubella are infected, their babies may be born with birth abnormalities, such as hearing difficulties, cataracts and cardiac deformity (congenital rubella syndrome). The frequency of birth abnormalities caused by rubella infection during pregnancy is 1.8–7.7 per 100,000 births (0.002%–0.008%). The frequency of birth abnormalities by weeks of pregnancy when the infection occurs is more than 50% at 4 weeks' gestation and about 35% at 8 weeks' gestation
Cue to action (mother's discouraging comment)	Your mother said that you do not need to have the vaccination because even if you contract it, you will recover by just staying in bed for several days	Your mother said that you do not need to have the vaccination because she believes that you already contracted rubella in childhood
Cue to action (friend's encouraging comment)	One of your friends said that they would have the vaccination if it would prevent or alleviate the symptoms of rubella	One of your friends said that you should get vaccinated because your belief that you had rubella as a child might be mistaken

We piloted the survey to measure the reliability of the questionnaire using a test–retest approach, adapting the questions to reach a sufficiently high Cronbach's α (α = .90) with a subgroup of respondents: .89 for the influenza vaccination and .82 for the rubella vaccination.

At baseline and after being presented with each explanation of risk or cue to action, respondents rated their intentions to receive each vaccine along a 6-point Likert scale, where 1 indicated no intention of having a vaccination and 6 indicated strong intention to have a vaccination. The results were dichotomized so that scores of 1, 2 and 3 were converted into 0 (*no intention*) and scores of 4, 5 and 6 were converted into 1 (*intention*).

Data analysis

Respondents' vaccination intentions were examined using multiple logistic regression analyses using stated intentions before being provided any information as a baseline to compare with intentions after being provided different risk information and advice. McNemar tests were used to compare baseline intentions with intentions after being provided risk and nonmedical information. The level of significance was set at 5%. IBM SPSS Statistics version 25.0 was used for all statistical analyses.

Ethical considerations

Participation in this study was voluntary and anonymous; individuals could not be identified by researchers. Respondents were asked if they would like to participate in the online survey, and the questionnaire was distributed only to those who agreed for it to be sent. Agreeing to receive a questionnaire did not constitute consent to participate. Respondents who entered the survey site were considered to have given agreement and informed consent after they clicked to agree to participate and submitted their answers; they were free to opt out at any time. This study was approved by our institution's Ethics Committee (Approval #821).

RESULTSParticipant profile

The questionnaire was electronically distributed to 2501 individuals. Of these, 1030 respondents (41%) completed the survey, of whom 515 were male and 515 were female. Macromill implemented an automatic cut-off for enrolment in each age group to ensure a 1:1 ratio of males to females and an even distribution among the five age groups:

20s, 30s, 40s, 50s and 60s and older (*n* = 103 per group). The respondents' mean age was 45 years (*SD*: ±14.65). Slightly more than approximately half (*n* = 556, 54%) had attended a 2-year college or higher. Approximately one-third of the respondents had one or more children under 20 years of age (*n* = 297, 29%). At baseline, before being provided any risk information, 440 (43%) stated an intention to have the influenza vaccination and 665 (65%) stated an intention to have the rubella vaccination.

Exploratory factor analysis was performed on three groups of factors: (1) information-seeking behaviours, (2) preinformed vaccination intentions (baseline) and postinformed vaccination intentions (minor risk, severe risk, susceptibility, mother's discouragement and friend's discouragement) for influenza vaccinations and (3) pre- and postinformed vaccination intentions for rubella vaccinations.

Comparison of vaccination uptake intentionsInfluenza vaccinationIntentions to have influenza vaccination (multiple logistic regression analyses)

No gender association was found with intention to have the influenza vaccination. Overall, respondents in their 40s and 50s, regardless of gender, did not intend to have the influenza vaccination at baseline; intentions did not change after risk information or advice was presented (*p* <.05 for all associations; Table 2; Table S1).

Table 2 Intention to have influenza and rubella vaccinations (multiple logistic regression analysis: *n* = 1030)

		No information (baseline)		Minor risk		Severe risk		Susceptibility		Maternal discouragement		Friend's encouragement	
		Adjusted odds ratio (95% CI)	*p* Value	Adjusted odds ratio (95% CI)	*p* Value	Adjusted odds ratio (95% CI)	*p* Value	Adjusted odds ratio (95% CI)	*p* Value	Adjusted odds ratio (95% CI)	*p* Value	Adjusted odds ratio (95% CI)	*p* Value
Influenza vaccination intention													
Age													
20–29 (Ref.)			<.01		<.01		<.01		<.01		<.01		<.01
30–39		1.21 (0.82, 1.81)	.34	1.02 (0.68, 1.51)	.94	1.19 (0.80, 1.77)	.39	1.15 (0.77, 1.71)	.50	1.18 (0.80, 1.76)	.41	0.99 (0.67, 1.48)	.97
40–49		0.73 (0.49, 1.11)	.14	**0.56 (0.37, 0.84)****	<.01	**0.62 (0.41, 0.94)***	.02	**0.52 (0.35, 0.79)****	<.01	0.63 (0.42, 0.95)*	**.03**	**0.58 (0.39, 0.87)****	.01

50–59	**0.61 (0.41, 0.91)***	.02	**0.49 (0.33, 0.73)****	<.01	**0.55 (0.37, 0.82)****	<.01	**0.48 (0.32, 0.71)****	<.01	**0.55 (0.37, 0.83)****	<.01	**0.55 (0.37, 0.82)****	<.01
60 and over	1.22 (0.83, 1.81)	.32	0.87 (0.59, 1.28)	.47	0.94 (0.63, 1.39)	.75	0.83 (0.56, 1.23)	.35	0.97 (0.66, 1.44)	.89	1.00 (0.68, 1.48)	.99
Gender												
Male (Ref.)												
Female	0.88 (0.69, 1.14)	.34	0.87 (0.68, 1.12)	.28	0.83 (0.64, 1.06)	.14	0.88 (0.69, 1.13)	.32	0.88 (0.68, 1.13)	.31	0.93 (0.73, 1.20)	.58
Has child/children <20 years												
No (Ref.)												
Yes	1.37 (1.91, 1.85)	.05	1.29 (0.95, 1.74)	.11	**1.47 (1.08, 1.99)***	.01	**1.38 (1.02, 1.88)***	.04	**1.42 (1.05, 1.92)***	.03	**1.52 (1.12, 2.06)****	.01
Education level												
High school or less (Ref.)												
More than high school	1.19 (0.92, 1.53)	.18	1.22 (0.95, 1.57)	.12	1.24 (0.96, 1.59)	.10	1.13 (0.88, 1.45)	.34	1.12 (0.87, 1.44)	.38	1.11 (0.86, 1.43)	.41
Rubella vaccination intention												
Age												
20–29 (Ref.)		<.01		**.01**		.02		<.00		<.01		<.01
30–39	0.65 (0.42, 1.01)	.58	0.71 (0.46, 1.10)	.13	0.70 (0.46, 1.07)	.10	**0.60 (0.39, 0.94)***	.03	0.67 (0.44, 1.01)	.06	0.75 (0.50, 1.12)	.16

40–49	**0.44 (0.29, 0.69)****	<.01	**0.52 (0.33, 0.80)****	<.01	**0.54 (0.35, 0.82)****	<.01	**0.47 (0.30, 0.74)****	<.01	**0.47 (0.31, 0.74)****	<.01	**0.43 (0.29, 0.66)****	<.01
50–59	**0.40 (0.26, 0.62)****	<.01	**0.51 (0.34, 0.78)****	<.01	0.64 (0.43, 0.96)*	**.03**	**0.52 (0.34, 0.79)****	<.01	**0.45 (0.30, 0.70)****	<.01	**0.54 (0.36, 0.79)****	<.01
60 and over	**0.49 (0.32, 0.75)****	<.01	**0.52 (0.34, 0.79)****	<.01	**0.54 (0.36, 0.81)****	<.01	**0.48 (0.32, 0.74)****	<.01	**0.47 (0.31, 0.72)****	<.01	**0.52 (0.35, 0.78)****	<.01
Gender												
Male (Ref.)												
Female	1.05 (0.81, 1.37)	.69	0.89 (0.69, 1.16)	.40	1.00 (0.77, 1.29)	.98	1.22 (0.94, 1.59)	.14	**0.66 (0.50, 0.87)****	<.01	0.79 (0.61, 1.02)	.07
Has child/children <20 years												
No (Ref.)												
Yes	1.20 (0.87, 1.65)	.27	1.40 (1.01, 1.93)*	.04	**1.59 (1.16, 2.18)****	<.01	**1.89 (1.35, 2.64)****	<.01	1.05 (0.75, 1.47)	.77	1.01 (0.81, 1.49)	.55
Education level												
High school or less (Ref.)												
More than high school	1.27 (0.98, 1.64)	.75	1.17 (0.90, 1.52)	.24	1.17 (0.91, 1.51)	.23	**1.34 (1.03, 1.75)***	.03	1.09 (0.82, 1.44)	.56	1.13 (0.87, 1.45)	.37

Note: gender: male = 0, female = 1; age: 20–60s and over; having a child/children: yes = 1, no = 0; education level: more than high school = 1, high school or less = 0. Bold values indicate statistically significant values. Abbreviation: CI, confidence interval.

*

p <.05.

**

p

≤

.01.

As for statistical interactions, females in their 40s had higher influenza vaccination intentions after receiving severe risk information (*p* = .02, 34 of 103, 33%) and susceptibility information (*p* = .01, 37 of 103, 36%). Conversely, females 60 and older showed no intention of having influenza vaccination at baseline (*p* = .02, 57 of 103, 55%); intentions remained unchanged by provision of any risk information (*p* <.05 for all associations). Those in their 40s who had children intended to have the influenza vaccination at baseline (48 of 111, 43%) and after any risk information was provided (*p* <.05 for all associations). Those in their 30s with children indicated an intention to be vaccinated only when provided severe risk information (*p* = .04, 63 of 97, 65%). Highly educated respondents in their 30s and 40s intended to have the vaccination at baseline (64 of 118 [54%] and 44 of 102 [43%], respectively) and after any risk information was provided (*p* <.05 for all associations; Table S2).

Comparison of intentions between baseline and after provision of different risk information and advice (McNemar tests)

Intentions to have the influenza vaccination significantly increased from baseline after being provided minor risk information (9% increase, *n* = 41 more than baseline), susceptibility information (10% increase, *n* = 42 more than baseline) and a friend's comment (8% increase, *n* = 34 more than baseline; *p* <.01 for all associations). Even severe risk information and a mother's discouragement did not influence the respondents' vaccination intentions (Table S3).

Rubella vaccinationIntentions to have rubella vaccination (multiple logistic regression analyses)

Overall, gender was not associated with intention to receive the rubella vaccination. However, females (*n* = 515) were significantly more likely to refuse the rubella vaccination after being hypothetically discouraged by their mother (*p* <.01, 76%, *n* = 390; Table S1). Regarding statistical interactions, females in their 30s (*n* = 103) and 40s (*n* = 103) were significantly more likely than other age groups to intend to have the vaccination at baseline (74%, *n* = 77 and 59%, *n* = 61, respectively) and after any risk information was provided (*p* <.05 for all associations). However, females 50 and older (*n* = 206) were statistically significantly more likely than other groups to refuse the rubella vaccination after a mother's discouragement (83%, *n* = 172; both, *p* <.05).

Both education and stage of life had a huge impact on intention to be vaccinated, even at baseline. Women with children under 20 years (*n* = 168), respondents in their 40s with children (*n* = 111), highly educated respondents with children (*n* = 158) and highly educated respondents in their 40s (*n* = 102) all responded to information about minor risk with slight increases in intention to have the vaccine (1%, 7%, 3% and 3%, respectively). Severe risk information decreased intention somewhat for most of these groups (2%–3% decrease among women with children, highly educated respondents with children and highly educated respondents in their 40s), though there was a 3% increase in intention for respondents in their 40s with children (*p* <.05 for all associations). Susceptibility information seemed to generate larger increases in intention than any risk information about having the vaccination (7% increase among women with children, 9% increase among those in their 40s with children, 4% increase among highly educated respondents with children and 6% increase among highly educated respondents in their 40s; *p* <.05 for all associations; Table S4).

Comparison of intentions between baseline and after provision of different risk information and advice (McNemar tests)

A number of inputs significantly decreased intentions to have the rubella vaccination from baseline, including severe risk information (7% decrease, *n* = 45 fewer than baseline), hypothetical maternal discouragement (56% decrease, *n* = 372 fewer) and even a friend's hypothetical encouragement to have the rubella vaccination (36% decrease, *n* = 242 fewer; *p* <.01 for all associations). Hearing a mother's discouragement first seemed to influence subsequent responses to a friend's encouragement. Therefore, a McNemar test was conducted on the results to assess the relationship between the mother's discouragement and the friend's encouragement. There was a significant increase in vaccination intention when the friend's encouragement was provided (44% increase, *n* = 130 more than after mother's discouragement; *p* <.01; Table S3).

Comparison of information-seeking behaviours with vaccination intentions

For our measure of self-efficacy, approximately half of the respondents indicated that they engage in each of the health information-seeking behaviours surveyed. Over half of the respondents (*n* = 577, 56%) stated that they would compare the advantages and disadvantages of a medical procedure if treatment were required; 49% (*n* = 509) reported reading the warning labels on over-the-counter flu medication, 49% (*n* = 508) stated that they researched the risks of having an influenza vaccination and 62% (*n* = 643) stated that they researched the risks of having a rubella vaccination. Elderly individuals, as well as females more generally, were statistically significantly more likely to seek vaccination information and assess the risks and benefits (Table S5).

Influenza vaccination

Researching the risks of medical procedures was significantly related to intentions of having the influenza vaccination at baseline (27%, *n* = 275) and after being provided any risk information or comments (29%, *n* = 301 minor; 27%, *n* = 278 severe; 29%, *n* = 299 susceptible; 27%, *n* = 280 mother's comment; and 28%, *n* = 291 friend's comment; *p* <.01 for all associations). Those who researched the risks of the influenza vaccination had significantly higher influenza vaccination intentions after being provided any risk information (*p* = .02, 26%, *n* = 264 minor; *p* = .01, 24%, *n* = 244 severe; *p* = .04, 25%, *n* = 260 susceptible; Table S6).

Rubella vaccination

Comparing the advantages and disadvantages of having medical procedures was significantly related to intentions of having the rubella vaccination at baseline (38%, *n* = 394), after being provided minor (39%, *n* = 399) and severe risk information (36%, *n* = 370) and a mother's discouragement (18%, *n* = 189; *p* <.05 for all associations). Those who had researched the risks of the rubella vaccination had significantly higher vaccination intentions even after being provided a mother's discouragement (*p* = .02, 21%, *n* = 213; Table S6).

DISCUSSIONDemographic aspects of vaccine hesitancy

The influenza vaccination is required annually, at personal expense and is self-protective, particularly for the very young and elderly, while the rubella vaccination is needed much less frequently and offers direct, long-lasting benefits primarily to women of childbearing age and children. Despite these differences, older respondents expressed more vaccine hesitancy towards both vaccinations than younger respondents. Among older respondents, intentions to have either vaccination were low at baseline and were largely unaffected by provision of any risk or susceptibility information or opinions of their peers. Japanese seniors generally seemed to have already made up their minds not to have the influenza vaccination, fitting the complacency model of vaccine hesitancy.[10–12] Similarly, older individuals were generally uninterested in rubella vaccination, seemingly oblivious to the risks of being infected and spreading rubella to others who are not vaccinated. This resistant attitude poses a considerable barrier to efforts by the Japanese government to increase uptake and is of public health concern, as the elderly are at a much higher risk of serious illness and death from influenza if unvaccinated, and can spread rubella infection.[13,18] Surprisingly, this demographic group also reported being proactive in obtaining vaccination information and considering its benefits, but despite this apparent self-efficacy, they were still impervious to vaccination uptake.

Those in their 30s and 40s—particularly females, those with children and highly educated respondents—were more likely to express influenza vaccination intentions after receiving information on risk (even severe risk) and susceptibility. It is possible that this demographic, most likely to have young children at home, has better information about vaccination benefits and more favourable attitudes to vaccination based on their children's vaccination experiences at their paediatrician and/or at school. Additionally, connections made with other parents through their children would allow for an exchange of information, possibly leading to an increase in vaccination uptake.

Peer and family influences

Remarkably, even for older generations whose mothers are likely infirm or deceased, maternal influence was stronger than any of the medical information provided about the rubella vaccination. Japanese culture and family patterns may influence these responses. In East Asian cultures including Japan, people tend to respect the opinions of their elders because of their life experience[27] and also view themselves as interdependent with others in specific contexts.[28] Respecting one's elders still influences older generations: knowing that one's mother had a negative opinion of vaccination could decrease vaccination intention. However, considering that we did not observe any maternal influence on influenza intention among older age groups, maternal discouragement might instead provide a convenient excuse for refusal of the rubella vaccination, which would lead to vaccine hesitancy due to complacency.[10–12]

Hypothetical advice from one's mother was intentionally based on a potentially unreliable source (her memory) as well as medically incorrect information. Regardless, a sizeable proportion of respondents of all ages reported that this advice would decrease their intention to receive the rubella vaccination. Respondents who were influenced by maternal advice appeared to accept vaccination information unquestioningly. A previous study has reported that parental influence, especially maternal influence, affects young adults' decision-making about preventive vaccinations for women's diseases.[25] Focusing on increasing support for rubella vaccination among mothers, especially mothers of grown children, may boost vaccination intention in those of reproductive age, but further research is required.

Peer influence on younger generations was not particularly evident in this study, as peer encouragement did not seem to increase vaccination intention in younger cohorts as it did among the middle-aged with children at home, who are more likely to be exposed to information and opinions through school activities through their children and parental meetings at school. Peer influence seemed to have no effect on rubella vaccination intentions. Those with high information-seeking behaviours generally had higher vaccination intentions, especially for influenza. An exception was the elderly, who had high health information-seeking behaviour, but lower vaccination uptake. High self-efficacy among the elderly appeared to be influenced or reinforced by peers; therefore, providing information and vaccinations in gathering places like existing community resources for seniors might enhance vaccine uptake.[29]

Effect of informational inputs and sequencing on vaccine intentions

We examined intentions around vaccination for two very different vaccinations. Barriers to action are logically much higher to achieve personal and population protection when it comes to influenza vaccines than rubella, given the out-of-pocket cost and frequency of vaccination required. Providing information based on increasing risk level helps people better appraise differences in risk. The MHLW home pages describing the influenza and rubella vaccinations describe their risks in the side effects section, not in conjunction with information about susceptibility to disease or the benefits of vaccination. In our study, information on both the risks of side effects as well as susceptibility to adverse outcomes from getting the disease was provided sequentially, following the HBM categories, so that individuals could consider the benefits.

Providing risk information in a sequential manner seemed to effectively allow younger generations to rationally consider the advantages and risks of having vaccinations, especially for influenza. In contrast, older generations indicated low intention to have either vaccination at baseline, and presentation of medical information about vaccination risks and their susceptibility did not change their minds, despite high self-efficacy around health decisions. Vaccine hesitancy in the elderly should be a focus of future research.

Implications for vaccination campaigns in Japan

In Japan, a high-income nation with a well-developed vaccination programme, vaccine hesitancy may be driven by mistaken impressions about vaccinations, some of which may be driven by misinformation provided by peers or on the Internet; however, poor messaging, changing recommendations and outreach by vaccination campaigns may also play a role.[3–5,13] The Japanese Health Department (MHWL) seemed to have provided important information about vaccines only sporadically.

For both vaccinations, those aged 50 and older showed high vaccine hesitancy and were unswayed by information in our survey, despite self-reported high levels of health information-seeking behaviours and widespread availability and accessibility of vaccinations. High vaccine hesitancy in this vulnerable group is problematic, and further research will be needed to develop appropriate messages to motivate older vaccination recipients. Other factors may also encourage vaccine hesitancy in older age groups, who are more likely than others to encounter difficulty due to cognitive and physical mobility issues in accessing and paying for vaccines. Our study design did not tailor risk information by age group, but highlighting elderly individuals' higher susceptibility to adverse outcomes of influenza infection in vaccination messages may be one avenue to increase influenza vaccination rates in Japan. Involving family physicians in vaccine campaigns might complement information provided by national campaigns, help the elderly better understand the need for each vaccination and address any concerns about the side effects of vaccination. Higuchi et al.[5] showed that family physician recommendation was positively correlated with pneumococcal vaccination intention among the elderly in a rural area of Japan.

The Japanese government has promoted rubella vaccination primarily by focusing on the risk of congenital rubella syndrome in unborn children—an important benefit to women of childbearing age and their children. However, this emphasis may have inadvertently contributed towards indifference among those older than reproductive age. Sensitizing older individuals to understand that if they are infected, they could spread rubella to pregnant unvaccinated females and cause birth defects in children might motivate them to get vaccinated. Overcoming rubella vaccine hesitancy among these populations in Japan may require messages that help this group view vaccination uptake as a prosocial contribution.

Limitations

Use of an Internet survey excluded individuals who do not have online access or do not use computers or smartphones, potentially under-representing the very poor and very old. The survey relied on self-report, which may be unreliable and could include some social desirability bias (e.g., respondents may have over-reported intention to be vaccinated before receiving any vaccine information, which would diminish the true effect of providing risk information). Using a private marketing firm's database for the study population relied on their roster of registered participants, which may introduce some selection bias. However, the vast majority of Japanese people are highly computer literate, and the large number of responses across Japan indicates that geographic reach was good.

Other limitations pertain to study design and analysis. Due to changing policies and recommendations around vaccination, the proportions of unvaccinated individuals are not evenly distributed by age group in Japan, particularly for rubella, and some respondents probably had had adult rubella vaccination, which may have decreased the observed effect of the risk information provided. The way in which different types of information were provided (minor and severe risks, susceptibility, mother's and friend's advice) may have created an order or cumulative effect. Additionally, our questionnaire design made it impossible to ascertain whether the impact of advice from friends and family was attributable to the content of the advice or the relationship with the person giving the advice. However, within-subjects designs have two advantages: Higher statistical power and a lower probability of failing to detect a true difference.

Subjective expressions such as ‘the severity is high’ and ‘the probability of the outcome is so low’ may have been understood differently by different respondents according to their risk tolerances and subjective interpretations of these phrases. Using congenital rubella syndrome as the example of susceptibility for the rubella vaccination may have skewed favourable intentions towards women of reproductive age. However, these are common ways to communicate vaccination risk information to the public used by major national healthcare organisations, such as the CDC and MHLW. Additional research is needed to evaluate how the citizens of Japan and other countries perceive these messages.

Our analytical decision to collapse our 6-point Likert scales to a dichotomous scale introduced potential bias, but is a common approach in social research to allow for analysis of a discrete outcome of interest (in this case, vaccination intention or not). As Japanese people, like people from other East Asian nations, tend to choose the middle choices in questionnaires,[30] dichotomization was an attempt to allow respondents to feel comfortable with their response while capturing meaningful responses.

CONCLUSION

Messages and information to increase vaccine uptake in Japan and elsewhere must target specific demographics with tailored approaches that target the main factors underlying vaccine hesitancy for specific vaccines and for each sociodemographic group, particularly the elderly, who show higher vaccine hesitancy than other groups despite higher susceptibility to many vaccine-preventable diseases. Risk information about severe side effects tends to decrease vaccine intention and should be delivered carefully and in the proper context (e.g., alongside benefits and susceptibility) to groups most concerned about these risks. Messages to motivate individuals to receive vaccines that may not benefit them directly, such as for rubella vaccine promotion among men and older individuals, will require inventive approaches, possibly by appealing to the sense of shared social obligation that animates Japanese culture.

The findings of our study confirm studies from other East Asian countries that have identified high vaccine hesitancy, particularly among the elderly, for a range of different vaccinations. Our findings highlight the need for vaccine campaign strategies that identify segments of the populations where vaccine hesitancy is high and to develop culturally appropriate and effective messages and approaches tailored to the concerns and norms of different age and educational groups.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

DATA AVAILABILITY STATEMENT

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

DETAILS

Subject:	Health beliefs; Vaccines; Rubella; Susceptibility; Health belief model; Seasons; Severity; Influenza; Health status; Regression analysis; Meningitis; Influence; Immunization; Perceptions; Decision making; Risk perception; Older women; Older people; Uptake; Age groups; Polls &surveys; Vaccination
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Doing involvement: A qualitative study exploring the 'work' of involvement enacted by older people and their carers during transition from hospital to home

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ProQuest document link

ABSTRACT (ENGLISH)

Context

Being involved in one's care is prioritised within UK healthcare policy to improve care quality and safety. However, research suggests that many older people struggle with this.

Design

We present focused ethnographic research exploring older peoples' involvement in healthcare from hospital to home.

Results

We propose that being involved in care is a dynamic form of labour, which we call ‘involvement work’ (IW). In hospital, many patients ‘entrust’ IW to others; indeed, when desired, maintaining control, or being actively involved, was challenging. Patient and professionals' expectations, alongside hospital processes, promoted delegation; staff frequently did IW on patients' behalf. Many people wanted to resume IW postdischarge, but struggled because they were out of practice.

Discussion

Preference and capacity for involvement was dynamic, fluctuating over time, according to context and resource accessibility. The challenges of resuming IW were frequently underestimated by patients and care providers, increasing dependence on others post-discharge and negatively affecting peoples' sense and experience of (in)dependence.

Conclusions

A balance needs to be struck between respecting peoples' desire/capacity for non-involvement in hospital while recognising that ‘delegating’ IW can be detrimental. Increasing involvement will require patient and staff roles to be reframed, though this must be done acknowledging the limits of patient desire, capability,and resources. Hospital work should be (re)organised to maximise involvement where possible and desired.

Patient/Public Contribution

Our Patient and Public Involvement and Engagement Panel contributed to research design, especially developing interview guides and patient-facing documentation. Patients were key participants within the study; it is their experiences represented.

FULL TEXT

INTRODUCTION

Shorter hospital stays, which support patient preference to be at home and reduce strain on acute care resources, can result in people needing ongoing care, often requiring multi-agency input.[1] Unfortunately, it has been estimated that one in 10 patients experiences an adverse event in the immediate post-discharge period.[2] Alongside the stress associated with being hospitalised,[3] harm is also caused by systemic issues, such as inadequate care provision across care boundaries, including across settings.[2] Williams et al.[2] (p. e829) suggest that ‘there is great potential for significant reduction in harm from even small improvements in this process (of transition from hospital to home)'. Patient involvement has been suggested as a way of improving the quality and safety of patient care,[4,5] particularly by contributing to enhanced system functioning.[6] This is especially relevant when care delivery and system functioning are challenging, for example, when delivering care across settings, boundaries, and at transitional moments such as when patients return home after a hospital stay.

Following Murray et al.,[7] we consider involvement to be nuanced, dynamic and relational, changing over time and influenced by context and interaction. In this way, patient involvement has the potential to operate in multiple ways to influence system functioning. For example, Schubert et al.[8] suggest that by navigating a 'fragmented system', patients/caregivers can 'identify and prevent mistakes from happening, and participate in improving their care' by enabling care co-ordination across multiple settings and providers. Likewise, O'Hara and Lawton[9] argue that patients have the potential to act as 'information conduits' across settings, thereby improving safety and reducing harm. However, despite being the highest users of the National Health Service (NHS), research shows that older people, in particular, struggle to be involved in their care,[10–12] therefore minimising potential contributions towards patient safety. Moreover, little is known about the *desired* involvement of older people from their perspective across the transition from hospital to home, especially over time.

Within this study, we explored what older people (aged 75+) understood by 'involvement', how they 'did' involvement and where there were opportunities for enhanced involvement, during and after a hospital stay, in ways that were acceptable to them.

METHODS

We undertook a longitudinal focused-ethnography[13] exploring the involvement and experience of older patients from hospital admission to 3 months post-discharge.[14] This enabled us to explore 'involvement at transitions' as a specific phenomenon through inquiry and engagement with older people in everyday life and over time, something limited within the current body of literature. We adopted an inductive, pragmatic approach, with analysis being data-driven and interpretive. Specifically, we aimed to move past individual accounts of experiences and perceptions to identify 'underlying ideas, assumptions, and conceptualisations'[15] from the corpus of data, including from multiple participants, while remaining rooted within individual accounts and experiences.

Research question

Can older people be more involved in their care? If so, how and in what ways?

This was the first study in our programme of work seeking to improve the quality and safety of care through development of an intervention designed to increase patient involvement, specifically in older populations. Consequently, inherent in the programme design, and this study's research question formulation, was a theoretically informed assumption that older people *can* be more involved in their care and that being so will have a positive impact on that care.[4–8] However, we wanted to remain open to older peoples' experiences and preferences around involvement and so we also aimed to explore:

To what extent do older people feel involved in their care? What are their perspectives on this?

Where are the opportunities for older people to be more involved in their care, should they desire this?

To what extent do older people feel *able* to be (more) involved in their care? What has, or would help them to, feel able to be (more) involved in their care?

We felt that being open to different experiences and perspectives about involvement, while being committed to making improvements, would increase the likelihood of developing a person-centred intervention, sensitive to the lived experiences and preferences of those we were seeking to help.

Sample and setting

Community-dwelling adults aged 75+ were the target study group as they are most likely to experience variability in care at transitions. End-of-life patients were excluded because they tend to have dedicated post-discharge care pathways. Likewise, people being discharged to live in residential care were excluded as they were likely to experience different care at transitions to their community-dwelling peers due to readily accessible postdischarge support.

A total of 32 patients aged 76–99 years were recruited from six hospital wards across multiple specialities from three hospitals within two NHS trusts in Yorkshire, North of England (see Table 1). A total of 18 family members were also recruited. We purposively recruited a diverse group: individuals of different ethnicities (with translation assistance), people with and without relatives performing a ‘carer’ role, and a variety of ages including the ‘oldest old’ (aged 85+). Patients with cognitive or language impairments and those lacking capacity to consent were included, provided they had suitable support.

Table 1 Patient demographic details

Mean age	79
Median age	84
Age brackets	
75–79	*N* = 7
80–89	*N* = 15
90–99	*N* = 10
Male	*N* = 14
Female	*N* = 18
Asian: Pakistani	*N* = 2
White: Other White background	*N* = 2
White: English/Welsh/Scottish/Northern Irish/British	*N* = 28

Recruitment and initial interviews/observations and early follow-ups were completed in hospital, during which staff were also spoken to informally during observation work. Further contacts with patients took place in intermediate care settings and in patients' own homes.

Recruitment

Patients were recruited shortly after admission to the hospital. Initially, decisions about which patients to approach were opportunistic; sampling became more purposive as the study progressed.

Senior ward staff helped identify eligible patients and made initial approaches. Researchers discussed the study with patients and their family, if present; all those approached were given a participant information sheet and the opportunity to ask questions as they considered participation. All participants provided written informed consent and were assigned pseudonyms to maintain their anonymity. The study was approved on 8 March 2017 by Wales 7 NHS research ethics committee (17/WA/0057).

Data collection

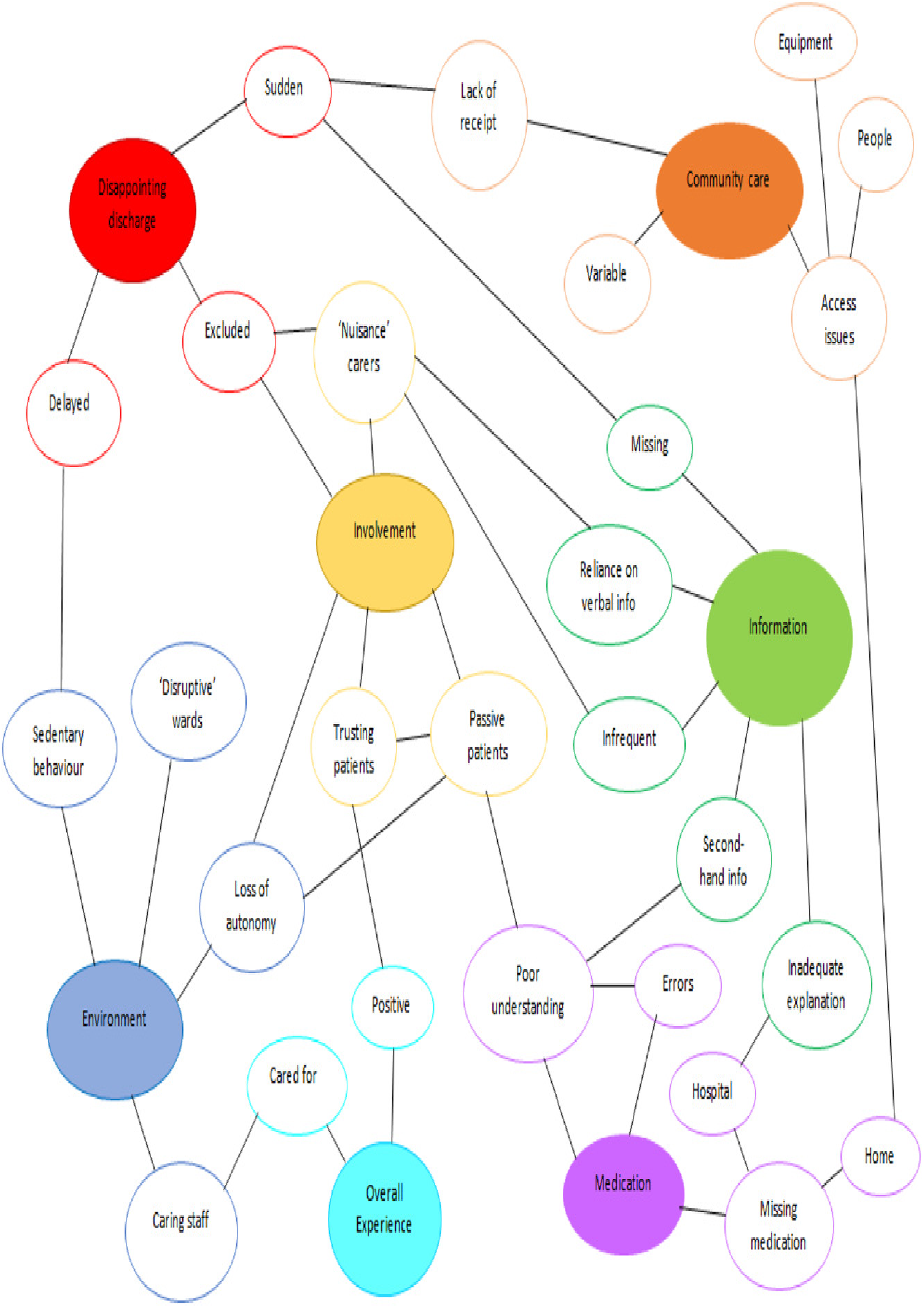
Semi-structured interviews were the primary means of generating data, supplemented by observations,[14] ‘go-along interviews’[14,16,17] and relevant contextual information from patients' care records. We looked at care records after initial interviews to explore the extent to which people knew and understood the reason for their admission. We also looked at care records when people moved to new care facilities and were unable to recall information about transfer dates and next steps. This facilitated accurate data capture and enabled timely follow-up. All patients consented to this access.

Each contact with patients was recorded as a field visit (FV). One hundred and sixty FVs were conducted in total (by authors N. H., R. S. and L. H). The fewest number of FVs with a participant was three; the highest was nine. The timing of FVs varied according to patients' care journeys, but broadly occurred at admission, before/at discharge, shortly after discharge, several weeks post-discharge, and 3 months post-discharge and/or at readmission. Interviews were audio-recorded, where possible. Observations were recorded through field notes. Researcher interpretation and key reflections were noted after FVs; these were used to provide contextual information during analysis.

Data analysis

Tacit analyses were done throughout the period of data collection by authors N. H., R. S. and L. H., who each reviewed their own data and met regularly throughout the project to discuss key ideas. Additionally, N. H. listened to voice recordings/read transcripts generated by each researcher. A thematic analysis[15,18] was led by N. H., with regular input and sense-checking from R. S. and L. H. to ensure that the identified themes represented the whole data set.

Key ideas were organised by N. H. into categories and subcategories, followed by identifying patterns and relationships between these categories. Similarities and differences between categories were used to construct themes and subthemes and the relationships between them (see Figure 1). Additionally, comparison of themes across FVs for each participant was done to explore continuity and change in perspective and experience over time.



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FINDINGSInvolvement work

For health care professionals (HCPs) to deliver care to patients, work needs to be done. That is, decisions need to be made, activities undertaken, and tasks need to be completed—often by multiple people, over time, and within different contexts. Care delivery work is, predominantly, visible and acknowledged *as* work—HCPs are employed to carry out these tasks, for example. However, our study also found that *receiving* care required patients (and/or their relatives) to do ‘work’ too, including decision-making, undertaking activities, and completing tasks. We consider the work that people do as, and on behalf of, patients to be the ‘labour’ of involvement, conceptualised in this paper as ‘involvement work’ (IW).

We propose that IW has three dimensions—cognitive, emotional and instrumental (see Table 2). These dimensions often coexisted and were experienced and/or enacted simultaneously. IW also operated along a continuum, with people moving between states of ‘Non-involvement’ at one end and ‘Involvement’ at the other. Being involved was a dynamic, interactional, and relational process. For example, during her first admission, Pearl (91) wanted HCPs to ‘look after her’—she was tired and felt that being in hospital provided respite from doing everyday tasks that she normally managed (patient-desired non-involvement). However, HCPs became concerned that Pearl was unable to manage independently at home because she was both reticent and struggling to mobilise independently on the ward. They recommended Pearl return home with a care package or move into residential care; Pearl was asked to decide between these options (cognitive IW). This triggered feelings about loss of independence and worry about losing her home (emotional IW). Resolved to stay at home, Pearl became as active as possible on the ward (instrumental IW moving her along the continuum towards ‘involvement’), determined to prove to HCPs that she was motivated and capable (emotional IW). In the meantime, three of Pearl's daughters were having ongoing discussions with each other and with HCPs to decide upon and make post-discharge arrangements (cognitive and instrumental IW).

Table 2 Dimensions of involvement work

Cognitive	Emotional	Instrumental
This tended to involve activities such as decision-making, weighing up options, planning for future care, and understanding information and processes. This type of involvement often included interaction with others, especially healthcare professionals, frequently as providers of information	Emotional involvement work is about the emotions that are generated and ‘managed’ before, after or when receiving care or when enacting other forms/dimensions of involvement work	This included undertaking activities, or co-ordinating or integrating work, such as chasing up test results, medications or appointments
	Interactions with others was a key aspect of emotional involvement work	It often included interactions with others, especially when navigating systems and co-ordinating activities, although it also included tasks that could be undertaken independently
Examples		

Ray (76) spent time postdischarge researching a new medication to decide if he was happy to take it. He then discussed his concerns with his GP	Trevor (84) was motivated to be involved in decision-making about his discharge because he was very anxious to get home to his wife, who lives with dementia and struggles to manage without him.	Philip (81) chased up his missing medication postdischarge by contacting the GP and community pharmacy to arrange a new prescription
Katherine (83) did not want to take her new medication, but she discussed this with her consultant at a postdischarge outpatients' appointment. Together, they agreed that she would take it to manage her health condition	Martin (83) built good relationships with staff during a long hospital stay. This facilitated trust and positive affect between the staff and Martin, giving him confidence and an increased willingness to engage with therapy, despite it being challenging and painful	Shirley (93) realised that hospital ward staff were busy and so she walked to the toilet independently instead of asking for a commode at the bedside

For Pearl, enacting IW was challenging—sometimes impossible—and frequently invisible. For example, on the admitting ward, Pearl began going to the en-suite toilet independently because she could not find her buzzer, though staff rarely knew about it (invisible IW). However, after moving wards, Pearl no longer knew where the toilet was, and this made it difficult to go to the toilet alone; moreover, staff on this ward encouraged Pearl to use a commode instead of walking to the toilet at the end of the ward (challenging IW). Then, during another ward move, Pearl's walking frame was misplaced, resulting in Pearl being unable to walk around independently at all (impossible IW due to lack of resources). Pearl rarely communicated any of her feelings or difficulties to others because she did not want to be 'a nuisance' (hidden IW). Moreover, Pearl's daughters told us how difficult it was to get enough information from HCPs to make necessary decisions and arrangements (cognitive and instrumental IW). Getting information required persistent chasing (instrumental IW) and caused stress and frustration (emotional IW), none of which they communicated to Pearl because they did not want to worry her (invisible IW).

Pearl's case is a good example of how IW undertaken by patients/relatives, and the resources required to enact this, can remain hidden from others. Consequently, unlike the work of HCPs, IW remained largely invisible to and unacknowledged by HCPs, patients, and families alike. The consequences of this were twofold. First, 'entrusting' IW was common. We found that because the hospital healthcare system was geared towards the visible and acknowledged work that HCPs do, this set up expectations about the roles and behaviours of healthcare staff and patients operating within the system: Most patients desired minimal involvement during their hospital stay, seeing much of the cognitive and instrumental work as the responsibility of HCPs and/or their families. Hospital processes seemed to tacitly support these expectations by promoting and prioritising care delivery work, and minimizing or failing to support opportunities for involvement.

Second, we found that enacting IW required resources, which was also largely unacknowledged by staff and patients, although it was frequently articulated as an issue by relatives. Because the provision of and access to resources were variable and/or unequally distributed, doing IW was sometimes challenging, even when desired.

Entrusting IW

This involved actively or passively minimizing participation in one or more types of involvement and took two forms: outsourcing and delegating. Both forms were common within our cohort of patient participants. For some people, outsourcing and delegating were enduring experiences; for others, they were transient experiences, usually adopted during episodes of acute ill-health.

Outsourcing

'Outsourcing' involved handing over responsibility for IW to other people, primarily to HCPs. This approach was one of 'do [task] *for* me'. This was often due to patient expectations about the role of HCPs as knowledgeable decision-makers, capable care providers, and the people whose job it was to perform tasks in hospital. However, 'choosing' to outsource IW to HCPs was often an interplay between patient preference and ‘going along’ with usual hospital processes, which tended to undertake activities on behalf of patients as standard—for example, HCP kept and dispensed medication, even when patients usually managed this. Many patients were willing to accept this because they trusted hospital staff.

I go along with it, it's the hospital, they know what they're doing. (Lillian, 80)

However, sometimes, outsourcing activities became more about ‘compliance’ than a patient's desire to avoid doing the task themselves. This led patients to outsource IW to HCPs because they wanted to be ‘good patients’.

I do as I'm told; I don't want to be a nuisance. The staff have got so much to do. (Jeannie, 89)

Delegating

‘Delegating’ was also a means of handing over responsibility to others. This was often partial and usually to unpaid caregivers, for example, relatives. This approach was one of ‘do [task] *on my behalf*’, and patients typically remained influential while delegating IW. For example, patients frequently informed family members of their preferences and relatives communicated these preferences to care providers; relatives often became proxies for patients. Sometimes family members explicitly acknowledged this role, describing themselves as ‘advocates’ for their relative. For most relatives, however, doing involvement activities on behalf of patients was undertaken as an obligation; their role as ‘delegate’ was treated matter-of-factly and often remained unacknowledged by both patients and their family members.

Entrusting IW to others was the most frequent and desired form of involvement in hospital and was supported by standard hospital care processes, within which hospital staff undertook many cognitive and practical aspects of involvement for patients as part of caring for them. However, desire to entrust IW to others was not static and it varied, primarily according to time and location (see Table 3).

Table 3 Involvement work across time and location

Time	Admission early hospital stay	Hospital stay predischarge and discharge period	Postdischarge
Location	Hospital	Hospital	Home or intermediate care (IC)
Involvement work	Outsourcing	Variable: Delegating; desire to contribute to decision-making; outsourcing; desire to resume autonomy with activities of daily living (ADLs)	Variable: Desire to/resuming autonomy; outsourcing to social care; delegating

Summary	Patients often relinquished control of their treatment and care to healthcare professionals (HCPs) at admission. Patients viewed themselves as 'non-experts' and HCPs as experts. This was the case even when patients were used to doing these activities for themselves at home	Some people wanted to resume normal daily activities as they started to feel better, though opportunities were often limited. Others, however, were happy to continue being cared for by staff and continued to outsource responsibility, even when encouraged to start resuming some autonomy	Desired and actual involvement work varied postdischarge. Some patients resumed autonomy with few problems; others struggled to readjust to independent living. Sometimes, this was because they still felt unwell. Others, however, had adapted to institutional living, had become deconditioned, and were unable to manage at home. This was often a surprise to patients and relatives, despite a hospital stay where most ADLs had been managed for them and sedentary behaviour was common.
	Early in admission, outsourcing decisions and care-related activities were often done because patients were not able, or did not want, to do these for themselves. Some expressed relief that staff were undertaking activities for them, experiencing their hospital stay as respite	As discharge planning continued, many patients became more interested in being involved in decision-making; being able to decide place of residence was a concern across the sample. Some patients felt able to contribute to discussions themselves. However, many patients preferred to delegate their involvement to relatives.	Sometimes resuming involvement work was made more difficult by inadequate information, especially when prescriptions had changed, and patients were unaware of this. This caused confusion and unintentional noncompliance
			Patients were more likely to continue entrusting care-related activities to others when they were in IC settings (outsourcing); had packages of care (outsourcing); or family involvement (delegating). Regardless of setting, almost all participants were happy to continue to outsource medical decisions, especially those who had good relationships with their GP

Participant examples/ quotes	‘That's a medical decision, isn't it? I have nothing to do with it… I don't know zilch’, (Leslie, 84; acute medical unit for older people [AMUfOP])	Pearl (91) did not speak during care planning meetings with her social worker. Instead, Pearl outlined her wishes to her daughters for them to discuss on her behalf. Pearl felt that her daughters were more effective in these meetings than she could be—this was due to hearing loss and a lack of confidence in her own ability to navigate a complex system.	Leslie (84) did little for himself in hospital, but once back at home he recommenced cooking for himself, managing his medicines, and tracking and chasing up appointments
	‘I know the kids are worried because I'm in hospital… but I'm having a bit of a rest’. (Pearl, 91; AMUfOP)		‘[We thought] it would all fall into place once she got here [home], but that's not the case, she's refusing to walk, she's fallen twice so far because she can't get in or out of her bed, she's struggling. She was ringing for a cup of tea’. (Lillian's niece - Lillian, 80)
			‘I mean, I don't want a miracle, I just want them [the doctors] to explain it to me and then I can sort things, you know. Because I mean now, before, how many tablets? Now I'm taking about six I think, I was taking three before then’. (Katherine, 83)

Maintaining IW

Not all patients wanted to outsource IW during their hospital stay. However, those wishing to retain autonomy frequently had to *resist* hospital processes; this often required undertaking additional work.

Resisting processes

Although there was some variation between wards, standard processes for managing and caring for patients were broadly similar across locations and allowed minimal room for individual patient preferences. Ward-based environments were homogeneous, with limited scope for personalisation; for example, patients had almost no input on ward temperature, lighting, care schedules, and choice about food and drink provision was limited. This was a source of frustration for some patients, especially as they began to feel better or during lengthier hospital stays.

I said to a nurse this morning, ‘Could I please go down …and get my own water? I've managed to cope with that [laughs]. But can I? No! No, she wouldn't let me make tea, but then she wouldn't bring me any tea! [Laughs]’. (Katherine, 83; Stroke rehabilitation ward)

Katherine became so frustrated by everything being done for her that she started handwashing her clothes, crockery, and cutlery in the sink in her room, despite staff telling her this was unnecessary. For Katherine, resuming activity was crucial to her self-identity as an independent person.

Another process common across wards was ‘falls prevention’. Most patients were considered by HCPs to be at moderate-high risk of falling and reported being encouraged to remain in bed or seated at the bedside. After speaking to HCPs about this, a senior nurse said that while, ideally, they would enable patients to remain as active as possible, this was extremely resource intensive and they rarely had sufficient staffing levels to facilitate and support physical activity. Consequently, minimizing physical activity felt like the safest option for patients at risk of falling. Many participants were compliant, not wanting to be bothersome, or were worried about falling themselves. However, some patients actively chose to ignore instructions, for example, choosing to walk independently, even when encouraged or told they should sit down. For example, Ray (76) declined to use the wheelchair brought to him when he moved around the ward. HCPs were persistent in offering the wheelchair, despite Ray's confidence and ability in walking independently, and what was initially a ‘decline’ had to become a more active ‘refusal’.

Resources for IW

Involvement was often resource intensive, frequently requiring knowledge and information, social support, and material resources (see Table 4). Some patients had limited access to resources such as informal support, and this resulted in an increased reliance on health and social care services; interestingly, patients relying on formal care provision often struggled to resume IW post-discharge.

Table 4 Resources for involvement work

At times, resources needed to be externally provided (e.g., information about medication or expected post-discharge care, and equipment) and it was problematic when these resources were not supplied. Conversely, active resource provision by HCPs appeared to improve peoples' experiences and facilitated them in managing their health/care post-discharge. This included resources such as patient-friendly written information about medications, which enabled people to check what they should be doing once at home or provided the basis for conversations with post-discharge care providers.

Alongside resources provided by others, the capacities and capabilities of patients themselves could be resources to doing or resuming IW. In particular, feeling confident communicating with HCPs seemed to be a key facilitator for active involvement for both patients and relatives, especially when seeking information, challenging/resisting processes that minimised involvement opportunities, and influencing decision-making. Overall, we found that patients with access to multiple resources, that is, both their availability and the means to utilise them, were often more effective at maintaining or resuming IW according to their preferences and were more likely to have a positive influence on their care when they did choose to be involved.

Consequences of entrusting or enacting IW

Although maintaining IW was challenging during hospitalisation, it appeared to enable people to resume involvement more effectively post-discharge than those who entrusted IW to others throughout their stay. Outsourcing, in particular, seemed to contribute to loss of confidence and deconditioning in undertaking activities. This sometimes meant that patients felt less able to manage at home than they had before going into hospital, especially initially. For example, one participant, Mary, attempted to resume her pre-hospital activities, but had become deconditioned during her hospital stay, resulting in a subsequent fall at home and readmission to hospital. Conversely, we found that participants who maintained active involvement reported ‘getting back to normal’ sooner than people who had outsourced and delegated.

Alongside maintaining capabilities, involvement also influenced subjective experiences of (in)dependence. Crucially, it appeared that congruence between desired and actual involvement was more important to perceptions of (in)dependence than levels of actual dependence. Mary, for example, was happy to outsource tasks and be reliant on others, but was desperate to maintain choice about where she lived; her sense of independence came through being involved in decision-making about place of residence. It was this that constituted meaningful involvement for Mary. Conversely, Katherine retained autonomy regarding decision-making and was influential in decisions about discharge planning. However, Katherine felt dependent on others because she wanted to be more involved in her practical care than she could be. Her subjective experience of independence was low because her actual levels of involvement did not match her desired levels.

Lack of resource provision could also impact on post-discharge experiences by minimising opportunity for involvement in hospital, with visible consequences for patients and staff—missing mobility aids increased reliance on staff to help patients mobilise, for example. However, some problems did not become apparent until patients left hospital and as such were likely to remain invisible to hospital staff, who may not be aware of issues unless problems were significant enough to trigger readmission. For example, having no understanding of new medication is not necessarily a problem while HCPs are dispensing it in hospital. However, once patients become responsible for this post-discharge, lack of understanding can lead to unintentional medication noncompliance.

Alongside consequences for patients, enacting or entrusting IW had an impact on both care providers and families. For HCPs, active involvement could save them time and reduce care delivery work. For example, patients going to the toilet independently meant that staff time was not needed to help patients. However, some people—especially relatives—felt that they were treated as a ‘nuisance’ by staff when they enacted IW or when they sought out resources for IW. Relatives, in particular, said that because information provision was minimal, they frequently had to seek this out. However, doing so often meant interrupting HCPs during tasks and some people said that staff tacitly communicated displeasure at such interruptions. Information flow was largely controlled and dictated by HCPs and people frequently struggled with this, feeling limited power to effect change or have an influence unless this was facilitated by HCPs.

However, the power dynamics of IW should not be seen as unidirectional. By having the decision on whether to enact or entrust IW to others, patients were able to impact both positively and negatively on the care delivery work that HCPs did and the IW that relatives undertook. The power to say ‘no’ to doing IW was particularly potent; HCPs wanted to (and were also duty-bound) to care for patients, and family members often felt obliged to provide time, energy, and any financial cost it took to undertake IW on their behalf. IW, then, is always an interplay between people and is often negotiated relationally and interactionally.

DISCUSSION

The findings of the study suggest that most participants were not actively involved in their care in hospital. While non-involvement was largely desired during this time, it was also tacitly promoted by hospital processes, which automatically assumed responsibility for most tasks people normally engaged in. ‘Non-involvement’, then, was often a kind of ‘collaborative accomplishment’ between HCPs and patients: from the point of admission, many patients wanted and expected to ‘outsource’ and ‘delegate’ their IW to others, while care delivered in hospital often failed to enable active patient involvement—even when desired—by doing ‘IW’ on behalf of patients. At times, this seemed to benefit both patients and care providers—patients wanted to be ‘looked after’ and staff wanted to care for patients in ways consistent with hospital processes, which implicitly supported non-involvement. At times, shortages of care resources, especially staff, also lent itself to patients being uninvolved; some patients sensed that the most helpful role they could play was as a passive patient. Non-involvement, then, was sometimes a type of ‘collusion’ between patients and HCPs. This may provide some short-term ‘benefits’, but as noted, it can also result in longer term consequences, especially post-discharge. These were infrequently anticipated by care providers or patients. Importantly, involvement preferences were dynamic, varying according to time and context, with some people expressing or demonstrating a desire to resume IW at a later point in their journey, especially post-discharge. Moreover, the point of discharge marks the moment when patients become responsible for their IW again, because outsourcing cognitive and instrumental IW to HCPs is no longer possible outside a hospital setting. This happens whether resuming IW is desired or not. However, resuming IW was sometimes challenging, especially when people had outsourced/delegated to others, and were therefore out of practice; others lacked resources to be involved in their care. Consequently, opportunities for increasing involvement within this cohort may be difficult without adjusting patient expectations, implementing broader system changes, and ensuring adequate access to resources. A culture of non-involvement can impact the patient's transition of care in ways often unanticipated by both HCPs and patients. Enhancing involvement may be challenging in hospital, but the consequences could be far-reaching by enhancing experience and safety post-discharge.

Increasing patient involvement is likely to require a shift in both expectations (of and about patients and HCPs) *and* in the organisation of the work that goes on in hospitals. For example, patients who demonstrate some capability to do things while in hospital, but are resistant to doing them (preferring to outsource), can be encouraged, reassured, and motivated by staff to consider looking ahead to prepare for their forthcoming independence post-discharge. Likewise, where staff recognise a patient's desire for autonomy in preparation for resuming life at home, they support rather than resist this. Other potential opportunities include altering hospital processes to facilitate greater involvement where possible, for example, increased patient involvement in medicines management,[19,20] and engagement with campaigns such as #EndPJparalysis.[21] Doing so may have 'knock-forward benefits'[22] for both patients—who can gain and maintain skills and confidence—and healthcare services, which could undertake fewer tasks for patients. In agreement with Carman, however, interventions need to be designed to address the factors that impact on patient involvement, including going beyond patient factors such as knowledge or motivation.[23,24]

It is also important to recognise that 'good' patient involvement will not look the same for all people and that for some, non-involvement (e.g., outsourcing) or delegated involvement may be the preferred approach. In these cases, facilitating greater involvement of relatives, where possible, could be beneficial. For other people, 'passive' forms of involvement, such as an understanding and acceptance of care and treatment plans, may be 'adequate'.[22] This means that information-sharing between HCPs and patients and their families is vital—not just as a means to active involvement, for example, shared decision-making, but as the means of involvement itself. Importantly, HCPs may need to take the lead with regard to providing information, as many older people are 'information receptive,' but not active in seeking information.[7] Active information provision may also be required if patients are to be 'information conduits' between parts of the system across the transitional journey.[4]

Patient expectations have been identified as a key factor in determining participation, with patient *desire* (to participate) proposed as a prerequisite of participation.[25] We too found that when patients expect and desire others to do IW on their behalf, they are less likely to participate in their care. This, combined with services geared towards passive patients, creates a 'perfect storm' of non-involvement, much of which may be desired by patients and tacitly welcomed by service providers. Carman argues that organisational characteristics, policies, and practices can (positively) influence patient participation.[23] However, despite potential system benefits when patients engage in IW, services appear to be predisposed towards non-involvement. This is often a consequence of the way work is organised, rather than deliberate exclusion by HCPs.

Alongside 'desired non-involvement',[7] approaches towards more active types of involvement and ability to undertake IW appear to be mediated through access to, and *ability to leverage*, multiple resources and are therefore subject to unequal distribution. Importantly, these include peoples' capacities and capabilities. The concept of 'patient activation' has been used to describe the 'knowledge, skills and confidence a person has in managing their own health and healthcare'; higher levels of activation are promoted as a means of improving health-related outcomes.[26] Greene and Hibbard[27] go as far as to say that 'patients *should* be more active and effective managers of their health and health care'. In some ways, our study supports such a proposal. We found that the patients in this study most effective at exerting influence and enacting IW in ways meaningful to them were proactive; had existing relevant knowledge; were confident talking to HCPs; and/or were able to resist, challenge, or work around problematic organisational processes within multiple settings. However, we also found that few participants felt able to do these things, especially when unwell. Consequently, it may be useful to consider concepts such as 'activation' as a *resource*—which people may or may not have access or ability to leverage at a given time—rather than an attribute of an individual. In agreement with Sinding et al.,[28] it is important to acknowledge the potential barriers that people can face when attempting to be involved. Otherwise, uncritical promotion of increased patient involvement may serve to aggravate existing health and social inequalities.

Moreover, an individual's (high) level of activation may not be sufficient to enable them to actually undertake more active forms of IW. Shim,[29] for example, proposes that individuals approach HCPs with 'a repertoire of cultural skills, verbal and non-verbal competencies, attitudes and behaviours, and interactional styles' that she refers to as an individual's cultural health capital (CHC). Shim suggests that the CHC individuals bring into consultations and interactions is crucial to how HCPs respond to attempts that people make to be involved in their care and can account for dynamics of unequal treatment between patients, regardless of how capable or competent people may actually be. This is because some cultural resources are more highly valued by clinicians than others, putting those without these resources at a disadvantage.[30] Likewise, Entwistle and Watt[22] propose that clinicians who view their patients as ‘capable and trustworthy’ are more likely to facilitate patient involvement and joint working, especially in decision-making. Sinding et al.[28] similarly propose that ‘involved patienthood’ requires HCPs to recognise and acknowledge the skills that patients have. This is not only dependent on whether patients have those skills but also on how well patients are able to demonstrate and communicate them to HCPs *and* how willing HCPs are to recognise and acknowledge them. Thus, patient involvement is not only something determined by individual patients but is instead something that is mediated—positively or negatively—through interaction, especially with service providers as individual HCPs, and/or through organisational practices.[7]

Importantly, being ‘involved’ is not only related to achieving particular ends, for example, deciding upon a course of treatment, managing medications, being active and mobile; it can also be crucial to a person's sense and experience of (in)dependence. Secker et al.[31] suggest that independence is two-dimensional, encompassing aspects of reliance on others and ‘experienced independence’, which is the self-assessed perception that a person's degree of choice, social usefulness and autonomy are consistent with that which they desire. Within Secker et al's.[31] model, a person may be reliant on others and simultaneously experience a high or low sense of independence about their identity and degree of self-determination. Likewise, someone may have low reliance on others, but experience a high or low level of self-assessed independence depending on the degree to which they feel they have choice and autonomy. Our findings are consistent with this. In this respect, then, how someone experiences independence is likely to influence what type of IW is meaningful to them. Likewise, the IW people can engage in—especially within institutional settings—is likely to be particularly influential on someone's subjective experience of independence, regardless of how reliant they are on others to do things for them.

For some people, then, lack of involvement and reliance on others will be detrimental to independence, while for others, reliance on others will be consistent with being independent *if* they can retain autonomy over the things that are important to them. Therefore, ‘meaningful’ involvement is not ‘one-size-fits-all’; rather, it requires a person-centred approach that takes account of a person's desires, ‘psychological make-up, biography, social context and cultural heritage’,[31] alongside the resources they have access to.

LIMITATIONS

As with all research, our study has limitations. We recognise that observational methods and data generated within shared environments may introduce bias into findings. For example, people may change their behaviour while being observed. However, by spending extended periods of time on wards and with participants, we feel that people became comfortable around the researchers, enabling us to capture naturally-occurring behaviour. We also believe that data generated by observational methods provide insights that go beyond verbal accounts and therefore have utility despite these limitations.[32] We are also aware that hospital wards offer limited privacy for personal conversations and for patients to express their care experiences, thereby introducing the potential that accounts are limited. However, we took every effort to use private rooms where possible and build trust and relationships with participants, which we believe encouraged honesty. Also, by following up with people post-discharge, we also provided opportunities for them to share experiences in private spaces, outside of care environments.

We acknowledge that qualitative research is rarely representative, and our findings are therefore not generalisable to all older people transitioning from hospital to home. However, we believe that the in-depth nature of the work, comprising multiple data generation methods, provides findings that are credible, dependable, and contribute to research in this area. Moreover, our project patient and public involvement groups have repeatedly reviewed the findings at various stages of data collection and analysis. They felt that we captured important themes and perspectives, many of which mirrored their own experiences of being community-dwelling older adults, all of whom had experienced transitions of care from hospital to home, suggesting transferability of our findings.

CONCLUSION

Receiving and being involved in care often require patients and families to engage in ‘work’ that remains largely hidden and unacknowledged. Multiple factors influence the involvement that people desire and enact, including patient characteristics, relational dynamics, resource availability, interactions with others, and system processes.

However, in hospital, many people ‘entrust’ IW to others and struggle to resume activities. This can result in increased reliance on people and services post-discharge, alongside a diminished sense of independence. Enhancing involvement could contribute to positive patient experience and safety. Doing so will require encouraging IW when people are reticent, facilitating IW when people show willingness and desire, and resourcing IW to ensure that burden is minimized and inequalities are not aggravated.

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CONFLICT OF INTERESTS

The authors declare that there are no conflicts of interest.

AUTHOR CONTRIBUTIONS

All authors declare that they made substantial contributions to (a) the conception and design, or analysis and interpretation of data; (b) the drafting of the article or revising it critically for important intellectual content; and (c) approval of the version to be published.

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

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In the works: Patient and public involvement and engagement in healthcare decision-making

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ABSTRACT (ENGLISH)

[...]a positive attitude towards the instrumental and ideological values of involvement often lends support to the conclusion that patients should always be encouraged to climb Arnstein's famous ladder of participation: the more, the merrier. Often, rational, argumentative ways of participation have won out over emotional ones, for one pushing back experiential wisdom in favour of more readily objectified contributions, this even though emotions contain powerful, convincing, predictive and sometimes good (and sometimes malicious) drivers for decision-making processes. DATA AVAILABILITY STATEMENT Data and the original report (in Dutch) that support this letter are available from the corresponding author upon reasonable request.

FULL TEXT

In the September 2019 Special Issue of Health Expectations on Patient and Public Involvement and Engagement (PPIE) initiatives, Hickey and Chambers[1] highlighted ‘the importance of […] promoting PPIE across all areas of health and social care both nationally and internationally’ (p. 607). This resonates with the widespread recognition of PPIE's potential to improve the quality of decision-making and increase fairness, responsiveness and legitimacy. Such a positive attitude towards the instrumental and ideological values of involvement often lends support to the conclusion that patients should always be encouraged to climb Arnstein's famous ladder of participation: the more, the merrier. Reflecting on the Special Issue's contents, Hickey and Chambers do note a considerable gap between ideal and practice. Indeed, many authors have described the complexities surrounding the implementation of PPIE. These complexities include limited attention of professionals, policymakers and researchers, a lack of enthusiasm among patients and citizens, issues around the representativeness of those who participate and lack of clarity about the results.

We propose that it is time to move beyond discussing PPIE as something that we can never have enough of and to start examining more thoroughly the *work* necessary to make PPIE work in healthcare decision-making. In organizational studies and elsewhere, the ‘turn to work’ has emphasized the need to consider the situated and shared effort, purposeful and strategic, of people to affect their social–symbolic context.[2] Hickey and Chambers themselves advocate an appreciation of PPIE as coproduction. They write that such a view of PPIE entails careful and inclusive relationship development wherein all those involved are respected and where all contributions are valued (1). We agree that PPIE requires an inclusive approach and that initiating and sustaining PPIE initiatives require considerable effort. However, we deem it necessary to take it one step further. We hold that uncritical promotion of PPIE distracts from the highly situated and contextualized efforts needed to make PPIE work. In this sense, such promotion risks actively thwarting promising attempts to ‘bridge the gap’. Concretely, it may undermine the PPIE values and goals as patients' input is stymied by the mould in which it is poured.[3]

We propose that considering PPIE not only as coproduction but also as work means that each PPIE initiative should be tailor-made in terms of whom to involve, how to involve them and how to value their contributions. A short note on each is presented here.

Whom to involve? The outcomes of PPIE initiatives strongly depend on who is involved or engaged or the way in which they are being represented. The type of work required in many PPIE initiatives appears to suit primarily highly educated, or even ‘professionalized’, people[4]; reaching and involving more of them might not necessarily bring more quality to a decision-making process. Questions for reflection and empirical research include how to increase the diversity of participants in PPIE initiatives and how to reach a specific group.

How to involve patients and the public? In any PPIE initiative as elsewhere, the method used to involve diverse perspectives actively shapes ‘the patient’ and ‘the public’ that is being attended to. The method is thus not a neutral element. As PPIE is situated and contextualized work, the method's effect largely depends on the specifics of the situation. We suggest that this means that methodologies of participation require calibration and realignment on the way. It evokes questions such as the following: What kind of public does this method produce here and does this match our goal(s)? What kind of public(s) are left out?

How to value their contributions? Often, rational, argumentative ways of participation have won out over emotional ones, for one pushing back experiential wisdom in favour of more readily objectified contributions, this even though emotions contain powerful, convincing, predictive and sometimes good (and sometimes malicious) drivers for decision-making processes. Emotions are deemed necessary for practical and moral decision-making and may thus serve as a ‘beneficial guide’ in PPIE initiatives.[5] How to value all types of contributions but emotive ones, in particular, offers food for thought. Storytelling and narrative analyses might help.

Conceptualizing PPIE as work helps us explain the gap between ideal and practice; it helps us move away from linear and generalist ‘ladder’ approaches to PPIE. Instead, it encourages us to consider the practical work needed for PPIE initiatives. Careful consideration of whom to involve, how to involve them and how to value their contributions should inform this. Hopefully, this will result in tailor-made PPIE initiatives in terms of matched processes and goals, which are arrived at through careful reflection and resource use. Specifically, we encourage thinking and empirical research on how to increase the diversity of perspectives, recalibrate methodologies and value emotions. These elements appear to have been underexposed and underutilized so far.

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Data and the original report (in Dutch) that support this letter are available from the corresponding author upon reasonable request.

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Access and communication for deaf individuals in Australian primary care

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ABSTRACT (ENGLISH)

Background and Aims

The Australian Deaf Community face barriers that impede their access to, and communication within, primary health care settings. This study aimed to identify barriers and facilitators to access and communication for deaf individuals and Auslan interpreters in Australian general practice settings.

Methods

Semi-structured interviews were conducted with eight Auslan interpreters and four deaf participants recruited from interpreter organisations and social media. Transcripts of interviews were coded inductively and deductively based on a model of access to health care.

Results

Patient, provider and contextual factors were reported. Patient barriers included English and Auslan fluency levels within the Australian Deaf Community. GP clinics varied in the degree of accommodation to the needs of deaf people. There were barriers related to the communication methods used by health care providers and their use of interpreters. Visual aids and flexibility in terms of the GP clinics' appointment systems facilitated access. Contextual barriers included the shortage of Auslan interpreters and the complexity of the National Disability Insurance Scheme.

Conclusion

The main barriers identified concerned the availability of interpreters, accommodation by health providers, cultural sensitivity and the adequacy of communication methods. Research is needed to explore the limitations of the National Disability Insurance Scheme and interventions to improve GPs' skills in communicating with Deaf individuals.

Patient or Public Contribution

A researcher with a hearing impairment and experience in working with people with hearing impairments was consulted on study design and interview questions. Recruitment was assisted by Auslan interpreter agencies and a Deaf Community Facebook group.

FULL TEXT

INTRODUCTION

The Australian Deaf Community (ADC) consists of profoundly deaf or hard of hearing individuals who preferentially use Australian Sign Language (Auslan) to communicate.[1] Johnston[1] estimated that there were approximately 6500 Deaf signers in Australia in 2001, although this may be an underestimate as it did not account for deaf individuals who adopted use of Auslan later in their lives.[2]

There have been significant barriers to deaf individuals accessing primary health care and communicating with health care providers. These include the lack of text alternatives for phone-based booking systems and the use of inadequate communication methods such as lip-reading and written English.[3–6] The latter is problematic because written English is heavily dependent on the deaf individual's English literacy. Both international and Australian research has identified low English literacy levels within the Deaf Community and poor English literacy as the primary barriers to accessing preventive health information.[4,5,7–9]

Auslan interpreters provide a vehicle for communication between deaf individuals and their health care providers, but are employed infrequently in health care consultations.[9–11] The Australian Disability Discrimination Act (1992) mandated equitable access to health care for deaf individuals, especially through the employment of Auslan interpreters where necessary. However, many health care providers lack knowledge of how to arrange Auslan interpreters and there is a shortage of interpreters across Australia.[8,10,12] The shortage of Auslan interpreters is well documented, with the Australian Department of Social Services' 2004 survey of 491 deaf Auslan users identifying that 49% of deaf adults who had been to a doctor (GP or a specialist) had been unable to secure an interpreter in the preceding year.[10] The NSW Deaf Society's interpreter service identified that it could not fill 79 requests for Auslan interpreting in serious medical, legal, mental health, social services and personal situations over a 1-month period in 2014 under the National Disability Insurance Scheme (NDIS) scheme. The NSW Deaf Society attributed such workforce shortages to factors such as a high attrition rate of interpreters due to dissatisfaction with working conditions and the highly casualized nature of Auslan interpreting work. The average turnover period for an interpreter was equal to or less than that of the average time it took to train and accredit a new interpreter in 2015.[9]

There is a paucity of available research on the Deaf Community's access to health care in the Australian setting. This study thus aimed to explore the barriers and facilitators to both access and communication within the general practice setting experienced by both deaf individuals and Auslan interpreters in Australia.

METHODSSample and recruitmentAuslan interpreters

Auslan interpreters who were fully accredited by the National Authority for Translations and Interpreters, had previous experience in interpreting in the primary health care and were older than 18 years of age were included in the study.

Interpreters were recruited via email from two different interpreting agencies: An Australia-wide agency and an interpreting agency whose service was localized to a metropolitan area. All Auslan interpreters were hearing people (not hearing impaired). The recruitment of interpreters was stopped when thematic saturation was achieved.

Deaf participants

The inclusion criteria for deaf individuals were that they had to be hearing-impaired or profoundly deaf, used Auslan as their preferred mode of communication, culturally identified as a part of the Deaf Community and were older than 18 years of age. Deaf individuals who used sign languages other than Auslan (e.g., British Sign Language) and those who preferentially used spoken English as their preferred mode of communication were excluded.

Consent process: Interpreters and deaf people were sent the written participant information and consent forms via email and signed consent forms were sent back to the researcher before the interview. The information sheet invited participants to contact the researcher if they had any questions about the study and consent. None did so. All participants were asked if they had any questions before the interview. None did.

Data collection

The interview questions were developed on the basis of the relevant literature[3,4,6–8,13] and pilot-tested with two participants (Appendix A). Similar questions were asked of the interpreters and the deaf participants. The questions investigated the barriers and facilitators of communication for the ADC in accessing GPs, personal experiences with the primary health care system and/or health providers and facilitators of communication with health care providers in the primary health care setting.

Qualitative interviews were conducted with Auslan interpreters and with deaf participants between June and August 2020. Semi-structured interviews were conducted via telephone with Auslan interpreters. Interviews with deaf participants were conducted via online platforms with Auslan interpreters for translation. The researcher used spoken English for all interviews. The interview duration ranged from 30 to 60 min.

Ethics approval was granted by the UNSW's Human Research Ethics Committee (HC191007).

Data analysis

The audio recordings of interviews were transcribed, imported into Nvivo1218 and then coded inductively using the model of access to health care described by Levesque et al.[14] Interpreter interviews were also coded deductively. This framework conceptualized access from the perspective of both patients and providers in five dimensions of provider-side factors: (1) Approachability; (2) Acceptability; (3) Availability and Accommodation; (4) Affordability; and (5) Appropriateness and five corresponding patient-side factors: (1) Ability to perceive; (2) Ability to seek; (3) Ability to reach; (4) Ability to pay; and (5) Ability to engage. The first three interviews were coded by all three authors together to check the coding framework and coding decisions. Subsequent interviews were coded by Phoebe H. Lee and 60% of the codes were checked by Mark F. Harris or Catherine Spooner. Disagreements in coding were discussed by the group of three authors.

RESULTSParticipants

All Auslan interpreters were fully certified with the National Accreditation Authority for Translators and Interpreters (Table 1). The deaf participants reported varying degrees of hearing loss. All deaf participants expressed a preference for Auslan as their primary method of communication (Table 2).

Table 1 Demographic information of Auslan interpreters

Interpreter	Sex	Age bracket	Interpreter experience (years)	State
1	F	40–60	20+	NSW
2	M	20–40	0–10	NSW
3	F	40–60	10–20	NSW
4	F	20–40	10–20	WA
5	F	20–40	10–20	Not provided
6	F	40–60	20+	WA
7	F	Not provided	Not provided	NSW
8	F	Not provided	Not provided	NSW

Abbreviations: F, female; M, male,

Table 2 Demographic information of deaf participants

Deaf participant	Sex	Age bracket	State
1	F	30–40	NSW
2	F	65+	QLD
3	M	30–40	VIC
4	M	20–30	NSW

Abbreviations: F, female; M, male.

Approachability/ability to perceive

For deaf individuals who used Auslan as their primary language, English literacy was an important barrier to accessing and understanding health promotion material.

If you go to the NSW Health department, you'll see heaps of information in languages other than Auslan. And same thing happened with COVID because the Federal Department of Homeland Security [sic], put out all this information in different community languages and not Auslan and I went up to them and said 'you gotta do it in Auslan, too'. And they're like, 'Oh, no, we don't do that. Because we only do written languages, we can't do video'. I7

Deaf individuals added that even if there was information available in Auslan, the information did not cater for the diversity of Auslan levels in the ADC.

But sometimes, you know when you don't understand all. Even the news. It'll have the captions or they'll have the interpreter. He will still ask because it's not necessarily gearing to his level of communication. And sometimes the interpreter isn't clear with their signs, or we don't use that interpreter, there's too much in delay, and they're using the same signs, and the captions. You know when you compare the signs that they're using and the caption they're using I find it very difficult, but for a lot of Deaf people, it does go over their heads'. P2

Acceptability/appropriateness

Interpreters described instances where GPs used culturally inappropriate terms to refer to deaf individuals.

Especially with a new doctor, like they hadn't seen their doctor before the deaf walked up with a sore foot or something. And the first thing the doctor would say is: Oh, have you thought about one of those bionic ears? I7

…I saw deaf people get really pissed off and it just completely ruins the relationship before it even starts. The doctor doesn't realize that they're saying something that's really. They don't do it on purpose. Or I've even had doctors use the term 'deaf and dumb'. I've definitely had doctors say 'hearing impaired' which also pisses Deaf people [off] so but you can't get them across all that like you're not going to get them across every aspect. But I think a good interpreter will …say, I think the term you're looking for is deaf, would you like me to interpret that as deaf as to not cause offence or something like that? I7

Availability and accommodation

Both interpreters and deaf participants identified phone-based appointment systems as a barrier to access for deaf individuals, with deaf participants stating that the National Relay Service (NRS) was inadequate to ensure prompt access.

For me, the National Relay Service that I use to book would take quite some time. It's an exaggerated amount of time, which potentially then misses out on appointments. As a hearing person, they can get an appointment straightaway. So that's a big barrier for deaf people in terms of prompt access. P4

SMS- and email-based appointment systems were identified by deaf participants and interpreters as facilitators of access by interpreters and deaf participants.

So, I just use the [proprietary] system, or email. I try not to use the NRS as much as I can. The reason being is signing isn't sufficient, most of the time. P2

Before the introduction of the NDIS, GP clinics were responsible for booking interpreters. However, under the NDIS, it is the deaf individuals' responsibility to book their own interpreters for private medical appointments, including GP consultations. However, interviewees reported that the introduction of NDIS exacerbated the pre-existing shortage of Auslan interpreters, an issue compounded by a lack of training programmes across a number of Australian states, as well as the absence of a specialized training pathway for Auslan interpreters to work in a medical setting.

No, the booking system itself is relatively adequate. It's just literally a fact that there aren't enough of us. So, I would, on average before COVID happened, I'd say, I would say 'no' to about 90% of work and still be working full time. I3

Even if interpreters were booked for an appointment, the waiting times at GP clinics meant that the interpreter would often have to leave before the appointment began.

But now the waiting room is my biggest issue, because there's such delays at the GP. So when I finally get an interpreter, they often have to go because the wait time so long so it's a no win situation. P1

Video remote interpreting (VRI) was identified by interpreters as a potential tool to overcome barriers concerning interpreter availability by interpreters by reducing ‘downtime’ getting to and waiting for interpreted appointments.

So the interpreter drives all the way there, tries to find parking, navigates traffic, gets to the job, it's 10 min and then they're sitting in their car for, I don't know, an hour before the next job because they book an hour, my minimum is an hour and a half so we can't overlap that. So, so a lot of there was downtime in between jobs but now with VRI we're at home. And we can take up to 10 calls a day, which is, which is what's happening now that COVID has sort of subsided a bit. I6

However, some deaf individuals reported that VRI was not always used to its full potential, resulting in an inability to see nonverbal communication.

I can't see the doctors face when he's using his, when she's using her facial expressions. I'm only looking at the interpreter. Some deaf people don't mind, but most of my friends do, they'd like to be able to see that the interpreter with the, with the doctor side by side. And so that they could see how bad how serious, or how non-bad or non-serious it is because you can't see the doctor…. Others will use, and don't mind. But for me, I don't like it at all. P2

Affordability/ability to pay

NDIS was limited to deaf individuals under the age of 65. For individuals over the age of 65, interpreters can be booked through the National Australian Booking Service (NABS). One deaf participant expressed concern because this was limited to medical care and not available for aged care. Although NDIS has granted deaf individuals more autonomy in booking interpreters for the medical setting, several limiting factors were raised by interpreters and deaf participants. One such factor was the NDIS requirement that individuals estimate the funding that will be required for interpreters for medical appointments over the next year.

They need to estimate how much funding they'll need for interpreters, or at least they'll need to give some indication. And it's practically impossible to give that. I2

Another issue was that some clinics required double appointments to be booked when a patient was accompanied by an interpreter to allow extra time for communication. The patient was expected to pay the additional fee.

I also have heard of some practices that recognize that it's good practice to book a longer appointment when interpreters are involved, but often I've heard of some of them wanting to pass the cost of that on to the deaf person so whereas they might, you know, the practice might bulk bill for standard length appointment. If I have to book a long appointment, they won't bulk bill that. They will charge a gap. I8

Appropriateness/ability to engage

A lack of cultural awareness of providers was reported to be a substantial barrier in communicating in the primary health care setting. Deaf participants reported that the most frequently used methods of communication in the absence of interpreters—lip-reading and hand-written notes—were inadequate.

And some doctors I've seen out of pure luck I think will communicate with me using pen and paper. But their handwriting is not very easy to understand. So it's almost like in complete italics and I can't understand it or barely understand the sentence. P1

Both interpreters and deaf participants identified barriers even in the presence of interpreters. Lack of provider knowledge about how to use Auslan interpreters affected the quality of communication, rapport between the provider and the patient and the effective use of time during the consultation. Limited time compounded this problem.

I'm not finished explaining before the doctor sort of is giving more information, or the client hasn't finished signing to me, before you know, pushing in and asking more so a little bit more time and patience so always good for nice smooth interpreting appointment. I5

Visual aids were discussed as an important facilitator of communication, especially because Auslan is a visual language.

They like it when a doctor is able to use pictures to articulate what's going on. So if there's a word, they bring it up on the screen, so that you can then put two and two together. P4

Deaf Awareness Training was frequently suggested as an intervention by both interpreters and deaf individuals to facilitate better communication. Interpreters discussed the potential of their roles as cultural navigators and/or educators.

In the absence of interpreters, deaf participants reported that family members would often interpret for them. However, they also reported that they expressed that this compromised their autonomy and privacy.

My daughter, she can hear. She's now 11 years old. And she comes with me a lot of the time because I don't leave her at home on her own. And the doctor will go, 'Oh, great. She's here', and they treat her like an interpreter. But my daughter doesn't understand medical words. She's 11 years old. She doesn't understand the implications of what certain things mean. The name of medications are often long and complicated, and she doesn't understand that. So it's not something she feels comfortable doing either. P1

DISCUSSION

This study aimed to explore the barriers faced by the ADC in accessing and communicating within the primary health care setting and found many such barriers.

There are few studies currently that discuss the perspective of and the challenges faced by Auslan interpreters. The strength of this study is that by exploring such challenges, it provides a foundation for addressing the inadequacy of both the quantity of Auslan interpreters in the health care setting in Australia and the quality of their training. Furthermore, this study was able to reveal a discrepancy between the deaf patients' needs and the interpreters' perceptions, elucidated by patients who forgo interpreter use, which is only possible with both the deaf participants' and the interpreters' involvement with the study.

The barriers were analysed using the Levesque access framework and are discussed below.

Approachability

Deaf participants and interpreters reported significant barriers to accessing the information on health services. Consistent with the literature, participants reported a diversity of English literacy levels and expertize in Auslan in the ADC.[15,16] Deaf individuals with low levels of Auslan skills, in the absence of sufficient English literacy required to understand health information, found health information that had been translated into Auslan difficult to understand. The variation in Auslan skills compounds the lack of health information available to the ADC, since most health information is currently unavailable in Auslan.[13]

Availability and accommodation

Participants reported barriers to using traditional phone-based appointment systems, preferring text-based appointment systems.[3] This included not only arranging appointments but also follow-up confirmation or rescheduling. Although the NRS was available as a speech-to-text converter for appointments arranged by phone, deaf participants reported that the service was time-consuming, preventing timely access to often urgent care. A facilitator of access was the receptionist's familiarity with interpreters as well as the understanding that interpreters could only be present for a limited time, thus ensuring that the patients were able to be seen during the time that the interpreter was booked.

There were significant problems with the booking of Auslan interpreters. At the time this study was conducted, NDIS had superseded NABS for funding all medical interpreting services for deaf individuals under the age of 65. This shifted the responsibility of booking interpreters for GP consultations from the clinics to the deaf individuals themselves. Some interpreters identified this as a positive change, with patients being able to become more autonomous and empowered, as well as ensuring that the interpreters were requested for a future appointment. However, deaf participants are required to predict the amount of funding that they will require over the course of a year for medical interpreting. This can be impossible to predict, given that many health appointments are in response to new/unexpected health matters.

Although NDIS contributed to income stability for interpreters, it has also increased the number of nonmedical appointments for Auslan interpreters, reducing their availability for medical consultation. This issue has been compounded by the high attrition rate of Auslan interpreters due to poor working conditions, a highly casualized workforce and the restricted availability of training for Auslan interpreters.[10] Strategies to address the shortage of Auslan interpreters include promoting Auslan interpreting as a genuine career pathway in secondary education, providing training for specialisation in interpretation in health care settings and retention of the current workforce through professional development, competitive remuneration and career flexibility.[17]

VRI has been suggested as a potential tool to help overcome interpreter shortage, especially in rural and remote areas.[18] Interpreters in our study were consistently positive about the use of VRI, in particular noting that it could save travel time. Deaf participants, on the other hand, expressed mixed views. Some reported that doctors were sometimes unable to show themselves via video, so nonverbal communication could not be observed. This affected the ability to develop rapport with the doctor. Furthermore, the widespread adoption of VRI requires access to appropriate technology, the Internet and the skills to use it. Participants from both groups reported that the coronavirus disease 2019 (COVID-19) pandemic had prompted a significant number of people to access and develop skills to use such technology, resulting in an increase in people's acceptance and skills in using VRI.

Appropriateness and ability to engage

Both interpreters and deaf participants discussed the inadequacy of communication methods commonly used by health care providers, namely, lip-reading and written English, in the absence of interpreters. The insufficiency of lip-reading and written English as communication methods with deaf individuals has been well documented in the literature.[4,5,8,13] Previous studies suggested that both patients and providers overestimate the efficacy of these communication skills, when deaf people typically understand less than 30% of what an individual says through lip-reading, and instead gain understanding from contextual clues. Cultural sensitivity and visual aids were highlighted as two of the most prominent factors in ensuring that first, the deaf participant could communicate fully to the provider, and second, the provider can ensure the understanding of crucial information. Family members were often inappropriately asked to undertake the roles of interpreters. However, relatives not only risk inaccurate interpretation or withholding of information but their use also impinges upon the privacy and autonomy of the patient.[8,9]

Even when interpreters were available, the use of fully certified Auslan interpreters was insufficient to ensure complete understanding and a satisfying doctor–patient interaction. A significant proportion of health concepts do not have an Auslan sign.[19] Therefore, Auslan interpreters have often been required to ‘unpack’ the meaning of medical terms to the deaf patients. Furthermore, specific training for interpreting in the medical setting is not included in Auslan; interpreters currently do not train specifically for the medical setting, which can mean that more time is required to fully interpret the meaning. Compounding the problem, some clinics would require double bookings for patients accompanied by interpreters, with the patient incurring an additional fee.

Deaf Awareness Training for helth care providers was highlighted as the key interventional strategy by deaf participants and interpreters. Deaf Awareness Training in Australia is conducted by local Deaf Societies, usually by a deaf person, and seeks to raise cultural awareness and the communication needs of the ADC.[2]

Implications and further research

This study described the barriers that the ADC has faced in their access to and communication within the primary health care system. However, further research is required to ascertain the facilitators that can mitigate such barriers, especially regarding the national, systematic shortage of interpreters.

Furthermore, this study shows a discrepancy even among the ADC in their experiences and perceptions of health care. There is considerable variation between deaf individuals for factors such as level of hearing impairment, age of sign language acquisition and whether they were raised in a hearing or a Deaf environment. By stratifying data according to these factors, new themes may emerge.

Future research could also extend beyond primary health care and explore the needs of the ADC in the broader health care system, including tertiary and emergency health care.

Limitations of the project

Deaf participants were all recruited online, and only online interviews were possible because of restrictions due to the COVID-19 pandemic at the time. This may limit the generalizability of our findings, especially for individuals without access to or skills in using online technology. The small number of deaf participants recruited meant that we were unable to reach data saturation, so further research with deaf participants would be valuable.

It is possible that there was a negative bias in the study results. Deaf individuals were very vocal about their negative experiences with their access to health care access. The individuals were recruited from an ADC social media page, which individuals have been observed to utilize to discuss negative experiences that they have had as hearing-impaired persons. Interviews were conducted in an inductive manner. As more themes surrounding negative experiences of deaf individuals had emerged, less questions were subsequently focused on exploring positive experiences regarding the health care system.

CONCLUSION

It is known that the ADC has faced significant barriers to accessing primary health care due to the lack of availability and use of Auslan interpreters, insufficient cultural knowledge, health care providers' attitudes regarding the ADC and systemic barriers. This study contributed knowledge about these barriers by identifying, for example, appointment systems that did not accommodate the needs of deaf people, inadequate availability of interpreters, culturally inappropriate GP practices and ineffective GP communication methods. The study described how these barriers can be addressed through tools such as visual aids and text-based clinic appointment systems. Strategies to address systemic access barriers were identified. These included increased resources and training for interpreters to work competently in the health sector and changes to how the NDIS system funds individuals for Auslan interpretation in primary health care settings.

More research is needed to inform ways to increase the interpreter workforce and to improve the skills of primary care providers to use them. There is also a need for research to inform how to improve NDIS-funded access to interpreters for the ADC.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Phoebe H. Lee conducted the entire data collection and wrote the first draft of the article under the supervision of Catherine Spooner and Mark F. Harris. Phoebe H. Lee conducted all interviews as part of a research elective for medical training. Phoebe H. Lee was trained and supervised by Mark F. Harris and Catherine Spooner. All three authors made substantial contributions to the conception and design, analysis and interpretation of data; were involved in revising the article critically for important intellectual content; have given final approval of the version to be published and have participated sufficiently in the work to take public responsibility for appropriate portions of the content; and have agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author if approval is obtained from the UNSW Human Research Ethics Committee. The data are not publicly available due to privacy or ethical restrictions.

AAPPENDIXAUSTRALIAN SIGN LANGUAGE AND ACCESS TO PRIMARY HEALTH CARE

Interview questions for deaf participants

- 1.

  Do you think that deaf people experience barriers in accessing/booking general practice appointments, especially when compared with the hearing population? If so, what do you see as the main barriers?

- 2.

  Tell us about your own experiences in accessing and seeing a GP.

•3.

Is there anything that helps or makes it easier for deaf people in accessing a GP?

•4.

Tell us about your experiences when communicating with a GP.

•5.

Is there anything that helps or makes it easier for deaf people to communicate with a GP?

•6.

What have you found helpful in communicating more easily?

•7.

What do you see as the main barriers for deaf people communicating with general practice staff?

•8.

What about your own experiences in communicating with general practice staff or GPs?

•9.

How do you think the health care system could better respond to the needs of the Deaf community?

•10.

Is there anything more you would like to say or ask?

Australian sign language and access to primary health care

Interview questions for interpreters

•1.

What do you see as the main barriers in accessing general practice for deaf people?

•2.

Is there anything that helps or makes it easier for deaf people to see a GP?

•3.

What do you see as the main barriers for deaf people in communicating with general practice staff?

•4.

What have you found helpful in making communication easier between the patient and the GP?

•5.

(For interpreters) As an interpreter, how effective is the current National Disability Insurance Scheme/booking system for the GP setting?

•6.

How do you think the health care system could better respond to the needs of the Deaf community?

•7.

Is there anything more you would like to say or ask?

DETAILS

Subject:	Health care access; Hearing loss; Communication; Patients; Health care; Health insurance; Visual aids; Primary care; Interpreters; Recruitment; General practice; Cultural sensitivity; Accommodation; Health education; Family physicians; Hearing; Health information; Barriers; Contextual factors; Facilitators; Mass media; Fluency; Deafness; Interviews; Consent; Adequacy; Flexibility; Sign language; Insurance; Social media; Communication skills; Medical personnel; Disability; Literacy; Community health services; Health care industry; Health services
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Caring for a sick or injured child during the COVID-19 pandemic lockdown in 2020 in the UK: An online survey of parents' experiences

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ABSTRACT (ENGLISH)

Background

During the COVID-19 pandemic, the first UK lockdown (March to May 2020) witnessed a dramatic reduction in children presenting to primary/emergency care, creating concern that fear of the virus was resulting in children presenting late.

Methods

An online survey was co-developed with UK parents to understand the impact of the lockdown on parents' help-seeking for, and care of, their sick/injured child(ren). The survey was advertised through social media and snowballing to parents whose children had been ill/injured during the lockdown. Analysis used descriptive statistics, SPSSv25 and thematic analysis.

Results

The survey was fully completed by 198 UK parents. The majority asked for help (144/198): from their family doctor (78), national helplines (48) or an Emergency Department (23). Most reported that their decision-making had not changed, although how they sought help had changed. A few parents reported that the severity and duration of illness had increased because of uncertainty about and/or difficulty accessing services. Parents did not always report seeking help for symptoms rated red or amber by the Royal College of Paediatrics and Child Health. Parents reported accessing information through the internet or using information that they already had.

Parent Contribution

This was a collaboration with parents from survey development to dissemination, with two parents being integral members of our research team.

Conclusions

Our questionnaire was completed by parents who were not deterred from seeking help for their sick or injured children. Even for these parents, the lockdown changes to services created uncertainty about, and barriers to, accessing medical help for their children.

FULL TEXT

BACKGROUND

Before the coronavirus disease 2019 (COVID-19) pandemic, significant numbers of children in the United Kingdom were being brought to primary and secondary care services with relatively low rates of admission.[1–3] Given the low incidence of serious disease in children, policy makers and service providers felt that improvements could be made regarding parents' knowledge of childhood illness, when to seek help and how to care for their children with minor illness.[4–8]

During the first lockdown between March and May 2020 in the United Kingdom, when all nonessential shops and services including schools were closed, the numbers of children presenting to primary and emergency care fell significantly[9–13] by up to 50% for all presenting conditions. While serious illness, such as sepsis, is relatively rare, this dramatic fall led to concern that children were not being brought to medical services and were potentially becoming more ill at home. These findings were supported by surveys of United Kingdom, Irish[12] and Dutch[14] paediatricians who were asked to report children presenting late to hospital. Before and during the pandemic, a small proportion of children were reported to present late in the course of an illness, as indicated by RAG (red, amber, green) symptoms of illness severity (based on the Royal College of Paediatrics and Child Health's [RCPCH] safety net tool[15]). RAG systems ascribe a relative risk to a collection of physiological and behavioural characteristics and assign a green (safe for discharge), amber (needs evaluation) and red (needs specialist input and treatment) label to them. Examples include the UK's National Institute for Health and Care Excellence (NICE) Feverish illness in Childhood (2019) and Sepsis guidelines (2017).

However, it remains unclear whether late presentations increased during the pandemic.[16] Anxiety about using health services because of fear of infection, amongst the public, was reported during earlier epidemics: SARS (2003) in Canada[17] and Taiwan,[18] Ebola in West Africa (2014–2016)[19] and H1N1 (2009) in Hong Kong[20] and in Turkey.[21] In the United Kingdom, it was assumed that it was the worry about becoming ill with COVID-19 that was causing parents to keep their children at home when they were ill or injured.[22] Messages from the UK government initially asked the public to avoid using health services unless it was really necessary. These messages included '*only call 111* [the National Health Service (NHS) telephone helpline NHS111] *if you're unable to get help online'*. Although this advice no longer appears on government websites, it continues to be repeated across UK regional health service webpages.[23–25] This reduction in access to services may also have created positive outcomes for parent's self-care of their children, as they may have developed ways of coping with, and managing, their child's illness or injury independently.

At the time of this survey, there was no evidence to explain why the numbers of children presenting to healthcare had fallen, nor was there any information about whether parents were using other health services instead or seeking help or information elsewhere. Understanding how parents seek help for sick or injured children during a pandemic is essential if services are going to be configured to support parents to ensure timely access to health services in the future. We designed the survey reported here to gather evidence directly from parents.

AIM

This study aimed to understand the impact of the first UK lockdown on parents' help-seeking for, and care of, sick or injured children during the COVID-19 pandemic.

RESEARCH QUESTIONS

- How did parents seek help for sick or injured children during the lockdown?
- How did parents care for sick or injured children during the lockdown?
- How did parents' help-seeking for, and care of, sick or injured children change during the lockdown?
- Why did parents' help-seeking behaviours for sick or injured children change during the lockdown?

METHODS

The study used a descriptive survey design to rapidly gather data from a large sample of parents while the first UK lockdown was still in place. This approach enabled data collection while parents' experience of managing a child with an illness or injury during lockdown was fresh in their minds. An online SNAP survey (www.snapsurveys.com) was chosen to enable anonymized data collection without the need for face-to-face contact, thus avoiding any additional risk of exposure to COVID-19 infection. See Supporting Information Appendix S1 for the survey questions. Surveys have the advantage of facilitating the collection of data from a wide range of participants who are geographically disparate. The survey consisted of multiple-choice questions with 'other' options to add free text to explain alternative responses. Questions within the survey were designed using evidence from research exploring parents' usual care for sick or injured children at home and their decision-making about seeking medical help for their children.[26–30] Questions about the symptoms that their child had experienced were structured using the poster developed by the RCPCH to help parents know when to seek help for a sick or injured child.[15] The phrase 'Stay Home period' was used in the survey to refer to lockdown as this was the term used by the UK government at the time. The resulting questionnaire was reviewed twice by a small group of parents (drawn from a parent panel and parent members of existing research teams) to establish face validity. Phrasing and sequencing of questions were changed following each parental review. The survey took approximately 5–10 min to complete. A 'save and return later' option was provided, bearing in mind parents' busy lives. As the aim of this survey was descriptive, a power calculation was not performed. However, for a sample size of $n = 100$, the 95% confidence interval for a 0.5 (50%) estimate of proportions is approximately 0.4–0.6 (40%–60%).[31,32]

Parent contribution

Parents have been involved in the project as research team members and consequently have contributed to each stage of the work as their own lives permit. These parents reviewed the survey, helped to disseminate the survey through social media and commented on the write-up of the findings. Having more than one parent in our research team ensured stable engagement from our parent collaborators. This was important because family life can be unpredictable as the needs of children change from moment to moment.

Ethical considerations

Participant information about the purpose and conduct of the research was provided at the beginning of the online survey, which concluded with a statement that choosing to complete and submit responses to the survey equated to giving consent to their responses being used in the project. The survey introduction also included a statement about the anonymity of responses (no personal identifiable data were collected) and the corresponding inability to withdraw responses once submitted. Information was also provided on how the data will be used and disseminated. Ethical approval for the project was granted by the University of Plymouth's Faculty of Health research ethics committee on 5 May 2020 (Ref 2020–2216). Data will be stored securely on the password-protected University OneDrive for 10 years in accordance with University policy.

Study participants

We asked parents whose children aged under 18 years were ill or injured during the first pandemic lockdown living in the United Kingdom at the time to participate. We excluded those whose children had not been ill or injured and/or who were living outside the United Kingdom.

Recruitment

Parents were recruited through social media and snowballing. Information about the survey was posted on Twitter and Facebook and emailed to professional contacts (outside the NHS) with a request that colleagues share the information about the project with their contacts. The survey was also advertised on charity and other non-governmental organizations' websites (*n* = 15) and professional organizations' (*n* = 33) websites. We used Google Docs to keep track of where survey information was shared. This method was selected following the success of a survey of children's and parents' access to information about COVID-19 during the lockdown.[33] A short introduction to the survey for use on social media was circulated to all our contacts; see Supporting Information Appendix S2. The survey was open to parents from 7 May to 21 June 2020, by which time lockdown in the United Kingdom had eased, with some children returning to school and nonessential shops reopening. Despite additional advertising, at this point, survey completion had also fallen, probably as the survey no longer seemed relevant to parents.

Data analysis

Statistical data were analysed using descriptive statistics and SPSSv25. The free text data were analysed thematically, drawing on Braun and Clarke's[34] methodology to identify themes within the qualitative data. The level of severity of symptoms was identified using the RAG traffic lights coding in the RCPCH advice for parents.[15] These RAG ratings were then used to explore how parents responded according to professional categorization of the severity of symptoms.

RESULTS

The survey was fully completed by 198 parents who reported that their child had been ill or injured during the lockdown; please see Supporting Information Appendix S3 for the numbers of completions in each week the survey was open. Incomplete returns (*n* = 204) were not included in the main analysis. However, of these 204 incomplete surveys, 53 completed the two main questions related to help-seeking behaviour before lockdown and during lockdown; a breakdown of the completeness of surveys can be found in Supporting Information Appendix S4. This subset of 53 partial complete surveys was compared to the 198 completed surveys (Supporting Information Appendix S5). Completed surveys were fairly evenly divided between those concerning boys and girls (104/94;

52/48%). A quarter (25%) had a pre-existing illness, most commonly atopic illness (asthma, eczema, allergy). The majority of returns concerned illness in the age group of 5–12 years; see Table 1 for details on the age of the children by presentation.

Table 1 Age of the children by presentation

Age of the child	Illness, *n* (%)	Injury, *n* (%)	Total, *n* (%)
Under 12 months old	11 (91.7)	1 (8.3)	12 (6.1)
12 months or over, but under 24 months old	12 (70.6)	5 (29.4)	17 (8.6)
2 years or over, but under 5 years old	26 (70.3)	11 (29.7)	37 (18.7)
5 years or over, but under 12 years old	70 (70.7)	29 (29.3)	99 (50.0)
12 years or over, but under 16 years old	19 (73.1)	7 (26.9)	26 (13.1)
16 or 17 years old	6 (85.7)	1 (14.3)	7 (3.5)
	144 (72.7)	54 (27.3)	198 (100.0)

Parents with children of primary school age (5–12 years) were more likely to fully complete the questionnaire, and those with children over 12 were more likely to drop out from the start (Supporting Information Appendix S6). Those with children less than 5 years tended to complete data on age and gender and then drop out. There was no difference by gender. The remaining results are for the 198 complete surveys only.

Most families (126/64%) selected urban as a description of the area where they lived; 72/37% chose rural as a description of the area where they lived. The largest group of respondents were from the South West of England (83/42%), although the sample did include parents from every area of the United Kingdom (see Supporting Information Appendix S7).

Symptoms reported by parents

Parents reported a wide range of symptoms in the categories provided (Table 2), and a further 73 signs and symptoms were added in the 'Other' category. These 'Other' symptoms included 19 gastrointestinal symptoms, 15 'cough', 17 skin infections or inflammation, 3 dental problems, 3 foreign bodies, 4 sleepiness or fatigue, 3 mental health crises and one each of the following: allergic reaction, neck pain, hernia, shaking and loss of smell and taste. In each main symptom group, we identified those who also reported asking for help or not asking for help. The only significant difference between categories was for 'Other' symptoms—more 'Other' sought help than those with predefined symptoms ($\chi^2 = 8.7$, 1 *df*, $p = .003$); no correction was made for multiple tests. However, as this was a heterogeneous group, no clear conclusions can be drawn.

Table 2 Symptoms reported by parents (more than one answer possible)

Symptom group	Number of responses	Asked for help, *n* (%)	Did not ask for help, *n* (%)

Pain	107	73 (68.2)	34 (31.8)
Change in behaviour	58	42 (72.4)	16 (27.6)
Injury	54	43 (79.6)	11 (20.3)
Skin	39	33 (84.6)	6 (15.4)
Breathing	36	27 (75.0)	9 (25.0)
Dehydration	35	21 (60.0)	14 (40.0)
Temperature	26	19 (73.1)	7 (26.9)
Other	73	62 (84.9)	11 (15.1)

Each symptom contained a number of items reflecting those included in the RCPCH advice for parents[15] within which symptoms are rated for severity using RAG ratings. The RAG rating for each item was retained in the analysis and an overall RAG rating was identified for each child (the highest RAG-rated symptom reported by parents for the individual child; see Supporting Information Appendix S8 for examples of how this was worked out for individual children). This approach enabled us to map the RAG rating for the child against parents' reported help-seeking; see Table 3.

Table 3 Overall RAG rating for each child and parents who reported help-seeking

	Overall RAG rating for each child			
Parents reported help-seeking	Green	Amber	Red	Total
Did you ask for medical help for your child for this illness/injury?, *n* (%)				
Yes	36 (72.0)	78 (71.6)	30 (76.9)	144
No	14 (28.0)	31 (28.4)	**9 (23.1)**	54
Total	50	109	39	198

Note: The bold numerals highlight the number of children with red RAG rated (serious) symptoms whose parents reported not seeking help.

Abbreviation: RAG, red, amber, green.

Worryingly, 9 parents' reported symptoms rated red (for further details, see Supporting Information Appendix S9a) and 31 reported amber-rated symptoms for which they did not seek help. When asked what their usual response would be for this illness before the lockdown, 8 parents reporting red symptoms and 24 reporting amber symptoms said that they would normally care for their child at home. Interestingly, three parents who asked for help this time would not normally have done so and parents sought help for 36 children RAG-rated green (see Supporting Information Appendix S9b).

Parent's reported sources of help for a sick or injured child during the lockdown

The majority of parents did ask for help for their child (144/198, 73%), most commonly from their General Practitioner (GP)/family doctor (78), NHS111/NHS24 national telephone helpline (48) or an Emergency Department (ED) (23). See Table 4 for all sources of help reported. The total number in the table exceeds the number seeking help as some people reported using more than one source of help.

Table 4 Sources of help used by parents

Source of help	Number of responses
Emergency department	23
Called 999	5
Children's Assessment Unit or Open access to children's ward	2
Dental services	2
GP out of hours	4
GP phone consultation	2
GP surgery	64
GP website	8
Health professional family member	1
Health visitor	1
Homeopath	1
NHS111/NHS24	48
Pharmacist	1
Specialist nursing or medical services	5
Urgent care or minor injuries service	18
Video consultation	5

Walk-in centre	2

Abbreviation: GP, General Practitioner.

We asked parents to tell us more about their experiences of seeking help. These free text responses fell into two broad groupings: positive and negative experiences.

Positive experiences included receiving detailed advice that supported home care or provided information about what to do if their child deteriorated, GP consultation systems that facilitated assessment without face-to-face contact including video consultations, telephone consultations and the ability to send the GP photographs and helpful follow-up calls. Phone consultations were reported to be quick and thorough. Parents found these systems reassuring. Parents also reported positive experiences when having to seek face-to-face help as they found that the protective systems in place reassured them that the risk of COVID-19 infection in that health service was low.

Negative responses included fear of COVID-19, which was reported by two parents to have resulted in up to 7 weeks' delay in seeking help, fear of attending face-to-face services and panic when having to attend. One parent reported that the GP they consulted appeared to be scared to conduct a physical examination. The appearance of professionals in full personal protective equipment increased anxiety for one parent. Concern about burdening the NHS appears to be secondary to worry about contracting the coronavirus. One area that was repeatedly reported to present difficulties was NHS111. Several parents reported difficulty getting through, one parent giving up and going to ED, long waits for call backs of up to 6 hours and call handlers treating every illness as COVID related.

The impact of the pandemic on the way in which services were delivered was also reported to impair access to services, resulting in delayed treatment, with a consequent increase in the duration and/or the severity of illness. For example, one child had an ear infection that was reported to progress to perforation as a consequence of not being able to access treatment earlier. Access to mental health services was also reported to be difficult, with a no face-to-face consultation rule resulting in increasing severity of mental illness. Access to emergency dental services was reported to be impossible by one parent, leaving their child in pain.

Mixed experiences were reported by several parents who found that communication between different parts of the health service was at times poor and/or inconsistent; at other points in the illness journey for their child, they reported receiving excellent, informative care. The result of these mixed experiences was increased uncertainty about their child's illness and treatment.

Overall, the response of services to the pandemic has brought about positive and negative changes. Positively, the increase in virtual consultations was welcomed by parents, whilst negatively, access to some parts of the health service was severely impaired.

Parents' self-reported care of their sick or injured children during the lockdown

Responses to the question about what else, other than seeking help, parents did about their child's illness or injury revealed that 106 parents treated their child themselves, 90 parents waited to see if they got better, 76 parents looked for information on how to manage the illness or injury at home and 48 parents used information they already had.

Where parents responded that they cared for the child themselves, we asked about what they used to treat their child. Collated results of the responses in predefined categories and responses added in the ‘Other’ category are presented in Table 5. Paracetamol or ibuprofen was the most commonly reported home treatment. This may reflect the number of children who were reported to experience pain and/or cultural preference in the United Kingdom for antipyretics/analgesics as the first line of treatment at home.

Table 5 Self-care by parents

Home treatment reported	Number of responses
Antipyretics/analgesics (paracetamol/ibuprofen)	115
Home care	
General illness or injury care (rest, cuddles, treats, etc.)	83
Injury care (icepack, cleansing, bandaging, etc.)	45
Prescribed medication (Inhalers, topical/oral steroids or antibiotics)	19
Over-the-counter remedies (Vicks/Karvol, antihistamines, topical creams, gripe water, ear drops, throat lozenges)	16
Home remedies (e.g., honey and lemon, steam inhalation)	6
Nursing/medical care (e.g., chest physio., suction, OCD therapy etc.)	4
Complementary medicine	3
Medication from overseas (Smecta, France)	1

Parents' information-seeking

Most parents (122, 62%) used no sources of information, 32 parents (16%) used one source of information and 44 parents (22%) used more than one source of information. Parents who reported looking for information on how to manage the illness were asked about the source of this information. The most common choices were from the internet (39), including NHS Choices (33), NHS App (22), Google (17), GP website (6), other websites (7) and social media (1). Family (8), friends (6) and family health professionals (11) were also reported sources. Traditional media such as television, radio and print media were not reported to be used by any parents. Other things that parents reported using were peer-reviewed literature (2) and the *Little Orange Book* from the North East of England (1). Information that parents already had in the home was reported to be from a family health professional (13), family or friends (6) and internet sources (9). The 'Other' responses consisted of six parents who reported using information from previous contacts with health services, five parents who were health professionals and used their own professional knowledge, three parents who referred to information from a specific health professional, team or service and one parent who used information from health professional friends and NHS111.

Parents liked information that was clear and concise, explained the cause and management, provided reassurance and confirmed knowledge, treatment and the need for treatment. Parents also liked information that provided a perception of the availability of advice, if needed, and that it was safe to use services. Information was either verbal or written. Parents liked information that included the following:

- Safety netting information on what symptoms to look out for including symptoms of COVID-19, what to avoid, normal ranges and how long to wait before seeking help.

- Symptom-specific information such as fever, diarrhoea, vomiting, rashes, heatstroke symptoms, signs of appendicitis, etc.
- Information on how to care for their child.
- Information on treatment of their child's illness.

Unhelpful information was described as information that was too slow to access (NHS111/NHS24), not specific to the age of the child, vague, unclear, incomplete (on self-isolation and COVID-19 testing), confusing or conflicting. Conflicting information was reported to be scary, as was information on potential causes of an illness. The internet was unhelpful for some as it provided too much information. Social media was disliked for spreading gossip and rumours, while mainstream news media was reported to be ‘COVID scary,' with much speculation, reflecting the difficulties of living with uncertainty during the pandemic.

Information about the pandemic and when to use health services

We also asked parents about where they had seen information about the pandemic. The majority (156) had seen NHS sources of information or information from government sources (126). Other frequently reported sources were from family/friends on social media (52), experts on social media (44) and other online experts (33). Two parents specifically mentioned BBC News.

Parents reported seeing information about when to use NHS111 (158), GP services (136) and EDs (120), showing that although this messaging was reaching the majority of parents, there was a significant group who were less informed, adding to their uncertainty about where to seek help when their child was ill or injured. We also asked what new advice on health service use they had seen since the beginning of the lockdown. Many parents were aware of advice to stay at home, self-isolate if you have symptoms and phone first before seeking any face-to-face access to services.

Free text replies revealed that parents were aware of advice to either try not to call NHS111 in the early stages of the lockdown or to only call NHS111 with severe symptoms of COVID-19 to later advice to call NHS111 first before calling the GP or attending ED. Parents also reported awareness of advice not to attend GP surgery or ED unless it is an emergency. Parents reported that they had heard that walk-in centres, dentists and Child and Adolescent Mental Health Services (CAMHS) were all closed. Later on during the lockdown, parents reported having seen TV adverts reassuring people to continue to use the NHS, specifically not to hesitate to take a child to ED, which parents commented they had not seen before the pandemic. Appointments were reported to be replaced by phone calls, video calls, texts and emails. However, there were some free text replies from parents who were not sure, thought there were no changes or who found information unclear, confusing and were uncertain about what to do.

Impact of the changes to health services during the lockdown

The majority of parents (150, 75%) reported that the changes to health services had not affected the severity of their child's illness. Other parents thought that it had affected the severity of their child's illness (26), may have affected it (13) or did not know (9). Free text responses explained that, where there was an impact, it was related to the lack of a physical examination of their child and lack of access to, or delayed, investigations resulting in misdiagnoses (and wrong treatment), as it took longer to diagnose the illness and to obtain treatment. The consequences of these delays were reported to be more serious illness (physical and mental), longer duration of illness and slower recovery. Some parents also reported remaining uncertain about the nature of their child's illness.

More parents (42%) reported an impact on their child's treatment (51 yes/32 may be) rather than on the severity of their child's illness. Parents' free text responses included the following explanations for this impact. Cognitive behavioural therapy, operations and investigations were cancelled, as were routine treatment reviews for those with long-term health needs, routine immunizations and developmental checks. One parent also reported that the type of surgery changed to a more invasive form (open rather than keyhole). All of these will have effects in the longer term beyond the pandemic. Virtual assessment was reported to lead to incorrect treatment and possible overuse of antibiotics. One parent reported reducing the dosage of paracetamol administered to a child so that their stock would last to the end of their self-isolation period. Several parents reported the lack of access to physiotherapy services as it is ‘hard to do physio over the phone’. One parent expressed that the loss of this service may have long-term effects on the health of the child concerned. Positively, another parent reported that, when they did need to use the ED, they were treated quickly and effectively as the department was very quiet.

How did parents' help-seeking for, and care of, a sick or injured child change during the lockdown?

We asked parents whether or not they sought help for this episode of illness or injury in their child and what their usual response to this illness or injury would have been before the lockdown and compared their responses; see Table 6.

Table 6 Comparison of help-seeking before and during the lockdown

Did you ask for help (in lockdown), *n* (%)	Would you *normally* have asked for help		
	Yes	No	Total
Yes	130 (67)	13 (6.7)	143 (73.7)
No	25 (12.9)	26 (13.4)	51 (26.3)
Total	155 (79.9)	39 (20.1)	194 (100.0)

Note: *N* = 194 [excludes 4 (2.0%) people who did not know or who would do ‘Other’].

Given the anxiety expressed by many of the parents, it was surprising to find that most parents did not report changing their decision to seek help during the lockdown. Although 25 parents (13%) who said they would normally seek help did not do so during lockdown, a smaller group (13/7%) reported seeking help who would not normally have done so.

When we compared help-seeking for children with illness compared to help-seeking for injury, we found no significant difference (2 ×2 cross tabulation: $\chi^2 = 1.78$, 1 *df*, $p = .18$).

There were differences in the places that parents reported seeking help; see Table 7. Some of these can be explained as responses to the advice to Stay Home unless it is an emergency, such as an increase in the use of the NHS111 telephone advice line, video consultations and use of the GP website. Numbers reported to attend some face-to-face services fell (minor injuries unit/walk-in centre, GP surgery), but more parents reported using ED than they said they normally would.

Table 7 Where parents reported seeking medical help for their child's illness or injury

	Normally	Lockdown
Emergency department	11	23

Called 999	5	5
GP out of hours	4	4
Minor injuries unit	20	12
Urgent care centre	1	5
Walk-in centre	4	2
Video consultation	0	5
GP website	1	8
GP surgery	82	64
NHS direct/NHS 111/NHS 24	20	48
Somewhere else	9	16
Total asked for help	155	143
Did not ask for help	43	54

Abbreviations: GP, General Practitioner; NHS, National Health Service.

Why did parents' help-seeking behaviours for a sick or injured child change during the lockdown?

Parents who reported not seeking help during the lockdown were asked why they did not seek help. This was a multiple-choice question to which parents responded as follows: 27 were not sure their child was ill or injured enough; 19 were worried about catching COVID-19; 18 were worried about using a service needed by other people; 9 were worried about being criticized for using services if it was not an emergency; 8 were worried about it being busy and having to wait a long time; 4 parents reported that they did not have anyone to look after other children; and 1 parent reported that they did not have a car and did not want to use public transport. In the accompanying free text responses, some of the parents mentioned that their children's illnesses spontaneously resolved. Parents reiterated their fear of COVID-19 and consequently of using services, and their confusion about where and when to seek help. Some parents also mentioned their need for information and equipment to be able to monitor their child at home when access to services was limited.

DISCUSSION

We aimed to understand the impact of the first lockdown in the United Kingdom on parents' help-seeking for, and care of, a sick or injured child because the reduction in children seen by health services had raised concerns that parents were avoiding seeking help for their children because of the fear of COVID-19. Parents did report worries about contracting COVID-19; however, this anxiety did not appear to deter the majority of parents (73%) responding to this survey from seeking medical help for their child. There was a group of 25 parents (13%) who said that they would normally seek help, but did not do so during lockdown. Like the parents in Nicholson et al.'s[35] survey, parents may have been more anxious about contact with health services. A small group of parents (7%) sought help who said they would not normally have done so. This may reflect the impact of uncertainty about access to services on parents' help-seeking behaviour reported in earlier research.[36,37] There were some changes to the places that parents sought help, with the move to more telephone and video consultations. Surprisingly, more parents reported use of the ED than said they normally would have done for that illness/injury, contradicting results from attendance data that reported a reduction in ED attendance during lockdown in the United Kingdom and Italy.[9–13] However, this was a relatively small sample; consequently, the findings have limited generalizability. Of course, the overall incidence of illness or injury in children everywhere, during lockdown, may have been much lower than in normal circumstances. Children's exposure to all infections was reduced by social distancing measures and their restricted environments also reduced accidental injuries.[22]

A few parents reported that changes to services, especially the reduction in face-to-face consultations and the cancellation of some services, led to lack of access to, or delay accessing, healthcare, providing another explanation for the reduction in child consultations. National data on antibiotic prescribing showed a significant reduction during the first lockdown, particularly in the South West,[38] which may indicate a reduction in access to prescribing services and/or a reduction in infections in children and, in the South West, a reduction in the tourist population.

Most parents reported providing some care to their children independently at home, most commonly paracetamol or ibuprofen, which may be related to the high number of children for whom pain was reported as a symptom. The next most common symptoms reported were behavioural changes and injury, with symptoms of acute illness reported much less often, possibly also reflecting the reduction in all infections. Analysis of the professional severity scoring (RAG rating) of the symptoms reported highlighted a small group of parents who did not seek help for red or amber symptoms. Few parents reported using information already present in the home to help them manage their child's illness/injury. Most looked online for information, which can be scary, inconsistent or confusing.[8] Together, these results indicate that safety netting information, to help parents determine the severity of their child's illness and whether or not they need to seek medical help, is still not easily available in a reliable form for parents, repeating earlier findings.[8,39] Lim et al.[40] trialled a leaflet on the recognition of serious illness in children during the lockdown in the North East of England and found that parents felt it increased their confidence, although few had used the leaflet for a sick child. Mobile apps available in this area were not referred to by parents completing our survey.

Strengths and limitations

This was the first detailed survey that aimed to establish how the first UK lockdown during the pandemic influenced parents help-seeking for, and care of, ill or injured children. We involved parents at every stage from design of the questionnaire to editing this paper. Patient and public involvement is considered to result in better-quality research,[41,42] although there is no evidence concerning the most effective methods for doing so in child health research.[41] Multiple-choice questions provided a picture of responses for the whole sample, which were then augmented by the detailed free text responses.

The results included data from all four countries of the United Kingdom. However, far more people completed the question from the South West, illustrating the power of personal networks in engaging people in research, as the project leads were based in the South West. The sample included families living in both urban and rural settings and children across the childhood age range. However, the biggest group of returns was from parents of children aged 5–12 years. This does not reflect the age group with the highest incidence of childhood illness/injury or use of health services prepandemic,[3,43] but *may* represent the group whose parents were able to find time to complete the questionnaire. Alternatively, the reduction in infections may have been greater in this younger group of children. Public health services for the younger age group (0–2 years) were reduced/suspended[44]; consequently, this group of parents may have changed their help-seeking during the lockdown as they were unable to access health visitors (UK public health nurses). No data were gathered to indicate how help-seeking for this group of parents changed.

Use of symptoms drawn from RCPCH (2020) advice for parents enabled categorization of the severity of symptoms reported. This was also a limitation as it did not include symptoms that are known to cause parents to worry, such as cough, gastrointestinal symptoms or skin infections (commonly seen in primary care) that appeared in free text comments.

We did not collect information on ethnicity or socioeconomic status to maximize the number of returns, as we were not asking parents for detailed personal data. However, we did ask about the type of area where families lived and about their access to digital technology.

More parents might have completed the survey had there been funding available to advertise it or provide participating parents with incentives as illustrated by the survey conducted in Ireland.[35] Lack of funding limited survey advertising to our networks and social media; consequently, we could not reach those without internet connections within more marginalized populations, creating a sampling bias. Given the association between digital exclusion and poverty,[45] it is likely that we have not included the most disadvantaged families in our society whose health is poorer.[46,47] Had we have been able to capture data from these families, the results may have painted a different picture. We had a large number of people who did not complete the whole survey and so were not included in the main analysis. There is evidence that they were more likely to have been dissuaded from seeking help during the pandemic than those who fully completed the survey. We might extrapolate and assume that those who never started the survey were also more likely to have reduced help-seeking behaviour.[48,49]

CONCLUSIONS

The findings presented here show that in our sample, most parents were not deterred from seeking help for their sick or injured children. Instead, it was the changes to services during the lockdown that created uncertainty about, and barriers to, accessing medical assessment and treatment for their children. Together with findings showing that parents may not recognize potentially serious symptoms in their children, this indicated a need for easy access reliable safety netting information including contemporaneous information on local services.

When access to services is limited and parents have to monitor their children at home independently, parents also need equipment to assess their child's symptoms and a mechanism for communicating these symptoms to health professionals.

At the time of writing, the UK was in the midst of a third lockdown (January 2021). This highlights the importance of these findings being used to inform the development of interventions to improve parents' ability to determine when they need to seek help for a sick or injured child and support their access to services. Such resources will also help parents recognize the symptoms of COVID-19. Continued access to services, including the ability for clinicians to visually assess children, is also crucial to prevent an increase in the numbers of children presenting late with more serious illness.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

The original idea for the project came from Rachel Carter, and the project was led by Sarah Neill and Rachel Carter. The survey was designed by Sarah Neill and Rachel Carter. Joanne Hughes, Tracy Turner, Ray Jones, Damian Roland, Natasha Bayes, Alison Tavaré and Monica Lakhanpaul reviewed the survey, which was then revised by Sarah Neill. Ray Jones, Sarah Neill, Rachel Carter and Jade Chynoweth analysed the data. Sarah Neill wrote the first draft of the paper; all authors reviewed it and Sarah Neill revised it accordingly.

DATA AVAILABILITY STATEMENT

Data available on request from the authors.

DETAILS

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Do patient engagement interventions work for all patients? A systematic review and realist synthesis of interventions to enhance patient safety

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ABSTRACT (ENGLISH)

Background

Patients are increasingly being asked for feedback about their healthcare and treatment, including safety, despite little evidence to support this trend. This review identifies the strategies used to engage patients in safety during direct care, explores who is engaged and determines the mechanisms that impact effectiveness.

Methods

A systematic review was performed of seven databases (CINAHL, Cochrane, Cochrane-Central, Embase, ISI Web of Science, Medline, PsycINFO) that included research published between 2010 and 2020 focused on patient engagement interventions to increase safety during direct care and reported using PRISMA. All research designs were eligible; two reviewers applied criteria independently to determine eligibility and quality. A narrative review and realist synthesis were conducted.

Results

Twenty-six papers reporting on twenty-seven patient engagement strategies were included and classified as consultation (9), involvement (7) and partnership (11). The definitions of ‘patient engagement’ varied, and we found limited details about participant characteristics or interactions between people utilizing strategies. Collaborative strategy development, a user-friendly design, proactive messaging and agency sponsorship were identified as mechanisms to improve engagement about safety at the point of direct care.

Conclusions

Agency sponsorship of collaboration between staff and patients is essential in the development and implementation of strategies to keep patients safe during direct care. Insufficient details about participant characteristics and patient–provider interactions limit recommendations for practice change. More needs to be learned about how patients are engaged in discussions about safety, particularly minority groups unable to engage with standard information.

Patient or Public Contribution

Review progress was reported to the CanEngage team, including the consumer steering group, to inform project priorities (PROSPERO CRD42020196453).

FULL TEXT

BACKGROUND

Patients are often the only constant element in their healthcare journey and provide important contextual information for designing safe healthcare services.[1] The fact that patients can retrospectively identify unsafe events that occurred during their care is well established.[2–5] They also play an active role in their own safety by raising concerns or flagging inconsistencies and inaccuracies during healthcare interactions.[4] Over the past 20 years, interventions that encourage patients to discuss or raise concerns about inaccuracies relevant to their care have been implemented.[6–8] These interventions occurred simultaneously with evaluations of patient involvement in system- and service-level patient safety programmes, such as patient-led incident reporting systems.[9] The use of patient-centred tools and strategies to enhance safety has increased despite limited evidence about their effectiveness.

Limited research about the effectiveness of patient engagement, and the depth of engagement needed to promote safe care, is reflective of wider inconsistencies. There are various definitions of patient engagement, involvement and participation in the literature.[10] Carman et al.[10] defined patient engagement as ‘patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system’ (p. 224). The framework of engagement developed by Carman et al.[10] builds upon Arnstein's[11] work and classifies patient engagement across a continuum, ranging from patient consultation through to partnership. This engagement continuum spans three distinct spheres of patient engagement: direct care, organisational design and governance and policy making. In light of the variation in what constitutes patient engagement present in current research and practice, Carman et al.'s[10] definition and framework are used throughout this review. This paper focuses on engagement strategies implemented in the ‘direct care’ sphere of engagement. Carmen et al.'s[10] sphere of direct care aligns with the clinical point of care and refers to the period when clinicians deliver healthcare services or treatments to patients; this can be hospital or community based.[12]

With growing recognition of the value of engaging patients in healthcare design and delivery, and the susceptibility that some specific population groups have to adverse events, the need for better data about facilitating engagement is imperative. The literature identifies various system, service and clinical factors that support effective patient engagement such as education about their condition,[13,14] empowerment to engage[15,16] and the willingness and ability of clinicians and patients to communicate about safety.[17–20] The extent to which an organisation is committed to patient engagement is a measure in most organisational safety culture surveys, but there is little evidence of the enablers and system prerequisites to facilitate effective engagement.[21,22] Evidence of the enablers and system prerequisites for effective engagement have not been synthesized to support the implementation of such interventions.[22] Similarly, evidence about the nature and extent to which patients are engaged in safety is fragmented and lacks information about approaches for diverse populations, such as people from culturally and linguistically diverse (CALD) backgrounds or other communication needs.[8,21,23,24]

This systematic review aims to address the knowledge gaps identified above using a realist synthesis[25] to explore the following questions: (1) What interventions have been used to engage patients in safety during direct care and what is the mode of intervention (e.g., video, paper chart, electronic portal) and extent of engagement (e.g., number of opportunities, with whom)? (2) What types of patients and their contexts are described in the interventions? (3) What are the mechanisms that influence the effectiveness of consumer engagement approaches in enhancing safe care and treatment?

METHODS

A systematic review and realist synthesis were undertaken and reported in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) statement.[26]

Prospero registration number: CRD42020196453

Inclusion criteria: Studies published between January 2010 and December 2020 in English were included. All research designs were eligible, including qualitative, quantitative, multi- and mixed-method studies. All studies included participants who were healthcare consumers, patients, family members or other caregivers. Safety outcomes in the clinical encounters described encompassed increased notifications of or the prevention of safety breaches, errors, accidents, incidents, complications and infections. Selected interventions had to use patient engagement designed to minimize harm. Studies that did or did not include a comparator intervention were eligible.

Exclusion criteria: All studies outside the date range or published in a language other than English were excluded. Systematic or other literature reviews were not included, but their reference lists were searched. Studies that focused on methods beyond direct care, for example, to enhance governance or inform improvements to organisational safety for example, adverse event reporting systems or service governance, service planning, self-management or improving health, such as self-management for people with chronic conditions, were beyond the scope of the present review. Studies about patient involvement in training medical or nursing staff, patient attitudes towards safety or willingness to participate and studies about participatory research or codesign methods unrelated to safety were not included.

Study identification

The key concepts of patient engagement and unsafe healthcare were used to generate keywords, synonyms and phrases to inform a comprehensive search strategy (see File S1). The search strategy was applied to seven databases: CINAHL, Cochrane, Cochrane-Central, Embase, ISI Web of Science, Medline, PsycINFO January 2010 and December 2020. In addition to searching the reference lists of the included studies, hand searches of the following relevant journals were conducted to locate further potentially recently published eligible studies: *The Journal of Patient Safety*, *The British Medical Journal of Quality and Safety*, *The International Journal for Equity in Healthcare*, *BMC Health Services Research* and *The International Journal for Quality in Healthcare*.

Study selection and data extraction

Search results were exported to Endnote (X10) and duplicates were removed. Articles were then extracted to Covidence systematic review management software (Veritas 150 Health Innovation). Two reviewers (J. L. and B. J.) completed the initial title and abstract review, followed by an independent screening by a third reviewer (B. N). The inclusion criteria were then independently applied to full-text articles by two reviewers (B. N. and R. H.), with disagreements or uncertainty resolved through discussion. The following data were extracted: author, year, country, aims/objectives, setting, number of participants, participant characteristics, inclusion of diverse populations, method of data collection and samples, intervention/method of patient engagement, main findings and what worked (enablers, barriers).

Assessment of study quality

Due to the heterogeneity of the study types, the Quality Assessment Tool for Diverse Studies, a validated quality appraisal tool,[27] was used. Two reviewers (B. N. and K. J.) independently applied the 13 criteria to the included studies. The κ test was used to determine inter-rater reliability, and substantial reliability was confirmed (κ = .726).[28]

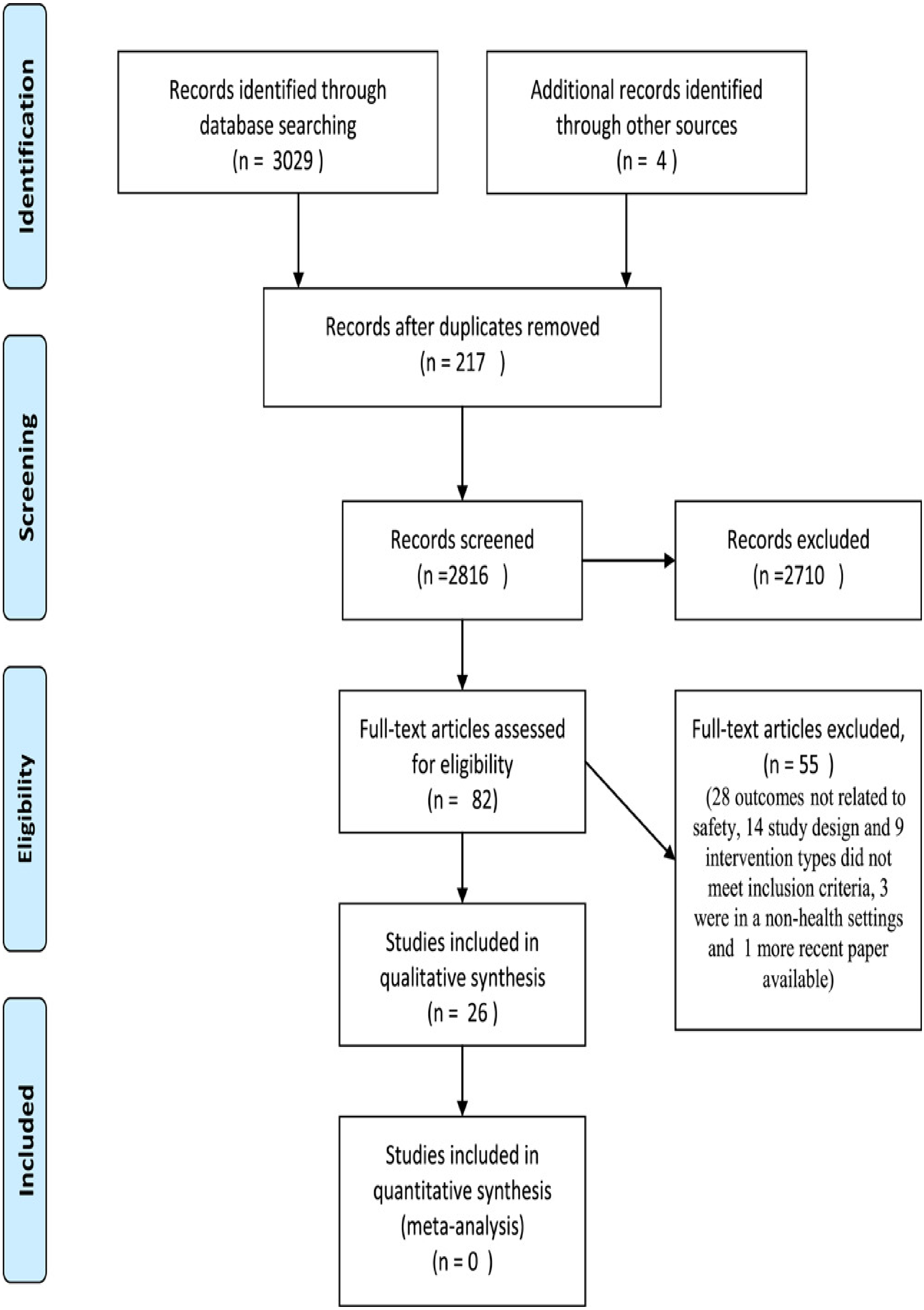
Data synthesis

Findings were synthesized using a narrative approach and the realist framework to explore which interventions worked, in what conditions and with whom.[25] Realist evaluation was selected because it examines the conditions that facilitate success rather than just information about whether the outcome or intervention 'worked'.[29]

Key findings relevant to the review questions were extracted, including barriers and enablers to implementation. Carman et al.'s[10] engagement framework was used to determine the extent of engagement in the interventions, and engagement strategies are described in relation to the three levels of engagement.

RESULTS

The systematic search produced 3029 papers, with 2706 studies excluded and 217 duplicates removed. A total of 82 full texts were reviewed and 55 were excluded (28 included outcomes not related to safety, 14 study designs and 9 intervention types did not fulfil the inclusion criteria, 3 were in nonhealth settings and 1 more recent paper available), leading to 26 included publications describing 27 strategies. Figure 1 shows the search and selection process.



Enlarge this image.

Characteristics of the included studies: Studies originated from the United States (13), the Netherlands (4), the United Kingdom (3), Canada (2), Vietnam (1), Australia (1), Korea (1) and Norway (1). Seventeen of the twenty-six studies were focused on inpatient safety, three on specific clinics or treatments and six were focused on treatment between face-to-face visits. The studies were conducted in a range of clinical areas including inpatient adult general medical services,[30–39] inpatient surgical departments,[40–42] adult oncology,[43] outpatient radiology clinics,[45,45] adult intensive care,[46] residential aged care facility,[39] inpatient paediatric services,[34,45–51] with two whole of hospital studies [52,53] and homecare visits, appointments, discharge and pharmacy community.[32,52,54]

Study quality: A score of 0–3 was assigned in the 13 categories used to assess quality (see File S2). Of the 26 included papers, most achieved high scores (2 or 3) in the categories of statement of aims (23), appropriate study design to address research aims (22) and format of data collection tool to address research aims (23). Fourteen studies contained limited details in the participation data provided (Criteria 9) and eight described involvement of 'consumers or stakeholders' (Criteria 12) in the process of study design and conduct.

Review findingsWhat interventions have been used to engage patients in safety activities during direct care, and what is the mode of intervention and extent of engagement?

Twenty-seven patient engagement strategies were reported in twenty-six publications (Table 1). The engagement activities are described in relation to approaches that were focused on consultation, involvement or partnership relative to the Carman Framework.[10] Evidence from each study of the effectiveness of a strategy in improving safety is presented in Table 1.

Table 1 Summary of the study findings

Note: Baker et al.[52] reported on three strategies; two fulfilled the inclusion criteria for this review.

Consultation: In the context of Carman et al.'s[10] framework, nine strategies summarized in Table 1 conceptualize engagement as *consultation*. What is distinct in this phase of engagement is that patients were consulted, or invited to provide input, about a specific safety issue/s within parameters of engagement set by health practitioners.

Four strategies involved staff-initiated engagement about a specific treatment or potential adverse event. Kim et al.[44] describe how direct questioning by staff to patients about the site of their X-ray at an orthopaedic clinic in Korea led to a significant decrease in X-ray site errors. Bergal et al.[40] describe a similar strategy implemented to reduce wrong-site surgery in the United States of America with less definitive findings, primarily due to few incidents of wrong-site surgery. van Gaal et al.[39] described a programme focused on reducing poor outcomes by staff providing education and opportunity for engagement in three areas (ulcers, urinary tract infections and falls) in 10 wards across four hospitals and aged care facilities in the Netherlands.[39] Rochon and Salazar[42] described a four-stage falls reduction process implemented in medical/surgical wards in a USA hospital. Although both van Gaal et al.[39] and Rochon and Salazar[42] reported decreased falls and fewer adverse events, limited details about interactions between staff and patients were reported. These two interventions have been classified as *consultation* due to the focus on patient education and staff-directed interaction.[39,42] One strategy sought to create engagement about a safety event by driving patient-initiated contributions through a feedback mechanism: the Patient Reporting and Action for a Safe Environment (PRASE) Tool. PRASE was trialled in 33 wards across 5 UK hospitals, which demonstrated a decrease in preventable harm at the ward level.[50]

Four strategies described staff adapting existing engagement tools to promote interaction by staff with patients in hospital settings and were relevant to this category due to the focus on patient education and staff-directed interaction.[31,37,41,55] Silkworth et al.[37] developed a 5-min video to encourage patients and their families to engage in a '2-way conversation' about falls risks on admission,[37] and Opsahl et al.[41] added a video to an existing falls prevention strategy. Both studies were conducted in acute care hospitals in the United States of America and both reported decreased falls and positive findings about using video to engage patients. Similarly, Duckworth et al.[31] and Dykes et al.[55] evaluated the addition of a multimodal approach (laminated, electronic or bedside display) to present information of a person-centred falls prevention plan (FallTIPS) in three large hospitals in the United States of America[31,55] (see Table 1 for effectiveness data).

Involvement: The *involvement* phase of engagement[10] indicates that patients were asked about their preferences and concerns, with the opportunity to interact and engage with practitioners about a specific health or treatment issue. This stage of engagement contains strategies devised by staff, offering opportunities for increased ongoing interaction between staff and patients that were not evident in strategies classified as *consultation*. Six strategies sought to enhance safety by *involving* patients (Table 1).

Only one strategy in the *involvement* phase of the continuum was related to face-to-face interactions between staff and patients, reporting on a strategy used in an outpatient interventional radiology clinic in the Netherlands.[45] Clinic patients were invited to attend an additional appointment before their interventional radiology visit to discuss their queries and concerns about the procedure, risk and consent, hence the classification as *involvement*. This strategy enhanced the relationship between the practitioner and the patient, led to increased informed consent and a reduction in deviations from process (Table 1). Two further online strategies were used to facilitate communication between patients and health practitioners[35,38] about specific areas of care. de Jong et al.[38] evaluated an online medication reconciliation and Heyworth reported on a similar pilot study of recently discharged patients from a USA veterans' hospital and reported that patients notified staff of medication discrepancies with potential for significant adverse reactions.

Three online feedback strategies provided an opportunity for patients to raise issues and interact with staff about safety concerns across their care experience. All three studies were hospital based and conducted in the United States of America.[33,34,53] Bell et al.[53] reported on the efficacy of open notes with a feedback tool,[53] Gerard et al.[33] explored patient experiences using electronic notes viewable by patients in a hospital setting[33] and Grossman et al.[34] reported on portals as a mode to engage with patients about safety. All papers reported positive findings in relation to opportunities for patients to raise concerns, although detailed data were not available about the impact of portals on safety outcomes (see Table 1).

Partnership/leadership: Strategies that create a partnership between healthcare providers and patients are at the endpoint of the continuum of engagement.[10] Almost half of the strategies (12) sought to provide patients with the opportunity to raise concerns about their treatment and 'work' with practitioners to improve the safety of their care and treatment, often with strategies using person-centred tools or designed to empower patients to alert practitioners of concerns.[30,32,36,43,46–49,51,52,54] Although all strategies in this classification enhance partnership, only six strategies included patients in the inception, design or evaluation of strategies.[46–49,52,54]

Of the range of strategies included, six described collaboratively developed tools[46–49,52,54] and processes designed to encourage and facilitate patient communication and feedback. All six studies reported positive impacts on patient safety, including decreased adverse events and increased identification of errors that would have resulted in harm (see Table 1). Four of the six strategies were 'bedside' tools collaboratively developed with patients designed to enhance quality and included 'safety' as one of many goals.[46–48,52] Dykes et al.[46] evaluated a suite of strategies implemented in two medical intensive care units in the United States of America.[46] Khan et al.[48] reported on a patient-centred project implemented in medical paediatric wards at one Canadian and six US teaching hospitals. Transforming care at the bedside (TCAB) is a codesigned bedside checklist designed to enable families to provide real-time feedback on various quality measures, including safety, implemented the TCAB in 19 units at 6 hospitals in Montreal, Canada.[52] Family-centred rounds evaluated in four US paediatric hospital sites used a similar approach to the strategies described above, concluding that patient-centred engagement is effective for identifying patient safety concerns.[47] A bedside safe-outcomes reporting tool was collaboratively developed to enable patients to measure risk and raise unsafe care issues in an inpatient paediatric renal ward in a United Kingdom.[49] The tool was pictorial for ease of use and patients recorded concerns as issues arose; this led to an increase in critical incident reporting by staff. The Fracture Recovery for Seniors at Home (FReSH START Toolkit) was collaboratively developed by staff, patients and their families and highlighted the value of collaboration with patients and caregivers in preventing complications.[52]

Three partnership or leadership strategies sought to empower patients to take responsibility for specific elements in their care as inpatients, although they did not report patient involvement in the design or inception of the strategy.[36,51,54] Seale et al.[36] report on the use of a flip chart and brochure with the aim of empowering healthcare consumers to take responsibility for safety, and alert staff to hygiene issues in an Australian hospital. Watt et al.[54] report on a Canadian strategy implemented in 200 community and inpatient healthcare settings that encouraged patients to ask five questions. The aim was to decrease medication errors and the paper reported on a study that showed the impact of this intervention on opioid use. Campbell et al.[51] reported on a strategy implemented in paediatric intensive care units in Hanoi, Vietnam. The strategy described was a bedside tool to encourage patients to remind staff to wash their hands (see Table 1 for effectiveness data).

The final three strategies of the 12 in this group were designed to assist patients to highlight issues at various points of direct care. A Norwegian developed online tool enabled improved communication between breast cancer patients and multiple practitioners, including communications about medications, and treatment.[43] The strategy progressed other strategies by providing patients with opportunities to clarify issues at a time of their choosing. Two studies highlighted the benefits of patient-held medication information.[30,32] Garfield et al.[32] evaluated medication reconciliation tools used by people who access primary and secondary healthcare organisations in greater London, UK, and noted the benefits of using patient-held medication management tools in various formats. Similar conclusions were reached by Buning et al.[30] in their proof-of-concept study exploring a mobile application for medication reconciliation in a Netherlands hospital. These three studies reinforced the need for flexibility and benefits of patient-managed tools that span various healthcare providers and agencies to increase safety when care spans various sites.

What types of patients and contexts are described in the interventions?

The included studies were predominantly conducted in inpatient settings (13 studies) or after discharge from inpatient stay (10); the remainder were conducted in outpatient clinics or community settings, including an aged care facility (4). Twenty-four studies were conducted in countries classified as ‘developed’ by the United Nations, 25 studies in countries classified as high income and one developing economy.[51] Participants were most often recruited from university or teaching hospitals (22), predominantly city based (17), and in the United States of America (13). Twenty-five studies recruited male and female participants; one study recruited only women.[43] Participant characteristics and demographic information were reported with varying levels of detail; all studies recruited participants over 16. Information about culture and ethnicity was variable, and only eight papers provided data about culture and language preferences.[31,32,36,46–48,50,53] No papers reported on any other diverse communication needs.

In 24 papers, engagement approaches were available to all eligible patients. Three papers excluded participants not from dominant language groups for methodological reasons.[36,45,50] In the remaining papers, participation was open to all; however, people who opted to participate were often identified as well-educated,[33] insured and[35,46] computer literate[35,46] and tended to be from the dominant language group.

Safety engagement strategies described were only available in the dominant language in 19 papers.[16,30,32,33,35,38,39,41–46,51–55] Two papers reported constrained resource-limited adaptation of information to meet diverse needs of patients, identifying the absence of key groups as a study limitation.[36,50] Six papers contained commentary about the suitability of tools for CALD communities, noting that more older non-Caucasian patients accessed the Open-notes tool than anticipated,[53] the benefits of a visual tool[49,51] and highlighting the need for alternative or adapted strategies.[36,40,47–49]

The question of the effectiveness of strategies ‘for whom’ is central to realist synthesis. The included studies are robust; however, they also have insufficient data to determine the extent to which vulnerable or minority groups were represented. The combination of limited socio-cultural data and a lack of description of how engagement tools were adapted or used means that the effectiveness of strategies for patients from CALD communities or other vulnerable groups is difficult to ascertain.

What are the mechanisms that influence the effectiveness of consumer engagement approaches in enhancing safe care and treatment?

The included studies were examined to articulate common factors identified as influencing the success of strategies to engage healthcare consumers in the delivery of safe care and treatment. Acknowledging the limited data about the inclusion of diverse participant groups (see Q2 and Table 1), four common factors were evident.

Patient–professional collaboration: Strategies across the continuum of engagement reported the value of opportunities for staff and patients to establish communication,[47] form partnerships[37] and emphasized the value of the ‘relationship’.[45] These findings are reflective of the evidence that underpins person/patient-centred approaches.[56] Some staff participants thought that collaborating with patients about safety could have unintended negative consequences for the practitioner/patient relationship.[41,53]

Pragmatic and user-friendly: Ten strategies emphasize the need for simple feedback systems about safety features that are not time consuming,[49] use plain language,[48] not solely reliant on text[49,51] and can be incorporated into existing documentation systems, interactions or portals.[30,44] Electronic portals and apps need a user-friendly interface[38] and focus on relevant safety concerns.[34,35] Questionnaires were time consuming and not suited to varied communication needs[49] or distressed patients.[50]

Promoting confidence and safety proactively: The benefit of increasing patient confidence or empowering patients underpinned the implementation success of the interventions across the continuum of engagement.[30,36,37,49,51,54] The advantages of a proactive approach to enhance safe care were emphasized,[49,51,54,55] along with the need for cultural awareness and sensitivity.[51]

Organisational sponsorship: All papers identify the need for an organisational culture that supports transparency and values health consumer input. Staff training, ongoing commitment of resources including practical adjustment of schedules,[37,39,41,42,48,51,54] staff consistency,[44] systematic/whole of agency approach[48] and management support[31,46,52] were identified as vital for consumer engagement interventions to be implemented effectively.

DISCUSSION

Our findings identified 27 strategies that used interactive technologies, dedicated additional appointments and verbal communication prompts to engage patients in ensuring safe care and treatment during direct care. Multimodal strategies were also used in several studies. Most of the strategies were implemented in inpatient settings. The strategies were predominantly evaluated in locations characterized by a significant cultural shift towards patient partnership. The included papers were largely from America (13), Northern Europe (3) and the United Kingdom (3). The nature of engagement across the strategies spanned the patient engagement classifications of consultation (nine strategies), involvement (seven strategies) and partnership (twelve strategies).[10] Working in partnership with patients and families is central to devising suitable engagement approaches for specific populations or settings.[10] It was notable that publications provided varied levels of detail in data about the type and degree of patient engagement in strategy development or implementation. In some instances, researchers identified limited inclusion of diverse patients as an issue to address; however, it was difficult for researchers to ascertain whether it was the patient engagement strategy or research data collection tools that precluded engagement.[32,38,45] While some papers included details about codesigning strategies with patients,[46–49,52,54] this aspect of engagement is most often absent, undefined or unreported. Insufficient information about such elements as the patient role in strategy design reflected limited evidence that the strategies described were theoretically informed. Lawton et al.[50] provided a theoretical background to engagement; similarly, the patient-centred strategies embedded engagement in such approaches.[46–48] However, the theoretical justification for strategy design presented in most papers was on content (e.g, falls prevention or wrong-site intervention), technical production (e.g., videos[37]) or staff implementation,[42,44] rather than on the nature or details of engagement.

Attributing changes in patient safety outcomes to a particular type of patient engagement was challenging due to the variation in the definition of engagement in the included papers, which is reflected in the wider literature.[10] Lack of consistency in defining ‘engagement’, coupled with limited details about strategy implementation and participant characteristics, created challenges in understanding the types of engagement strategies that work to achieve particular outcomes in particular populations or contexts of care. These shortcomings have been recognized in the literature, with Lawton et al.[50] concluding that the widely used practice of using adverse events reporting data to ascertain the impact of specific engagement strategies is unsuitable. Similarly, Wright et al.[5] highlight the challenges to measuring the impact of patient engagement strategies on safety and call for more detailed analysis of engagement.

Knowledge of intervention effectiveness, acceptability and feasibility is critical in the context of emerging evidence of both increased risk of safety events and barriers to engagement for particular patient groups. The needs of patients from ethnic minority backgrounds[23,57] and disability[24,58] have been highlighted in recent reviews.[21] There is emerging literature about the advantage of animation- or picture-based communication for various patient groups including people from ethnic minority backgrounds or with disabilities;[59,60] yet, only two included papers incorporated visuals to accompany text.[49,51] While brief commentary about the effectiveness of specific strategies for people from different ethnic backgrounds and the impact of lower health literacy was made, addressing the needs of diverse participant groups was not a focus of the papers reviewed. Our review therefore identified a need for strategies developed and evaluated with consideration of and input from diverse patient population groups, along with evidence of their effectiveness for people from different ethnic backgrounds, age groups, disability status and other critical patient characteristics.

Patient–professional collaboration, user-friendly strategies, proactive messaging and agency sponsorship were all recognized as enablers of patient engagement. Findings regarding the facilitators of patient engagement between papers in this review were consistent, confirming recent research seeking to empower patients to raise safety issues within a supportive culture.[15,16,22,61,62] The importance of agency sponsorship of a collaborative culture for engagement has long been emphasized in the change management and person-centred care literature.[63] Staff identified that agency support is required to address the potential impact of engagement on the patient/provider relationship and workload.[34] These concerns are reflective of Park et al.'s[8] systematic review, which found that staff were aware of the importance of engaging in safety, but were not always confident to do so. A comprehensive approach including a culture of transparency, collaboration and support to implement evidence-based engagement strategies is required.[62,64]

Implications

Patient engagement interventions are being deployed across health services to promote patient safety despite vast variations in the definitions and conceptualisation of the concept of patient engagement. Few studies have utilized theory-informed approaches or robust study designs to evaluate current techniques.

There are implications for health services in the challenges posed to scaling and spreading the adoption of potentially useful patient engagement strategies. There is a danger of unintended harmful impacts for those for whom the intervention may not be suitable. There are resource, financial and ethical implications, given the additional time and technologies required by patients and staff to take part in such interventions. This review reinforces the need for a multifaceted approach to patient engagement, incorporating agency culture, practices and appropriate engagement strategies.[9]

Therefore, researchers need to work collaboratively with health services to establish more robust evidence of (a) what the intervention mechanisms are in current strategies and (b) information about (1) the feasibility and acceptability of the strategies for all parties, (2) the end-users and (3) cost-effectiveness.

Strengths and limitations

The capacity to explore varied engagement strategies by using a realist synthesis supported by Carman et al.'s[10] engagement framework provided scaffolding for the review. Use of Carman et al.'s[10] framework was useful in light of the varied definitions of patient engagement evident in the included papers and the broader literature. Similarly, use of realist synthesis enabled comparison across a disparate group of studies of varying quality and synthesis of information to influence practice.

The findings of this review must be understood in the context of the limitations of the included studies. We identified limited geographical diversity in the countries where the research originated and a lack of studies that sought to compare groups, or samples that were sufficiently powered. By including only published material, valuable insight from nonpublished and nonempirical work may have been missed.[65] An additional limitation arises from the wide range of terms used to describe patient engagement in safety and the many different types of journals used to house patient safety research. The lack of evidence regarding the theoretical underpinning of the interventional approaches and their intended impact on patient engagement creates barriers to determining the intervention mechanism/s responsible for identified changes. The diverse purposes of papers included also created challenges, particularly papers that reported on a single element of a bigger project, multiple interventions across several sites or safety outcomes reported among a number of interventions carried out simultaneously. The levels of sensitivity and precision of bibliographic databases vary and can also affect the number of articles returned. We used several databases in addition to manual searching to broaden coverage, but there may have been omissions.

CONCLUSION

Despite the growing number of patient-centred tools and safety engagement strategies, evidence about use and effectiveness is limited. More details about how they are used and with whom are required to enable patients and practitioners to engage effectively. More clarity is needed to consistently define patient engagement along with further research to determine which strategies are effective. Little evidence exists about people from minority or vulnerable backgrounds in patient safety, which needs to be addressed due to acknowledged disparities in healthcare safety and engagement.

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CONFLICT OF INTERESTS

The authors declare that there are no conflicts of interest.

AUTHOR CONTRIBUTIONS

Reema Harrison and the CanEngage project team conceived the study. Stephen Mears completed the database search. Two reviewers (Jiadai Li, Benjamin Jones) completed the initial title and abstract review, followed by an independent screening by a third reviewer (Bronwyn Newman). The inclusion criteria were then independently applied to full-text articles by two reviewers (Bronwyn Newman, Reema Harrison), with disagreements or uncertainty resolved through discussion. Quality was assessed by two reviewers (Bronwyn Newman, Kathryn Joseph). Bronwyn Newman completed writing of the manuscript. Reema Harrison, Holly Seale, Elizabeth Manias, Merrilyn Walton, Ashfaq Chauhan and Kathryn Joseph provided feedback during analysis and reporting and reviewed the manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available in the Supporting Information Material of this article.

DETAILS

Subject:	Intervention; Patient safety; Health care; Databases; Minority &ethnic groups; Safety; Systematic review; Minority groups; Consumers; Data collection; Sponsorship; Teams; Patients; Synthesis
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Exploring a collaborative approach to the involvement of patients, carers and the public in the initial education and training of healthcare professionals: A qualitative study of patient experiences

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ABSTRACT (ENGLISH)

Objective

This study aimed to explore patients' experiences of their involvement in the design and delivery of interprofessional education interventions focussing on mental ill-health for students studying in undergraduate healthcare and healthcare-related programmes.

Design

A qualitative methodology using a Grounded Theory approach was used to undertake an iterative series of focus groups with members of a university's Patient, Carer and Public Involvement (PCPI) Group who have a history of mental ill-health and were involved in the development and delivery of educational interventions for students on undergraduate healthcare and healthcare-related programmes. Their experiences of being involved in teaching and learning activities, collaboration with academic staff and integration into the academic faculty were explored. Constant comparative analysis facilitated the identification and prioritisation of salient themes.

Results

Five salient inter-related themes emerged from the data: (1) reduced stigma and normalisation of experience of illness; (2) enhanced self-worth; (3) improved well-being; (4) community and connection; and (5) enduring benefits.

Conclusions

A supportive university community and a designated academic PCPI co-ordinator facilitate a supportive environment for patients and carers to develop as educators, contribute to the training of future healthcare professionals and improve their own personal well-being. Appropriately resourced and well-supported initiatives to integrate patients, carers and the public into the functions of an academic faculty can result in tangible benefits to individuals and facilitate meaningful and enduring connections between the university and the wider community within which it is situated.

Patient and Public Involvement

Patients have been involved in the design of the teaching and learning initiatives that this study was primarily focused on. Patients were given autonomy in determining how their experiences should be incorporated into teaching and learning experiences.

FULL TEXT

INTRODUCTION

The importance of engaging patients, carers and the public in supporting the initial education and training of healthcare professionals is well established.[1–4] Regulatory bodies require providers of academic programmes to demonstrate that patients are involved in the delivery of teaching and learning and that curriculums are aligned to patient-centred healthcare policy.[5–8] The benefits of patient involvement in healthcare education to the patients themselves, the students they support and academic staff have also been extensively evaluated and described.[9–11] The literature describes numerous examples of teaching sessions, assessments and full academic modules that have been supported by patients.[12–15] What is less prevalent are examples whereby full integration of patients, carers and the public into the core functions of an academic faculty has been achieved.[16–19]

In addition to involving patients in individual academic programmes, increasing attention has been paid to the wider civic responsibilities of universities. Institutions are now being encouraged to examine 'with purpose and rigour' how they should fulfil their duties to provide wider public benefit, enrich communities and enhance the connection between universities and places.[20] This raises questions about how this can be achieved and how the outcomes are measured.

The University of Sunderland made a commitment to fully integrate Patients, Carers and Public Involvement (PCPI) into all the core functions of the Faculty of Health Sciences and Wellbeing, including student admissions, curriculum development and delivery, assessment of students and their preparation to enter the workforce. The faculty is involved in the undergraduate training of a number of future healthcare professionals including nurses, doctors, pharmacists, occupational therapists, physiotherapists and paramedics. The commitment to full integration of patients has extended to the development of the physical resources of the University, including creating a 'patient flat', a private facility that acts as a safe space for patients during their engagement in University activities. There is also a full-time member of academic staff to support the PCPI members and their integration into the faculty, and financial resources to fund their engagement. Individual PCPI group members receive relevant training, including how to provide feedback on student performance and equality, diversity and inclusion requirements. There are currently 160 PCPIs members; a smaller group of their representatives is part of the faculty's governance structure, feeding into Academic Boards and the Faculty Executive. PCPI participants are patients, carers and members of the public who live with, or support people with, long-term physical and/or mental health conditions. Members are recruited directly from the local community, through patient support groups and charities, and via a relationship developed between the University and the Community Mental Health Team of a local NHS Mental Health Trust. As the project has developed, individuals have also joined through personal recommendation from existing group members. All PCPIs undergo a formal induction and training process facilitated by the lead academic (L. S.) and other experienced PCPI representatives.

In this paper, we evaluate the involvement of PCPIs in an initiative to enhance the multidisciplinary teaching and learning of the interface between mental and physical health in the faculty. Through evaluation of this project, we were also able to explore the wider integration of the PCPI group into the faculty and how this was experienced by individuals within it.

METHODS

Members of the PCPI group who had a history of mental ill-health collaborated with a multidisciplinary team of academic staff in the iterative design, development and delivery of a novel interprofessional (pharmacy, psychology and nursing) education (IPE) project. The initiative consisted of two conference-style events during the academic years 2016/17, 2017/18, which included a team-based learning case study, an immersive simulation session, a simulated ward activity and a patient narrative session (patients sharing their lived experiences of mental ill-health). The aim of the sessions was to enhance students' understanding of mental ill-health, how interprofessional collaboration can enhance the care offered to patients and how parity of esteem between mental and physical ill-health can be achieved. The session format was iterative and changed over the 2-year cycle; however, the content and delivery were co-constructed via collaboration between a team of interprofessional clinical academics and

PCPIs. Over the 2-year period of the IPE project's design and delivery, the university was also investing in the development of the PCPI group, the support available to them and integrating them into the core activities of the faculty including recruitment and assessment.

We adopted a Grounded Theory approach to guide the data collection and analysis, with an iterative process of analysis and further data collection to develop and refine salient themes.[21] Focus groups were chosen as a means of data collection to facilitate a deeper understanding of the participants' perspectives, and the dynamic nature can generate diverse views and experiences.[22] We offered individual interviews to those unable to attend a focus group.

Study population and sample

A sample of members of the PCPI group with a history of mental ill-health was invited, on a voluntary basis, to collaborate with the IPE project and all of these individuals were asked to participate in a qualitative evaluation. Before their involvement in the project, participants attended an informative briefing session with academic staff (L. S. and J. H). A total of 14 members of the PCPI group consented to participate in the project, and all took part in this evaluation.

Data collection

Focus groups with PCPI members who took part in the IPE group aimed to evaluate their experiences of doing so. The broader experiences of the PCPI's of working in the Faculty of Health Sciences and Wellbeing were also explored including their understanding of their role, interactions with each other, students and academic staff and experiences of the working environment. Everyone who took part in focus groups was provided with a participant information sheet (Document S1). An initial topic guide was developed by (L. S.) and (S. P.) that was refined by the multidisciplinary research team (Document S2), serving as a benchmark for exploration during focus groups. An experienced independent qualitative researcher (S. P.) with no involvement in the educational initiative or PCPI group facilitated all focus groups and performed the initial analysis to reduce risk of bias. Focus groups were audio-recorded and transcribed verbatim to aid qualitative analysis; focus groups took place at the University of Sunderland. Two individual interviews were conducted by the researcher to capture feedback from two participants whose roles were either as a facilitator or as a role-player, so different from the narrative storytelling. Participants were able to withdraw from the study up until the point that interviews/focus groups were transcribed and incorporated into the data set; no participants withdrew from this study. University Wellbeing services were available for all participants in case any element of the discussion caused distress.

Data analysis

Qualitative data were analysed using a Grounded Theory approach, whereby data were coded and categorized into emergent themes.[21] Strauss constant comparative analysis facilitated the exploration of new concepts and enrichment of data in subsequent focus groups.[22,23] Salient themes were identified and a thematic framework was developed by (S. P.); the interprofessional research team individually and then collectively reviewed and refined themes until definitive concepts and final interpretations were agreed. As focus groups took place over a number of months during the design and delivery of the IPE project, the emergence of salient themes during the process facilitated the redesign of the teaching sessions and further exploration of emergent themes during subsequent data collection.

Ethics

Ethical approval was granted by the University of Sunderland Research Ethics Group (reference 005067).

RESULTS

A total of 14 PCPIs comprising 10 males and 4 females whose ages ranged between 42 and 70 years participated in this project and its evaluation. Three focus groups and two interviews were held between February and December 2017. Focus groups and interviews took place at the University of Sunderland; up to 90 min was designated for either activity to be conducted.

Five salient inter-related themes emerged from the data[1]: reduced stigma and normalisation of experience of illness[2]; enhanced self-worth[3]; improved well-being[4]; community and connection[5]; and enduring benefits.

Reduced stigma and normalisation of experience of illness

All participants in this study had taken part in an initiative within the faculty to enhance the multidisciplinary teaching and learning of the interface between mental health and physical health. Participants therefore had a significant medical history of mental ill-health or having made significant behavioural changes as a result of living with a long-term condition(s). Participants reflected on the stigma that they felt was attached to their condition(s) before their involvement with the university PCPI group.

I couldn't bear to tell anyone. My GP even wrote on my sicknote that it was other issues. (PCPI 1)

The majority of those interviewed described the opportunity to talk about their condition to students as being beneficial.

I've found that talking about the, depression, very therapeutic because it, as you're talking to groups about it, you're analysing things yourself and you're seeing how one thing's followed another and why something's happened and what's the best way to recover and that sort of thing. So, I find it very useful for myself as well as for the students. (PCPI 9)

Participants felt that the interaction with each other provided them with an opportunity to reconcile themselves to their illness and/or diagnosis, which they had struggled to do in other contexts, for example, previous work environments. The regularity of these interactions, facilitated by being part of the PCPI group, provided the opportunity to feel acceptance from peers and normalized their experiences of mental ill-health.

It makes you realise… you don't really actually appreciate it that you are quite embarrassed… But when you talk about it and people's reactions are just ‘yes, of course, that's natural, that's normal’, it's just underlining again and again that it is okay. (PCPI 1)

The interactions with students also facilitated this normalisation and (it was proposed) helped students to understand the range of patient experiences they would be required to engage with when they enter the clinical workforce.

The diversity of the people that students here are going to be seeing… Cause they're going to walk in, these guys are going to walk in to a pharmacy, they're going to walk in to A&E and they need that (exposure) to these types of people. (PCPI 3)

Participants felt strongly that it was there role to help students to gain the confidence and skills to work with people with mental ill health.

I introduce myself; I tell them why I'm here, I'm here to help. I'm here to be the person that hopefully you will be sat in front of in four years' time. And you're here to practice on me. And it's my job to help you be that better person in four years' time. (PCPI 3)

However, interactions with students were not always positive; lack of preparedness or engagement was felt to be a barrier to the role of the PCPI in supporting students to adopt a greater patient-centred approach to their learning.

The ones that are just sat there and quite clearly they haven't read anything, they haven't read the case notes and you're left there sitting thinking ‘well, I'm wasting my time being here completely’.

Enhanced self-worth

In addition to providing the opportunity to understand and accept their condition through the relationships and connections made within the University, participants also described how their feelings of self-worth had been enhanced through their participation. Largely, this appeared to come from a feeling of their role being valued and contributing positively to the development of students. Participants recognized improved feelings of self-worth in themselves and in other PCPI group members with whom they worked.

I've seen it in (another PCPI group member)… Absolutely raves about it. Best thing ever… just gets him out, makes him feel valued. That's what it is. It's the feeling valued, the feeling of giving something back. It's just brilliant. Absolutely brilliant. So, presumably, that's the change people have seen in me, I'm now seeing in (another PCPI group member). (PCPI 1)

Improved well-being

All of the participants reported an increase in their feelings of well-being. This appeared to stem from being provided with the opportunity to contribute to the functions of the academic department and seeing the positive impact that they can have on a student's development. This replaced the loss of purpose felt when previous employment ended or could not be continued due to ill health.

Not being able to go out of the house… just kills me. I hate it. I absolutely hate it… It's- that's coming from depression and anxiety and all that, for me to be able to come and do this, I thought it was great and I loved it. I was buzzing when I got home… I was tired mentally but I was buzzing as well. I really enjoyed it. (PCPI 12)

Community and connection

The sense of enhanced self-worth and well-being that the participants described was often attributed to the sense of community that was facilitated by the University.

There's not many places really where that's available to you, is there? Where you can do something but in such a supportive environment… You couldn't go into your job and get that supportive environment or even volunteering. (PCPI 1)

Significantly, participants felt that this community was developed and sustained by the academic lead for the PCPI programme. The knowledge of each individual patient, their history and their ability to contribute to specific sessions was seen as key to the success of the PCPI programme and the welfare of all participants.

One of the strengths with (the PCPI Facilitator) is that they know every single PCPI by name. They know their journey, what their strengths are, what their weaknesses are… and they have the ability of selecting who would be most suitable for doing different activity… I'm confident that I would never be put in a position I would find too daunting to be able to help the other people. (PCPI 3)

Participants described the sense of pride that they felt for being part of the PCPI group and the university.

I tell people I work with the University. (PCPI 14)

Enduring benefits

The benefits to the participants of being part of the PCPI group were clear; what was also apparent was that these benefits had longevity. Connections between members of the group, with academic staff and students were sustained and enduring. PCPI participants were also able to witness the students' development and see their progress, which contributed to their sense of well-being and self-worth.

I'm on first name terms with them (students). And to see the development… And the progress, and to feel that okay, you're a very small cog in a very large organisation… But it is very rewarding. (PCPI 2)

DISCUSSION

Previous research has proposed that involving patients in the design of undergraduate curriculum can facilitate a more patient- and student-centred approach to mental health education.[24] This study provides further evidence that involvement in undergraduate healthcare education is beneficial to patients with a history of mental ill-health. The participants included a mixed group, comprising lived experience of either, or both, long-term mental and physical health conditions. Where participants had mental health conditions, these were mainly long-term or multiple episodes.

Belonging to a community of patients and carers who work in collaboration with academic staff to deliver teaching and learning can restore patients' sense of identity, help them to normalize their health problems and reduce the stigma that patients themselves can associate with mental ill-health.[13] In our study, the majority of the PCPI participants are paid an hourly rate for their involvement and have access to staff cards, a university email address and library access as part of the benefits of involvement.

The benefits of collaborative working with patients have been described in previous studies, with more recent examples that link both IPE and the potential to reduce mental illness stigma.[2,12,13] The NHS Long Term Plan[25] sets out a clear direction for the future NHS and places greater emphasis on service integration, including new models of care combining primary and secondary care and health and social care. The project that has been described here promoted not only collaboration between patients and academic staff but also cross-faculty cooperation, bringing together those from a range of healthcare professional backgrounds to deliver joint teaching and learning initiatives in a move towards replicating the desired models of integrated healthcare. Since its inception, the project has endured beyond the initial development stage and has now expanded to include other health and social care professionals in training.

Previous studies have outlined the challenges faced during attempts to achieve partnership between patients and academic faculties in the delivery of undergraduate education.[16] Efforts are often thwarted by difficulties in achieving representativeness and meaningful engagement and problems arising from an 'inequality of power' between service users and educationalists. Shortcomings in the supportive arrangements available to patients also hamper full inclusion into academic faculties.[26] Although the claim cannot be made that all of these issues have been solved by the resources and infrastructure put in place by the University of Sunderland, the results of this study show that some have been mitigated for. A dedicated member of staff to support patients and carers and act as their advocate within the faculty appears to be essential to the success of attempts at integration. This has also been important when constructing a response to the negative experience of patients when interacting with students who are difficult to engage. This has been addressed by the lead academic who has developed training for PCPI group members on how they can encourage participation, and work has also been done across the faculty to better prepare students to work with patients from the early years of their training.

As universities consider how they can meet their responsibilities to the wider communities in which they are situated, we have outlined an attempt by which meaningful engagement of patients can be achieved in a socially inclusive way. Working with undergraduate healthcare students provides a unique opportunity for those who may be facing isolation due to illness to re-establish enduring connections with others and gain new skills. These benefits have been shared with mental health NHS Trusts and a formal referral mechanism is now in place to facilitate patients who it is felt may benefit from joining the PCPI group to do so.

Limitations

The findings of this study relate directly to patients who have clearly demonstrated a willingness to become involved in educating healthcare students. Therefore, findings may not be generalisable to all patients with mental ill-health in other settings. The majority of PCPIs are paid for their participation in teaching sessions, which may potentially result in a positive bias towards the university.

Future work

Further exploration of referral pathways and means of identifying patients who may receive the most benefit from involvement in education could further enhance outcomes and patient care. Our study has focused on the therapeutic benefits associated with mental ill-health or long-term conditions; further work should look to explore the potential benefits to patients with other health conditions who are involved with undergraduate education.

CONCLUSION

Appropriately resourced and well-supported initiatives to fully integrate patients, carers and the public into the functions of an academic faculty can result in tangible benefits to individuals and facilitate meaningful and enduring connections between the university and the wider community within which is it is situated. This study suggests that a supportive community of patients and carers, contributing to interprofessional undergraduate healthcare education, can provide enduring benefits to its members. Universities should provide sufficient resources to support patient involvement in undergraduate education as a means of enriching the student curriculum and empowering patients to improve health outcomes. Clinicians and health charities should consider implementing referral pathways for appropriate patients and further explore collaborative opportunities to improve the health of patient volunteers.

Key to the success of patient involvement in an undergraduate setting is a supportive environment led by a dedicated member of academic staff; the importance of this role and a good understanding of each individual patient's history and ability to contribute to appropriate sessions are key to the welfare of the patient involved and the success of a patient-led curriculum.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Jessica Hardisty, Andrew Sturrock, Lesley Scott and Helen Driscoll designed the study. Hannah Cussons performed the literature search. Suzanne Powell performed the focus groups and interpreted the data. Jessica Hardisty, Andrew Sturrock, Lesley Scott, Helen Driscoll, Kathryn Davison and Suzanne Powell reviewed and refined the data. Jessica Hardisty and Andrew Sturrock wrote the paper, and all authors revised it.

DATA AVAILABILITY STATEMENT

Research data are not shared.

DETAILS

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Living with Chronic Illness Scale: International validation through the classic test theory and Rasch analysis among Spanish-speaking populations with long-term conditions

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ABSTRACT (ENGLISH)

Background

The Living with Chronic Illness (LW-CI) Scale is a comprehensive patient-reported outcome measure that evaluates the complex process of living with long-term conditions.

Objective

This study aimed to analyse the psychometric properties of the LW-CI scale according to the classic test theory and the Rasch model among individuals living with different long-term conditions.

Design

This was an observational, international and cross-sectional study.

Methods

A total of 2753 people from six Spanish-speaking countries living with type 2 diabetes mellitus, chronic obstructive pulmonary disease, chronic heart failure, Parkinson's disease, hypertension and osteoarthritis were included. The acceptability, internal consistency and validity of the LW-CI scale were analysed using the classical test theory, and fit to the model, unidimensionality, person separation index, item local independency and differential item functioning were analysed using the Rasch model.

Results

Cronbach's *α* for the LW-CI scale was .91, and correlation values for all domains of the LW-CI scale ranged from .62 to .68, except for Domain 1, which showed correlation coefficients less than .30. The LW-CI domains showed a good fit to the Rasch model, with unidimensionality, item local independency and moderate reliability providing scores in a true interval scale. Except for two items, the LW-CI scale was free from bias by long-term condition type.

Discussion

After some adjustments, the LW-CI scale is a reliable and valid measure showing a good fit to the Rasch model and is ready for use in research and clinical practice. Future implementation studies are suggested.

Patient and Public Contribution

Patient and public involvement was conducted before this validation study - in the pilot study phase.

FULL TEXT

INTRODUCTION

Nowadays, long-term conditions (LTCs) are the leading causes of disability and costs worldwide.[1] It is estimated that, by 2030, LTCs will account for three quarters of deaths globally, with considerable social and economic impact due to the exorbitant costs to the system.[2,3] In particular, cardiovascular and respiratory diseases, as well as diabetes, are the LTCs that account for the most deaths woldwide.[1]

Based on previous studies, living with an LTC is defined as a complex, dynamic, cyclical and multidimensional process that involves five different attributes, namely, acceptance, coping, self-management, integration and adjustment.[4] Living with an LTC is influenced by social and personal factors; therefore, living with an LTC is a unique, individual and unrepeatable process.[4,5] Health and social professionals need to have an in-deep understanding of what it means to live with an LTC from the person's perspective. They should focus on the psychosocial and spiritual areas of the person and not just on the condition as has been done thus far.[1,4,6] In this sense, use of patient-reported outcome measures (PROMs) is paramount to evaluate how the person is living with his/her condition.[7,8] Consequently, an interdisciplinary team could design individualized and comprehensive care pathways and recommendations to achieve positive living with an LTC as a final desired target.[7,8] Currently, most relevant available PROMs in clinical practice and research evaluate specific aspects of the LTC (e.g., stage, symptoms or severity) or outcomes of the process of living with LTCs (e.g., quality of life, satisfaction with life or well-being).[9] The Long-Term Conditions Questionnaire[10] is the only PROM that potentially evaluates how a person is living with/managing an LTC. However, this scale seems to evaluate quality-of-life outcomes and does not tackle items related to acceptance, which is an essential attribute when living with an LTC.[4] Inevitably, this left a gap regarding person-centred measures that can evaluate the process of living with an LTC. To fill this gap and based on previous empirical studies[11,12] and conceptual works,[4,13] the Living with Chronic Illness (LW-CI) Scale was designed.[14]

The LW-CI scale is a comprehensive PROM that evaluates the complex process of living with an LTC.[14,15] It is a 26-item self-reported scale with direct applicability in people living with LTCs. It was originally designed for Spanish-speaking populations living with an LTC.[15] The LW-CI scale has been previously published for Spanish-speaking populations in a pilot study carried out among patients living with different LTCs.[15] To date, the LW-CI scale has been tested separately in several LTCs, namely, Parkinson's disease (PD),[16,17] osteoarthritis,[18] chronic heart failure,[19] type 2 diabetes mellitus (T2DM)[20] and chronic obstructive pulmonary disease (COPD).[21] The results from each validation study showed that the LW-CI scale is a feasible, reliable and valid measure to evaluate separately the process of living with an LTC in a Spanish-speaking population. According to those validation studies,[16–21] potential modifications were proposed to achieve a better version of the LW-CI scale for each LTC in particular, such as simplifying the response scale, deleting some items or redesigning the domains. However, could those previous specific-disease validation results be extended across LTC populations? There is an opportunity to test the psychometric properties of the LW-CI scale in a sample representing diverse chronic health conditions to validate the measurement properties across persons living with different LTCs.

All LW-CI scale validation studies were conducted using a classical test theory (CTT) approach to evaluate reliability, validity and sensitivity to change along with acceptability and other parameters, mostly based on correlations and mean difference analyses. Only the LW-CI for people with PD was additionally tested using Rash measurement analysis.[17] The application of the Rasch model,[22] one of the most used applications of the item response theory, combined with the classic test theory approach is recommended for evaluating PROM.[23–25] The Rasch model[22] completes the information provided by the CTT because it provides additional and relevant information about the measurement properties of a scale such as unidimensionality and differential item functioning (DIF) by individual groups including LTC type. In addition, it also allows for the calculation of scores on a linear scale.[26]

Therefore, the aim of this study is to analyse the psychometric properties of the LW-CI scale according to the classic test theory and the Rasch model among people living with different LTCs. Suggestions for modification of the LW-CI scale are presented accordingly.

METHODSDesign

This was an international and cross-sectional study. This study is part of a multicentric and multidisciplinary research programme led by nurses (ReNACE Programme; https://www.unav.edu/web/programa-renace/proyectos) aimed at achieving an in-depth understanding of the complex process of living with an LTC from the persons' and family/carers' perspectives through the development of individualized interventions and comprehensive PROM.[11,12] In particular, this study has the general aim of achieving a unique and standardized international Spanish-speaking self-reported scale to evaluate how the person is living with his/her LTC in several Spanish-speaking countries.

Setting

Participants were recruited from different healthcare systems from six Spanish-speaking countries, namely, Spain, Cuba, Argentina, Ecuador, Mexico and Colombia. More concretely, private and public primary and specialized healthcare service-attending outpatients with LTCs were included. Additionally, individuals living with LTCs from the community were also approached, mainly from LTC organisations in Spain, such as the Parkinson's Disease Association.

Participants

Sampling of consecutive cases[27,28] was applied to select participants. The sample was composed of individuals living with different LTCs, namely, T2DM, COPD, chronic heart failure (HF), PD, hypertension and osteoarthritis. The following criteria were applied: (1) diagnosed with an LTC by a general practitioner or consultant (T2DM, COPD, HF, PD, hypertension and osteoarthritis); (2) adult patient (≥18 years); (3) able to read, understand and answer written questionnaires; (4) native Spanish-speaking person; and (5) able to provide written informed consent. The applied exclusion criteria were as follows: (1) presence of cognitive deterioration or psychiatric disorders, or any other disorder that could interfere with or impede the appropriate development of the study (e.g., blindness); (2) hospitalized patients; and (3) patients not fulfilling the established inclusion criteria.

According to international criteria, the sample size was estimated to fulfil the rule of 10 participants per item,[29] which exceeds the minimum of 100 subjects required for CTT. Therefore, considering that the LW-CI scale is a 26-item scale, the minimum sample size estimated was 260 participants per condition, aiming for a total of 1560 participants.

Assessments

Sociodemographic data, such as age, gender, marital status, employment situation and educational level, were collected. In addition, LTC-related information was collected, namely, age at disease and disease duration. In addition to sociodemographic and LTC-related data, the Spanish version of the following self-reported validated PROMs was used:

- 1.

  LW-CI scale[15]: The LW-CI scale is a self-reported scale that evaluates the complex process of living with an LTC. The LW-CI scale is a 26-item scale grouped into five domains: Domain 1: Acceptance (4 items); Domain 2: Coping (7 items); Domain 3: Self-management (4 items); Domain 4: Integration (5 items); and Domain 5: Adjustment (6 items).[15] All items are answered using a 5-point Likert scale from never or nothing (0) to always or a lot (4), except for Domain 1: Acceptance, which is reversely scored from never or nothing (4) to always or a lot (0). The LW-CI scale has a total score value ranging from 0 points, indicating negative living with the condition, to 104 points, reflecting positive living with the condition.

- 2.

  Duke-UNC Functional Social Support Questionnaire (DUFSS)[30]: The DUFSS is a self-reported measure that comprises 11 items evaluating diverse dimensions of social support such as confidant, affective and instrumental support. The score for each item varies from 1 (*much less than I would like*) to 5 (*as much as I would like*). The total score ranges from 11 (lowest level of support '*much less than I would like*') to 55 (highest level of support '*as much as I like*'). According to the Spanish validation study,[31] the DUFSS presented adequate psychometric properties, showing a Cronbach's α value of .9 and satisfactory construct validity.[30,31]

- 3.

  Modified version of the Satisfaction with Life Scale (SLS-6): Originally, this is a 7-item self-reported questionnaire.[32] For this study, the modified version of the SLS-6 was used because the original version and, in particular, one of the items were specific for a student population.[33] In this way, a modified version with a 6-item scale was used to evaluate the degree of overall satisfaction with life and regarding six areas: whole life, physical, psychological well-being, social relations, leisure and financial situation. Each item was rated on a 0 (*totally unsatisfied with life*) to 10 (*totally satisfied with life*)-point Likert scale. According to the Spanish validation study,[33] the SLS-6 presented satisfactory psychometric properties, with a Cronbach's α of .8 and internal validity values ranging from .4 to .7.[32,33]

- 4.

  Patient-Based Global Impression of Severity Scale (PGIS): This is an adaptation of the clinical global impression of severity[34] adapted for patients as a self-reported scale.[35] It is a global index that may be used to assess self-perception of disease severity of the person living with a disease. The PGIS is a 6-point Likert scale, ranging from 0 (*not ill at all*) to 5 (*extremely ill*). It has excellent construct validity and has been widely used in studies of chronic diseases.[36]

Data collection

For people living with PD, data were collected between January and June 2015, and for people living with T2DM, COPD, HF, hypertension and osteoarthritis, data were collected between November 2018 and May 2019 among the different healthcare centres and community settings of six Spanish-speaking countries. Although data collection was performed at different times, a detailed and standardized protocol was used to ensure data collection homogeneity and reduce possible errors during the process.[37] According to the established protocol, potential participants were approached through a health professional (nurse or physician) or member of the research group. An invitation letter and a participant information sheet as well as verbal information were provided about the study. Participants who agreed to participate signed the consent form and were asked to complete the sociodemographic and LTC-related data as well as PROM when they agreed with his/her health professional or researcher. Hence, participants completed the scales during consultations with the GP, specialized clinician, nurse specialist or primary care nurse. Participants who required help to complete the scales (e.g., due to vision problems) were assisted by a researcher. Once the participants finished answering the scales, a researcher reviewed the answers to identify possible missing data. Hence, no missing data were expected.

Ethical aspects

The study was approved by the research ethics committee of the principal investigator centre (reference numbers: 071/2014 and 2017.099) and all the included centres. This validation study was adjusted to the principles outlined in the Declaration of Helsinki (1964) of Law 14/2007 on Biomedical Research and Law 15/1999 on the Protection of Personal Data. All participants provided their signed consent to participate voluntarily after receiving verbal and written information related to the study. Signed consent was provided in front of the health professional or a member of the research group before completing the surveys.

Data analysis

Descriptive statistics, namely, central tendency measures and proportions, were used to determine the sociodemographic and LTC characteristics of the participants. The main data were ordinal or did not fit a normal distribution. Therefore, nonparametric statistics were used.

According to the CTT, the following psychometric attributes were analysed:

1. Feasibility and acceptability: The quality of the data was considered satisfactory if 95% of the data were computable. The limit for missing data was less than 5%,[38] and the mean, median and standard deviation (SD) were estimated to be roughly equivalent (≤10% maximum punctuation).[39] Floor and ceiling effects were deemed acceptable if they were less than 15%,[39] and the skewness was expected to be between −1 and +1.[40]

2. Reliability: Internal consistency was tested by Cronbach's α coefficient (criterion value ≥0.70),[41] item-total correlation (corrected for overlap; criterion value, $r_s \geq .30$),[23] inter-item correlation (criterion value, $r \geq .20$ and $r \leq .75$) [38,42] and item homogeneity (criterion value >0.30).[43]

3. Construct validity: For convergent validity, a moderate ($r_s \geq .35$–$.50$) or strong relationship ($r_s > .50$)[44–46] was hypothesized between the LW-CI scale and DUFSS and SLS-6, according to previous studies. A weak (r_s = .20–.34) or insignificant (r_s = .00–.19) relationship with age at diagnosis and disease duration was also hypothesized. These hypotheses were established to corroborate previous LW-CI scale validation study results in

specific LTCs.[16,18–21] Spearman's rank correlation coefficients were obtained for this purpose. Internal validity, defined as the intercorrelations between the LW-CI scale dimensions (standard, r_s = .30–.70),[40,47] was determined. For known groups' validity, differences in LW-CI scale scores in the participants grouped by gender and PGIS scores were analysed.[47,48] Mann–Whitney and Kruskal–Wallis tests with Bonferroni corrections were used for group comparisons.

For the Rasch model, the following measurement properties were analysed: fit to the Rasch model, reliability (person separation index [PSI]), adequacy of the response scale, item local independence and unidimensionality. In addition, DIF was analysed by the following factors: sex, age groups (70 years or younger vs. older than 70 years), disease duration (categorized by the median; up to 6 vs. 7+ years) and LTC type; DIF by country was not possible due to an unequal distribution of data from different countries, precluding comparisons.

According to the Rasch model, the response to a certain item is a function of the person's ability (or experienced level of the construct) and the item's difficulty (or the measured level of construct by that item), expressed in logits.[22] Fit to the Rasch model is observed when there is a nonsignificant χ^2 difference between the data and the Rasch model, with Bonferroni correction by number of items.[26] In addition, residuals should follow a normal distribution (mean of 0; SD of 1) and fall within the ±2.5 range. Large sample sizes might result in a high statistical power to detect small model deviations and unnecessary modifications. Therefore, for Rasch analysis, we included a random sample of 300 individuals.[49]

Reliability is expressed by the PSI, interpreted similarly to Cronbach's α. A threshold is the point of equal response probability between two adjacent categories. Its order is analysed and in the case of disordered thresholds, adjacent categories are collapsed. For items to be locally independent, we expect low correlations (<.30 of the average correlation) between item residuals.[50] Unidimensionality is measured through a principal component of the residuals, and person estimates are compared using *t*-tests. A lower bound of the associated binomial 95% confidence interval (CI) less than 5% indicates unidimensionality.[51,52] For DIF, analyses of variance (ANOVA) with Bonferroni correlation are conducted for all factors.[53] When several items present significant DIF by a certain factor, a top–down purification procedure is followed by creating two groups of items, with or without DIF, and comparing the estimates in an ANOVA to see if DIF remains.[54] Model modifications were evaluated iteratively.

SPSS 22.0 (IBM Corp.) was used for all CTT analyses, and RUMM2030 was used for Rasch analysis.

RESULTS

A total of 2753 people living with different LTCs were included in the sample. Osteoarthritis presented the lowest sample size (*n* = 291), and T2DM presented the highest sample size (*n* = 582). Demographic information is shown in Table 1. The age range was 20–98 years, with a mean age of 68.21 years (SD: 12.21 years). More than half of the sample was female (*n* = 1441, 52.3%), was married (*n* = 1555, 56.5%) and had basic/primary education levels (*n* = 1596, 58.1%). The employment status of the sample was mainly distributed between been retired (*n* = 934, 34%) and working as housekeeper (*n* = 827, 30.1%). All of the participants had at least one LTC, with a duration of 9.80 years (SD: 8.65; range: 0–67 years) and a mean age at diagnosis of 58.37 years (SD: ±13; range: 3–91 years).

Table 1 Participant characteristics (*n* = 2753)

Demographic variable	Response option	*N* (%)
Country	Argentina	60 (2.2)

	Colombia	1329 (48.3)
	Cuba	50 (1.8)
	Ecuador	60 (2.2)
	Mexico	53 (1.9)
	Spain	1201 (43.6)
Long-term condition	Type 2 diabetes mellitus	582 (21.1)
	Chronic obstructive pulmonary disease	612 (22.2)
	Chronic heart failure	603 (21.9)
	Parkinson's disease	324 (11.8)
	Hypertension	341 (12.4)
	Osteoarthritis	291 (10.6)
Gender	Male	1312 (47.7)
	Female	1441 (52.3)
Marital status	Single	316 (11.5)
	Married	1555 (56.5)
	Widower	612 (22.3)
	Separated/divorced	261 (9.5)
	Others	6 (0.2)
Employment situation	Active working	501 (18.2)
	Housekeeper	827 (30.1)
	Retired	937 (34)
	Other	487 (17.7)
Educational level	Basic/primary studies	1596 (58.1)

	Secondary studies	709 (25.8)
	University studies	359 (13.1)
	Others	83 (3)
	Range	Mean (standard deviation)
Age	20–98	68.21 (12.21)
Age at diagnosis	3–91	58.37 (13.00)
Long-term condition duration	0–67	9.80 (8.65)

CTT analysis

The results related to feasibility and acceptability showed that the LW-CI scale was fully completed by 2738 participants, with 99.46% of the data computable. Levels of missing data were low and broadly uniform across domains, ranging from 0 missing data (Domain 1: Acceptance) to 6 (Domain 5: Adjustment). The floor effect was absent in all domains and in the total score, whereas Domains 1: Acceptance and 4: Integration showed ceiling effects (19.1% and 15.6%, respectively). For the five domains and the LW-CI total scale, the difference between the mean and the median was less than 10%, the theoretical and observed ranges were coincident and the skewness values were between −1 and +1. Table 2 presents further feasibility and acceptability results.

Table 2 Feasibility, acceptability and reliability of the LW-CI scale

	LW-CI scale					
	Domain 1: Acceptance	Domain 2: Coping	Domain 3: Self-management	Domain: 4 Integration	Domain 5: Adjustment	Total
Missing data/fully computable data	0/2753	2/2751	5/2748	2/2751	6/2747	15/2738
Mean	10.66	18.54	10.62	14.69	14.99	69.52
Median	11	19	11	15	15	70
Standard deviation	4.40	6.07	3.72	4.04	5.94	18.37
Observed range	0-16	0-28	0-16	0-20	0-24	0-104
Floor effect (%)	2.4	0.5	0.4	0.2	0.5	0.1

Ceiling effect (%)	19.1	6.2	12.9	15.6	12.6	1.6
Skewness	−0.59	−0.43	−0.36	−0.66	−0.17	−0.21
Cronbach's α	0.87	0.81	0.76	0.79	0.85	0.91
Item-total correlation	0.618–0.80	0.418–0.65	0.488–0.60	0.388–0.67	0.498–0.68	–
Inter-item correlation	0.48–0.73	0.238–0.53	0.308–0.55	0.208–0.62	0.298–0.61	–
Item homogeneity	0.62	0.38	0.44	0.42	0.48	–

Abbreviation: LW-CI scale, Living with Chronic Illness Scale.

The results related to internal consistency showed that Cronbach's α for the LW-CI scale was .91 and that for domains ranged between .76 (Domain 3: Self-management) and .87 (Domain 1: Acceptance). All domains reached the present .30 threshold value for item-total correlation, and item homogeneity index values were higher than 0.30 for all domains. Inter-item correlation coefficient values ranged from .20 to .73 (Table 2).

Regarding convergent validity (Table 3), the LW-CI scale showed strong positive correlation coefficients with DUFSS (r_s = .62) and SLS-6 (r_s = .54).

Table 3 Convergent validity and internal validity of the LW-CI scale

	LW-CI scale					
	Domain 1: Acceptance	Domain 2: Coping	Domain 3: Self-management	Domain 4: Integration	Domain 5: Adjustment	Total score
Convergent validity						
Age	0.00	−0.10**	−0.10**	−0.05*	−0.12**	−0.10**
Age at diagnosis	0.02	−0.06**	−0.10**	−0.03	−0.09**	−0.08**
Disease duration	−0.02	−0.06**	−0.01	−0.02	−0.06**	−0.04*
DUFSS	0.30**	0.54**	0.47	0.54	0.50**	0.62**
SLS-6	0.40**	0.40**	0.40**	0.48**	0.50**	0.54**
Internal validity						
Domain 2: Coping	0.15	–	–	–	–	–

Domain 3: Self-management	0.14	0.66	–	–	–	–
Domain 4: Integration	0.27	0.68	0.67	–	–	–
Domain 5: Adjustment	0.23	0.64	0.62	0.63	–	–

Abbreviations: DUFFS, Duke-UNC Functional Social Support Questionnaire; LW-CI scale, Living with Chronic Illness Scale; SLS-6, Satisfaction with Life Scale.

*

p <.05

**

p <.01.

Regarding internal validity, correlation values for all domains of the LW-CI scale ranged from .62 to .68, except for Domain 1: Acceptance, which showed correlation coefficients less than .30 (Table 3).

LW-CI scale scores were significantly different for each category of PGIS (normal, mild, moderate, severe), gender and LTC (Table 4), with significantly higher scores for people with normal severity, women and individuals with hypertension (*p* <.05). Comparisons between subgroups of PGIS and type of LTC are presented in Table 4.

Table 4 Known groups' validity

Categories	LW-CI scale total mean (SD)	*p*
PGIS-based severity levelsa		<.001b
Normal	75.06 (17.20)	
Mild	69.84 (17.11)	
Moderate	71.12 (18.23)	
Severe	59.73 (18.51)	
Gender		<.001
Male	68.09 (18.13)	
Female	70.83 (18.50)	
Long-term condition		<.001c
Type 2 diabetes mellitus	71.53 (16.45)	

Chronic obstructive pulmonary disease	67.84 (18.86)	
Chronic heart failure	72.92 (20.14)	
Parkinson's disease	62.45 (18.57)	
Hypertension	75.20 (15.37)	
Osteoarthritis	63.19 (15.30)	

Note: Kruskal–Wallis test with Bonferroni correction for PGIS and long-term condition, Mann–Whitney test for gender.

Abbreviations: LW-CI scale, Living with Chronic Illness Scale; PGIS, Patient-Based Global Impression of Severity Scale; SD, standard deviation.

a

PGIS-based severity levels: normal, 0 points; mild, 1–2 points; moderate, 3 points; severe 4–5 points.

b

Except for mild–moderate comparison, not significant.

c

Except for Parkinson's disease with osteoarthritis, and chronic heart failure with type 2 diabetes mellitus and with hypertension comparisons, all not significant.

Rasch analysis

The first Rasch analysis, with all items, showed a significant model deviation: $\chi^2(234) = 560$, $p < .00001$. Because the total scale was multidimensional (19% significant *t* tests, 95% CI: 0.165–0.215), each domain was analysed separately. Table 5 presents the goodness of fit of the LW-CI domains, and Table 6 presents the individual item fit.

Table 5 Goodness of fit to the Rasch model of LW-CI scale domains

Attribute		Criteria	Domain 1: Acceptance	Domain 2: Coping	Domain 3: Self-management	Domain 4: Integration	Domain 5: Adjustment
Item fit residual							
Mean		0	0.067	0.545	0.441	0.634	0.371
SD		1	0.753	0.734	0.999	0.594	1.496
Person fit residual							
Mean		0	1.189	0.650	1.322	1.256	0.444
SD		1	1.730	1.224	1.544	1.490	1.362
Item–trait interaction							

$\chi^2(df)$	Low	18.771 (16)	23.790 (20)	13.783 (16)	15.493 (12)	33.994 (20)
p Value	NS	0.281	0.251	0.615	0.216	0.0262
PSI	>0.70	0.763	0.648	0.703	0.576	0.743
Unidimensionality						
Independent *t* tests	<5%	1.33%	1.33%	0%	1.33%	3.00%
95% CI binomial	a	(−0.011, 0038)	(−0.011, 0038)	–	(−0.011, 0038)	(0.005, 0.055)

Abbreviations: CI, confidence interval; LW-CI scale, Living with Chronic Illness Scale; NS, nonsignificant; PSI, personal separation index; SD, standard deviation.

a

Lower bound should be ≤0.05.

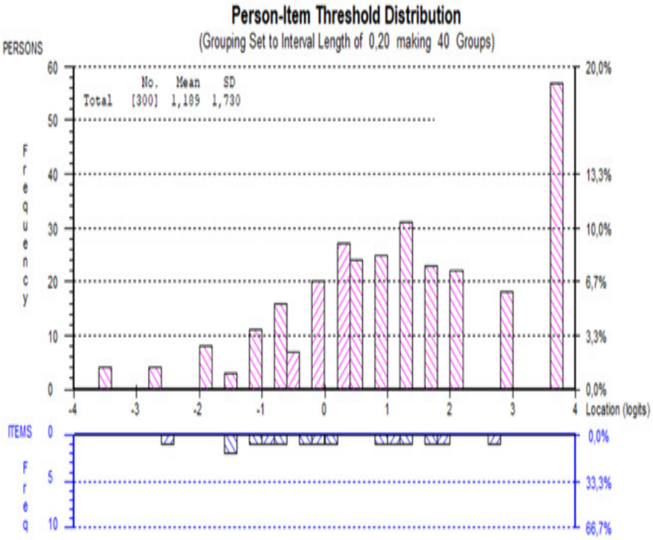
Table 6 Individual item fit

Item (response categories)	Location	Standard error	Fit residual	*df*	$\chi^2(df = 4)$	*p* Value
Domain 1: Acceptance						
Item 1: (0–4)	0.212	0.078	−0.283	175.75	6.051	.195
Item 2: (0–3)	−1.299	0.111	0.605	175.75	6.326	.176
Item 3: (0–4)	0.312	0.079	−0.825	175.75	5.827	.212
Item 4: (0–4)	0.775	0.079	0.77	175.75	0.566	.967
Domain 2: Coping						
Item 5: (0–3)	−0.075	0.074	0.096	206.2	2.828	.587
Item 6: (0–3)	−0.072	0.075	0.048	206.2	7.006	.136
Item 7: (0–2)	0.472	0.109	1.654	206.2	9.113	.058
Item 9: (0–3)	0.038	0.073	−0.018	206.2	2.542	.637
Item 10: (0–3)	−0.362	0.076	0.948	206.2	2.301	.681
Domain 3: Self-management						

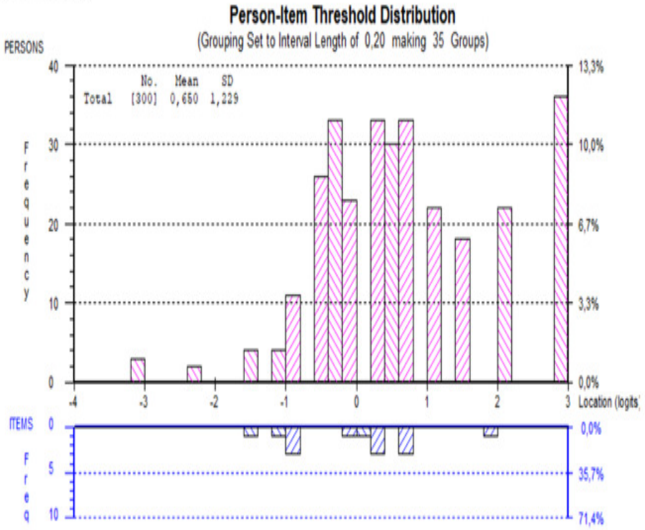
Item 13: (0–4)	0.436	0.075	1.731	168.75	0.937	.919
Item 14: (0–4)	−0.418	0.083	−0.471	168.75	5.131	.274
Item 15: (0–4)	0.202	0.073	0.711	168.75	2.934	.569
Item 16: (0–4)	−0.220	0.08	−0.209	168.75	4.781	.311
Domain 4: Integration						
Item 17: (0–3)	−0.322	0.094	1.261	143	2.981	.561
Item 19: (0–4)	0.365	0.078	0.078	143	4.211	.378
Item 20: (0–3)	−0.043	0.096	0.564	143	8.301	.081
Domain 5: Adjustment						
Item 22: (0–3)	0.467	0.08	0.38	204.2	1.281	.865
Item 23: (0–3)	−0.235	0.082	0.775	204.2	6.801	.147
Item 24: (0–4)	−0.806	0.066	−0.553	204.2	6.175	.186
Item 25: (0–3)	0.233	0.078	−1.347	204.2	13.897	.008
Item 26: (0–3)	0.341	0.082	2.602	204.2	5.839	.212

For the Acceptance domain, item 2 showed disordered thresholds, and categories 2–3 were collapsed. This dimension showed a good model fit, $\chi^2(16) = 18.772$, $p = .281$, with unidimensionality, PSI = 0.763, locally independent items and absence of DIF by age, sex, disease duration or LTC. The person-item threshold distribution shows a ceiling effect close to 20% (Figure 1).

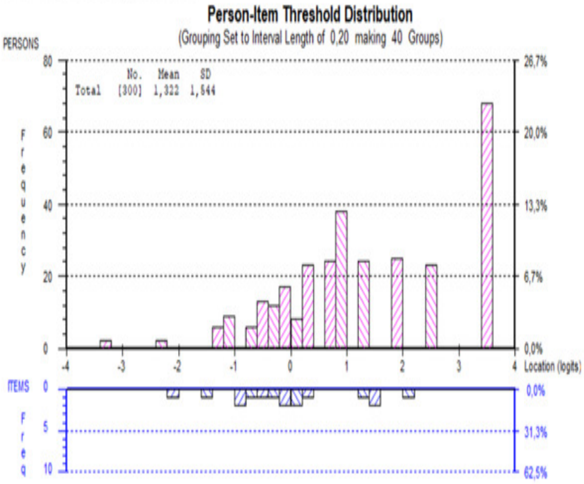
1. Acceptance



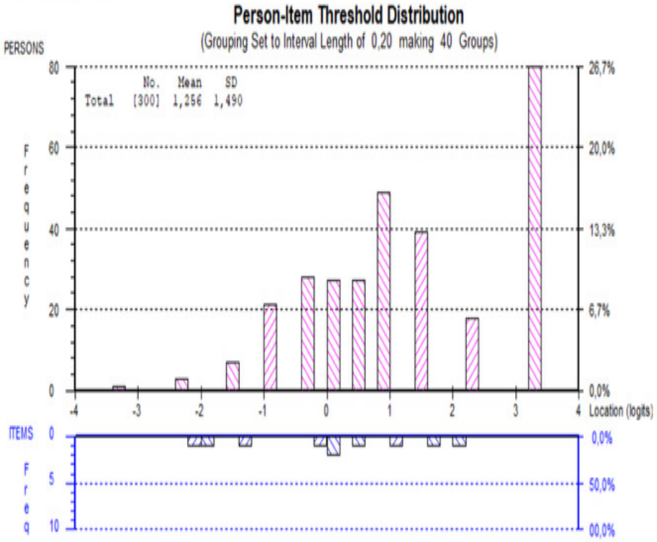
2. Coping



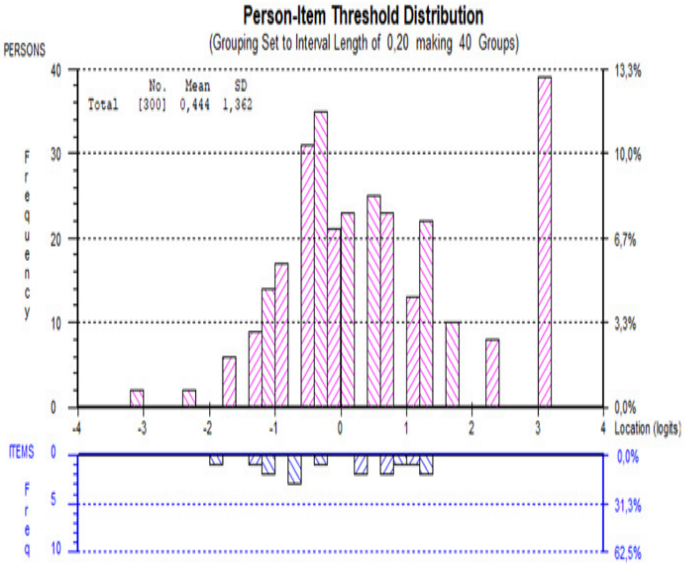
3. Self-management



4. Integration



5. Adjustment



Enlarge this image.

When performing a Rasch analysis of the Coping domain, three items (2, 11 and 12) showed a significant misfit:

Item 8 presented a low-fit residual (−2.501) and items 11 and 12 presented high-fit residuals (3.506 and 2.957, respectively). All Coping items were rescored due to disordered thresholds. The resulting scale presented an adequate fit to the Rasch model, $\chi^2(20) = 23.790$, $p = .252$, PSI = 0.648, unidimensionality and item local independency. Item 7 presented DIF by LTC type, and item 5 showed uniform DIF by disease duration (people with a more recent diagnosis underestimated scores).

The Self-management domain presented a good fit to the Rasch model, with ordered thresholds, unidimensionality, PSI = 0.703, locally independent items and absence of DIF: $\chi^2(16) = 13.783$, $p = .615$.

To obtain fit in the Integration domain, the following modifications were performed: Rescoring of all items due to disordered thresholds, and deletion of items 18 (fit residual: 3.454) and 21 (fit residual: 2.848). The modified scale presented a good fit to the Rasch model, PSI = 0.576, unidimensionality and item local independency, $\chi^2(12) = 15.493$, $p = .216$. Item 20 presented uniform DIF by LTC type. The person-item threshold distribution showed a high (26.7%) ceiling effect (Figure 1).

In the Adjustment domain, all items except one (item 24) were rescored due to disordered thresholds. After this, the domain presented a good fit to the Rasch model, $\chi^2(20) = 33.994$, $p = .0262$, PSI = 0.743, unidimensionality and item local independency. Although item 26 showed a marginally high-fit residual (2.603), it was nonsignificant. The initial DIF by LTC type in items 24 and 26 cancelled out in the top–down purification procedure.

DISCUSSION

This is the first study to analyse the psychometric properties of the LW-CI scale in a large sample of individuals with different LTCs in several Spanish-speaking countries. Currently, the LW-CI scale is the only PROM available in clinical practice and research that evaluates in a comprehensive manner how a person is living with an LTC.

Feasibility and acceptability

In general, all acceptability parameters fulfilled the standard criteria. Floor and ceiling effects could be explored using both CTT and Rasch analyses. The two domains with the highest ceiling effect at the item level, Acceptance and Self-management, also showed a ceiling effect at the threshold level in the Rasch analysis. This could be attributed to the fact that individuals involved in this study participated voluntarily, potentially implying some degree of acceptance as well as good management of the LTC and hence, in some cases, also a positive living with the disease. A large percentage of individuals tend to score in the highest levels of these domains, which might prevent observation of changes after an intervention in people with initial high scores. To verify this result, group comparisons in the Acceptance and Self-management domains should be performed with caution.

The quality of the data was satisfactory, exceeding 95% of computable data, due to the close supervision performed by researchers during data collection and the standardized protocol established for the data collection.

Reliability

Reliability was also explored using both CTT and Rasch approaches. The internal consistency of the LW-CI scale is satisfactory, with all domains exceeding the criteria of ≥0.70 for Cronbach's α. However, Integration and Coping domains showed lower reliability (PSI) in Rasch analysis, which may be due to a small number of items and the ceiling effect. A lower reliability might hinder the ability of these domain scores to discriminate between two individual groups.[55] In this sense, further studies are recommended to verify the reliability of both domains.

Convergent validity

Regarding convergent validity, the results corroborate the strong relationship between living with an LTC and perceived social support of the person as well as satisfaction with life. Living with an LTC presents low correlations with disease-related factors, namely, duration. Congruently, all items except one were unbiased by disease duration in Rasch analysis. Further studies are needed to confirm whether DIF by duration in item 5 (I try to cope and fight the disease) remains, as it was not identified in a study with a PD population.[17] In addition, two items showed bias by LTC type: Coping item 7 (I try to see the positive side of the disease) and Integration item 20 (Although I have the disease, I feel satisfied with my life). In item 20, people with hypertension tended to overestimate scores, whereas for item 7, there was no a clear pattern. Further studies are needed to confirm these DIF results, and the results at the item level should be interpreted with caution when comparing individuals. However, these two items represent less than 10% of the scale. Even though a previous study had found that one item was biased by age, we did not replicate this finding in the present study, showing the absence of DIF by age for all items.[17] Therefore, the LW-CI scale could be useful across a general adult (≥18 years) population living with at least one LTC in clinical practice. Convergent validity findings were also identified in previous validation studies[16,18–21] and additionally were confirmed through linear regression models performed with an LTC population such as PD.[5] According to these results, there is clearly a need to place the emphasis on the person and in his/her daily living with the condition, and not just on the disease. Each person with an LTC must be seen as a unique person, independent of the stage or the severity of the disease. Therefore, it is necessary to incorporate multidisciplinary and individualized interventions in current health and social services, focusing on the factors that directly influence living with an LTC, namely, social support and satisfaction with life. Consequently, possible negative aspects of the daily living with an LTC, such as lack of support, loneliness or dissatisfaction with life, could be prevented, and a more positive living can be achieved. In this sense, person-centred interventions or individualized health and social pathways could be implemented in clinical practice, incorporating nonpharmacological or disease-specific measures that address the factors that are paramount in the daily living with an LTC. Therefore, LTC programmes that mobilize and optimize the use of community resources and increase social networks and support seem to be the direction for the management of LTCs.

Internal validity

The internal validity for LW-CI scale domains was excellent, except for Domain 1: Acceptance, with correlation coefficients under .30 with the rest of the domains. This result is consistent with previous validation studies[16] and conceptual work[4] showing that Acceptance is always the first domain to achieve a positive living. Only when the person has accepted and assumed his/her illness can he or she move on to the other domains, such as Coping or Self-management. Therefore, according to the poor correlation that Acceptance showed with other dimensions of the LW-CI scale and based on the aforementioned conceptual framework, these findings were expected because Acceptance is considered an internal, illness-independent, process through which the person recognizes and accepts the reality. Interval validity was also supported by Rasch analysis, showing that each domain is unidimensional, and providing support for the calculation of domain scores.

Known groups' validity

The LW-CI scale demonstrated satisfactory known groups' validity, yielding significantly different scores between men and women, patient-based global impression of disease severity and LTC type. The result related to differences among types of LTC is understandable, as each condition has its particular symptoms and evolution. For example, PD is defined as a complex and disabling disorder characterized by being a neurodegenerative and progressive disorder, while hypertension is a cardiovascular condition that could be managed with healthy lifestyle patterns. In this sense, the individual may have a better or worst process based on the LTC characteristics. However, further studies are suggested to verify this result. Regarding gender differences, existing evidence also justifies the identified results. For example, Crispino et al.[56] stated that in general, women with PD showed more positive disease outcomes than men. Besides, other studies performed in individuals with T2DM[57] showed that women with T2DM are at greater risk than men of psychosocial maladjustment, a poorer cardiovascular profile and/or noncompliance with treatment goals. The observed significant differences by gender are not due to a bias, as no item presented DIF by gender. However, the significantly lower scores in hypertension individuals should be interpreted with caution, since two items were biased by LTC type. Therefore, LW-CI scores may be interpreted similarly across LTC types, thus allowing group comparisons, except for two items.

Rasch analysis

To achieve model fit in Rasch analysis, some modifications were performed. First, the response scale was simplified for some items, similar to a previous study with only a PD population.[17] This result suggests that individuals have difficulty in setting apart from some response options and that the response scale should be codified differently than what was initially proposed. This does not modify the scale administration. Another modification suggested by Rasch analysis was the deletion of certain items. Again, they might be maintained in the scale administration, as they can provide useful clinical information. However, when calculating linear scores, these items should not be considered, as they are either redundant or they measure a different construct.[26] In both the present study and the previous study,[17] item 8 was found to be redundant, and item 18 measured a different construct.

Recently, other measures have been designed and validated as the Long-Term Conditions Questionnaire[10] with Rasch analysis[58] in a wide and representative sample of people living with LTCs in three regions of England with the general aim of evaluating how people live/manage their LTC. However, despite the potential relevance of the Long-Term Conditions Questionnaire, this scale seems to evaluate quality-of-life outcomes instead of living with an LTC and excludes aspects related to acceptance, which is an essential attribute when living with an LTC.[4] Moreover, currently, there are multiple measuring scales that seem to evaluate the phenomena of living with an LTC.[9] However, existing scales evaluate the process in a fragmented way by measuring some elements of the process or related processes, such as quality of life.[9] Consequently, to our knowledge, the LW-CI scale could be considered the only available person-centred measure that evaluates the complex process of living with an LTC in a comprehensive manner. Using this scale, healthcare professionals could identify aspect/s of the process that the patient finds more challenging and consequently, referrals, interventions or signposting to services or resources could take place based on the assessment and identified needs. For example, the scale itself could be part of interventions through which patients could complete the scale at home, increasing their awareness of how they live with the LTCs and in their annual or periodic review with the GP, nurse or specialist, the results from the assessment could also be discussed for further support. This could be equally applied to research projects. At present, a cross-culturally adapted version of the scale has been produced in the United Kingdom (called the living with long-term condition scale)[59] and full validation study is ongoing, which would allow health and social care professionals to implement person-centred care pathways and referral processes.

This validation study is novel because the LW-CI scale is the first validated rating scale for assessing the phenomenon of living with an LTC. Moreover, this scale has been used for the first time to assess several highly prevalent LTCs in different Spanish-speaking countries using two complementary analytical approaches to ascertain its psychometric properties. Therefore, considering the results, the LW-CI scale could be used in clinical practice to evaluate the degree of living with several highly prevalent LTCs in different Spanish-speaking countries.

Limitations

We acknowledge that the limitations of the study are mainly related to the convenience sample, with a heterogeneous representation of LTCs and countries. Additionally, although country-based samples were not large enough to produce any country-based (cultural) analysis, further international studies are needed to test item bias by country as well as cultural differences within countries. Besides, considering the sample diversity, including people from six different countries, sociodemographic data related to ethnicity were not collected. Additionally, for this validation study patient and public involvement (PPI) was not conducted because the aim of this study was to statistically analyze the psychometric properties of the LW-CI scale. However, PPI was a key aspect during the development of the scale and piloting phase before the main validation studies. Finally, data collection was performed at different times for PD and the rest of the LTCs. However, to ensure homogeneity of the process and avoid errors, a clear and standardized protocol was followed, and data quality was equally valid for the purpose of this study. On the other hand, the strengths of this study are related to the sample diversity, including the highly prevalent and prototypical LTC population as well as the large age range population, which led to the real value of the LW-CI scale psychometric properties for a general LTC population. Finally, the combined application of the classic test theory approach and Rasch analysis is highly recommended for evaluating patient outcome report measures such as the LW-CI scale.

CONCLUSION

This study fulfils an important gap in the literature regarding person-centred measures to evaluate the process of living with an LTC. After some adjustments, the LW-CI domains showed a good fit to the Rasch model, with unidimensionality, item local independency and moderate reliability, providing scores on a true interval scale. This last feature is key for using the scale in clinical trials. Except for two items, the LW-CI scale was free from bias by LTC type. In this sense, although cautious use is suggested, the LW-CI scale is ready for use in clinical practice and research in Spanish-speaking populations living with different LTCs, which could lead to more person-centred care and individualized psychosocial interventions. Therefore, future implementation studies are suggested to assess the usefulness of the LW-CI scale in clinical practice.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Carmen Rodriguez-Blazquez, Maria João Forjaz, and Alba Ayala: *design of the work, data analysis, interpretation of the findings, drafting the article, critical revision and substantial contribution of the article, approval of the final version for publication*. Mari Carmen Portillo: *conception and design of the work, expert consulting, critical revision and substantial contribution of the article, approval of the final version for publication*. Leire Ambrosio: *principal author of the scale, principal investigator of the project and responsible for funding of the project, conception and design of the work, oversight of the project, data collection, interpretation of the findings, drafting the article, critical revision and substantial contribution of the article, approval of the final version for publication*. The corresponding author, in representation of the rest of the undersigning individuals, guarantees the precision, transparency and honesty of the data and information contained in the study and additionally that none of the relevant information has been omitted, and that all discrepancies among the authors have been adequately resolved and described.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

DETAILS

Subject:	Obstructive lung disease; Osteoarthritis; Heart failure; Questionnaires; Hypertension; Likert scale; Rasch model; Correlation coefficient; Validation studies; Public involvement; Chronic obstructive pulmonary disease; Parkinson's disease; Validity; Arthritis; Quantitative psychology; Biomedical materials; Diabetes mellitus; Illnesses; Lung diseases; Reliability; Patients; Coronary artery disease; Diabetes mellitus (non-insulin dependent); Diabetes; Clinical research; Chronic illnesses; Type 2 diabetes mellitus; Neurodegenerative diseases; Correlation coefficients; Domains; Citizen participation; Movement disorders; Coefficient alpha; Sociodemographics; Design; Patient-centered care; Congestive heart failure; Classical test theory
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‘It gives you the skills of how you can cope’: Exploring the self-reported experience of patients receiving in-centre haemodialysis on participating in chosen art activities

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ABSTRACT (ENGLISH)

Background

Increasing numbers of patients are receiving dialysis, particularly in high-income countries. Patients receiving haemodialysis often experience fatigue, anxiety, depression and boredom. It is suggested that arts activities could have a therapeutic effect.

Objective

This study aimed to explore patients' perspectives of participating while on dialysis in chosen arts and creative living activities provided by tutors at the bedside.

Design

Qualitative semi-structured interviews in the interpretive tradition were conducted, with thematic analysis.

Setting and Participants

Fifteen patients of different ages, genders and ethnicities who participated in an arts activity while receiving haemodialysis in an inner-city dialysis unit in England were included in this study.

Results

Participants reported positive experiences of engaging in art activities. Their views on the value of the activities were grouped into five themes: diversion from receiving haemodialysis, a sense of achievement, contribution to a more positive self-identity, increased confidence and motivation and a therapeutic talking relationship. Participants suggested that patient peer promotion of the activities could increase uptake, with patient choice of activity seen as important.

Conclusions

Participation in a chosen arts activity while receiving haemodialysis was perceived by patients to have positive psychosocial effects. We theorize three potential explanatory mechanisms for these effects: That the experience of participating in the activities engendered positive psychological states of ‘being in the flow’; enhanced self-esteem to add to personal coping mechanisms; and offered additional facets to the patient's identity that countered the stigmatizing effect of receiving dialysis.

Patient or Public Contribution

Patients and public representatives advised on the design, research methods and tools.

FULL TEXT

INTRODUCTION

Patients with end-stage kidney disease (ESKD) experience an irreversible loss of kidney function, requiring kidney replacement therapy (KRT) by dialysis or transplantation. Kidney transplantation provides the best quality of life, while dialysis is used as an interim measure or indefinitely for those unsuitable for transplantation. About 0.1% of the global population have ESKD, with most people on KRT living in high-income countries.[1] Increasing numbers of patients are in need of KRT,[1] with additional demand for dialysis associated with coronavirus disease 2019 (COVID-19) patients.[2] In 2018, about 26,000 adult patients received dialysis in the United Kingdom, with most patients (83%) receiving haemodialysis (HD) in a hospital or satellite dialysis unit.[3] People of Black and minority ethnicities, those aged older than 65 years and males are overrepresented in this patient group.[3] Patients attend a dialysis unit usually three times a week for 4–5 h at a time.[3] Patients are connected to a dialysis machine throughout. A major challenge for patients is the considerable impact on their daily lives. Patients often experience fatigue, low mood, anxiety, depression and boredom, in addition to medical complications due to the limitations of the dialysis in serving renal functions.[4] Many people on dialysis are known to experience a poor health-related quality of life.[5]

Over the last 20 years, interest has grown internationally in determining the benefits that participation in the arts, that is, visual arts, dance, film, literature, music, singing, crafts and online arts, may bring to well-being and quality of life.[6] Some Western European countries, such as Ireland and Norway, have policies that increase the contribution of art and culture to health and well-being.[6] In the United Kingdom, a parliamentary group has advocated for research into the potential health benefits of arts for people living with chronic diseases.[7] There is limited evidence assessing the benefits or otherwise of using creative arts in hospitals to improve the quality of life for patients receiving HD. A systematized literature search[8] was undertaken of six databases (PubMed, Web of Science—Medicine, Web of Science—Arts and Humanities, Scopus, Art and Architecture Source, Google Scholar) for English-language papers from the date of commencement of the database until 1 September 2019, later updated to 1 December 2020. Key words were used in the search (dialysis, HD, renal dialysis, arts, crafts, arts activities), combined with follow-up of authors and references in identified papers, and forward citation searching. Seven peer-reviewed publications were found reporting on evaluations of participatory arts activities for adult patients receiving in-centre HD.[9–15] Three of the papers were from the United States, two from England and one each from Ireland and Spain. The papers reported on different types of arts activities: single art activity (drawing),[9,10] two activities (creative writing and visual art),[15] multiple activities (e.g., printmaking, mosaic making, crocheting)[12,13] and mixed active and passive activities (e.g. mandalas qmaking alongside clown visits).[10,14] Five studies involved group activities,[9,11–14] and two studies involved individual activities.[10,15] The research methods were varied: an individual patient case study,[11] patient interviews by purposive sampling,[9,12,13] observational studies using survey instruments before and after a mixed arts programme [11,14] and mixed methods including a pilot randomized control trial and qualitative interviews.[15] The mixed arts programme study, which was performed in the United States with 46 patients, reported significantly improved scores on the quality-of-life domains described as social functioning and bodily pain, for patients who had high rates of participation.[11] The Spanish study, which included 41 patients participating in a mixed arts programme, found no statistical difference in anxiety or quality-of-life measures after the programme.[14] All seven published studies reported, mostly briefly, or on the basis of professional views or reports of health professionals, that the arts programme was positively viewed by participants. Our analysis of the five studies[9,10,12–14] that reported patients' reasons for the positive comments found that helping pass time and alleviating the boredom of receiving HD were the most frequently mentioned reasons. Although it is hypothesized that these activities improve mood and well-being, there is limited evidence of effect, particularly from the patient perspective,[15] or explanatory theories as to the mechanism of the effect.

This paper adds to the existing literature by presenting data from the perspective of patients on HD of their broad experience of participating in an arts programme in the United Kingdom, which offered choice from a range of activities and individual bedside tutorship during dialysis. This contrasts with previous studies focused on asking patients or professionals if their arts programme participation was a positive experience or not and on programmes with no choice (or only two options in the study reported by Carswell et al.[15]) and group tutorship. It is not known how many arts programmes are run in the 71 adult UK dialysis units, but a survey of 17 units found that few patients had the opportunity to participate in arts and crafts activities, although 26% of patients reported that they were interested in participating.[16] In one inner-city English NHS Hospital Trust, a hospital charity has provided an arts and creative living activities programme delivered by tutors at the bedside since 2016 for patients on HD. Patients were offered, unusually for these types of programmes, a wide choice of arts and creative living activities, including drawing, painting, sculpture, creative writing, languages and IT/screen-based skills. Between July 2018 and January 2020, 127 of the 294 patients receiving HD[4] engaged in an activity at least once. We investigated the research question from the patient perspective: what has been the patient experience, both positive and negative, of participating in a chosen arts and creative living activity/activities while receiving HD?

METHODSStudy design and setting

A qualitative design was used in the interpretive tradition,[17] enabling exploration of patients' perceptions and opinions and consideration of context in understanding their experiences. Guidance for ensuring quality when undertaking qualitative research[18] was used to assess validity and reliability in designing an appropriate methodological approach, including the interview protocol, the trustworthiness of the data collection and analysis and the extent of reflexivity. Eight patient representatives from an established patient and public involvement and engagement research expert group and from a kidney charity, volunteered to work with researchers, on a partnership basis,[19] to develop the study. They were closely involved in developing the study design, the data collection methods and tools and the data analysis approach. The study setting was an NHS Hospital Trust with an in-hospital unit and three outlying centres providing HD.

Participants

Eligibility criteria specified consenting adult patients, aged 18 years or older, who had engaged in an arts or creative living activity while receiving HD in the hospital trust in the previous 15 months. Patients were excluded if they were not clinically stable and well enough to take part or lacked capacity to provide informed consent. Sampling was purposive, designed to provide diversity in terms of age, gender, ethnicity, dialysis unit, activities experienced and extent of participation. The arts programme coordinator identified every second patient from their list of patients receiving HD in the programme and gave these details to the clinical team. The clinical team identified patients who fulfilled the eligibility criteria. A member of the clinical team made the initial enquiry about participation in the study and whether eligible patients were willing to have their contact details passed to a study researcher. Only patients indicating potential interest in participation were sent or provided with a consent form and study information sheet. This provided an explanation about the study and that they would be contacted a week later by a study researcher, which would give them an opportunity to ask any questions. They could choose to be interviewed by telephone or face to face while present in their dialysis unit and at a date/time of their choice. Four of the patients introduced to the researcher withdrew before consenting due to ill health. Recruitment continued until it was judged that data saturation in data collection had been reached, that is, when no new views or perceptions seemed to be elicited in interviews and data replication occurred.[20]

Data collection

Semi-structured interviews were conducted with open-ended questions and supplementary prompts to allow the key areas of interest to be explored without being prescriptive about content.[21] A topic guide was developed based on the study questions and informed by discussions with PPIE representatives. A key topic that they suggested for inclusion was how and when the offer of participating in an arts or creative living activity was made to patients, hypothesising that this may influence the patient experience. Other questions included participants' motivations for taking up an activity; attitudes and feelings about participation; any perceived changes in mood and well-being associated with undertaking the activity; and any suggested improvements. Discussion with the PPIE representatives also helped the research interviewer to reflect on how their background and experience could influence the data collection. Thirteen participants were interviewed face to face in their dialysis unit while receiving HD. One participant was interviewed by telephone and one participant was interviewed at the renal outpatient department of the study site. Interviews lasted between 18 and 52 min (mean: 29), were audio-recorded with permission and transcribed. Field notes were taken to record interviewer observations, analytical thoughts and issues raised. Interviews were undertaken between December 2019 and March 2020.

Data analysis

Inductive thematic analysis was used based on its epistemological and theoretical flexibility.[22] Transcripts were read through to familiarize with the corpus of the data and then analysed by one researcher using open coding and constant comparison, informed by the field notes. A framework of themes was developed from the analysis, together with a code book, and used to structure verbatim responses onto a spreadsheet. Where data did not fit generated themes, new codes were developed or existing ones were revised until all data were coded. This reflexive process[22] was undertaken independently by one researcher supplemented by collaborative discussion with the second researcher to reach consensus and for confirmation of themes. The study researchers also used these discussions to consider the role of reflexivity and how to minimize the influence of their beliefs, personalities and experiences on the data analysis and interpretation.[23]

RESULTS

Fifteen patients participated in interviews (Table 1).

Table 1 Participant characteristics

Characteristic	Participants ($n = 15$)
Age (years)	
≤49	1
50–64	7
≥65	7
Gender	
Female	7
Male	8
Ethnicity	
White British	4
Asian British	3
Black British	8
Time on haemodialysis therapy (years)	
<2	3
2–4	5
5–9	4
≥10	3

Fourteen participants were on HD. One participant had discontinued HD after receiving a kidney transplant and two others had restarted HD treatment after kidney transplant failure. All participants receiving HD were attending their dialysis unit three times a week for 4 h at a time on a dialysis machine.

The themes and subthemes extracted through analysis are summarized and described in Table 2.

Table 2 Summary of overarching themes and subthemes

Overarching themes	Subthemes

•1. Perceptions of the offer of activity participation and influences on take-up	•Relief from boredom •Opportunity to learn something new •Choice of activity
•2. Experience of undertaking an activity or activities	•Diversion from receiving haemodialysis •Sense of achievement •More positive self-identity •Increased confidence and motivation •Therapeutic talking relationship
•3. Suggested improvements	•Peer stories and peer support •Timing of activity sessions •Matching tutors and activities to patient profile

Perceptions of the offer of activity participation and influences on take-upRelief from boredom

For many participants, the offer of undertaking an activity was perceived as a welcome relief from boredom. Some participants described time as passing slowly during HD. Others talked about how time spent on HD was ‘empty’ time, or ‘time away from living’. Participants' accounts were often permeated by expressions of frustration, anger or distress. In a few cases, participants reported that because of the boredom, they would have been willing to take up almost any activity.

Look being incarcerated here is tedium. Anything that breaks up tedium is a welcome relief. If it includes a bit of creativity, if it involves a bit of education, all the better. (Patient 7)

Opportunity to learn something new

The anticipated learning benefits of taking up an arts or creative living activity were an attraction for several participants. For example, one participant mentioned the perceived appeal of learning new skills. Another participant talked enthusiastically about gaining new knowledge and another about the opportunity for personal growth. Some participants stressed how important and beneficial it was to them to embrace ‘active’ as opposed to ‘passive’ activities such as watching TV or sleeping while dialysing. They talked about the value of keeping positive and engaged. A few participants were keen to make positive comparisons between themselves and others. They perceived engagement in the programme to reinforce their self-image as more active, alert and involved than others receiving dialysis who spent their time more passively.

It's good to keep your mind active… Three days a week for us, in each session just lying here would not be good at all. It just makes you more alive, more with things, you take more interest in life. (Patient 1)

Choice of activity

Providing patients with a choice of activities was considered to facilitate uptake in different ways. First, some participants reported that being offered a choice had enabled them to select an activity of individual appeal.

Each individual has their own interests… S/he [tutor] had so many [activities] and I said I'm interested in this? Do you teach that? and she said ‘yes’… I went for it. (Patient 12)

Second, several participants reported switching between activities. In some cases, participants said they changed their activity because they did not enjoy their first choice, and in other cases because their chosen activity sessions were completed or no longer available and another option was on offer. Additionally, some participants expressed appreciation of the offer of choice as it demonstrated recognition that the HD community is made up of individuals, each with their own interests, not one homogenous group.

Everyone's got their choices. I think it's up to them really what they want to do… it's the patient's choice. (Patient 5)

Experience of undertaking an activity or activitiesDiversion from receiving HD

Participating in an arts or creative living activity was particularly valued for providing a positive distraction from HD. Some participants talked about being so focused on the activity that their mind was diverted from the problems associated with receiving HD. Others reported that time passed much faster. A few participants reported that doing an activity had been emotionally therapeutic. They described themselves as being distracted from their problems related to HD and felt better able to cope with the treatment.

You're not thinking about your dialysis, you're blanked out and thinking about what you're doing. It's amazing how focused you are… if you're busy doing nothing you have problems… It gives you the skills of how you can cope rather than just moan about it. (Patient 4)

Experiencing these benefits led some participants to describe a sense of positive anticipation about attending HD sessions in which they knew they would be doing their chosen activity.

It made me more happier for doing something. I got excited every Monday when s/he came I got something to do, at least it let the time pass quickly. (Patient 13)

Sense of achievement

Many participants positively described feelings of a sense of accomplishment resulting from engaging in an activity. No matter how much knowledgeable guidance they reported having from a tutor, perceiving themselves to be an agent of their own achievement and success was an important benefit. Some participants described mastering a new skill, others talked about discovering a talent they never knew they had or learning to do something never done before. Furthermore, such achievements were often reported with some incredulity; participants used words such as ‘amazed’, ‘shocked’ and ‘surprised’ to describe what they had achieved: ‘I didn't think I could ever like do something as good as that… I surprised myself’ (Patient 8).

Achievement was also reported in relation to using time on HD to do something constructive rather than it being ‘wasted’ time. Some participants described a sense of fulfilment about using dialysis time to learn or make something instead of sleeping.

Coming here for these kind of hours, if you learn something out of it, it's good. I've enjoyed it. When they're [the tutors] here at least I've learnt something. Not coming to sleep, learn something. (Patient 12)

Celebrating their achievements was reported by several participants as being particularly rewarding. Some participants mentioned feeling motivated because of receiving the approbation of their tutor. Others spoke about their pride and pleasure of having the product of their activity exhibited publicly in the hospital site.

More positive self-identity

Several participants reported experiencing a more positive sense of self and identity, beyond that of a renal patient receiving HD. The participants described this enhanced sense of self as resulting from positive changes in family and friends' attitudes to them following talking about what they were achieving in the activity or showing the output.

People they look at you and they kind of make dialysis define you… for instance, when I finished [activity], I took [the activity work] and I showed my partner and even he was quite surprised at my skill… I felt like for once he looked at me as someone that's capable of making something or doing something outside of being here [the dialysis unit]. (Patient 15)

Increased confidence and motivation

Engaging in an arts or creative living activity was also considered to be beneficial to participants' confidence and motivation. Some participants spoke about feeling more empowered as a result of mastering a new activity. For example, a male participant described how learning something new had given him more confidence in social situations:

It did make me feel in some situations maybe a little more confident… Initially it was just about the [activity] and then I suppose after you learn that you can manage, you think well I'm not that stupid. (Patient 6)

Other participants reported how the process of learning or creating had generated new possibilities and opportunities such as joining other local educational classes, restarting hobbies and pursuing employment.

I'm always failing I never push myself. If I can make an object, I don't see why I can't do what I want to do in future. (Patient 13)

Therapeutic talking relationship

A few participants reported that part of the enjoyment of undertaking an activity was the opportunity to talk with someone (the tutor) while on HD. 'It definitely made the mood a little bit lighter… just looking forward to speaking to somebody else' (Patient 6). For these participants, talking seems to have been therapeutic for a variety of different reasons: break from isolation; association with a human rather than a machine; discussion on topics other than dialysis; and an opportunity to discuss emotions.

Suggested improvements

Participants suggested several improvements for the arts programme. These suggestions were associated with more negative aspects of their experience of the programme. The suggested improvements were reported in three themes:

Peer stories and peer support

Peer patient promotion of the benefits of participation was a frequent suggestion to improve uptake of the programme. While appreciative of the promotion by tutors, several participants explained that patients who shared the lived experience of HD could provide a truer and more inspiring story of undertaking an activity while dialysing.

Maybe they should get other patients who have done it before, maybe they should speak to the patients who are dialysing and explain to them it's a good thing… they have something in common so they will understand where you're coming from. (Patient 13)

Some patients suggested that exhibiting their work on the dialysis unit walls might support their peers who knew less about arts or creative activities to understand what was involved and what might be achieved.

Timing of activity sessions

Several participants suggested that there needed to be more choice as to when activity sessions were undertaken to fit with the physical and emotional stresses of coping with HD. Some participants reported that there were occasions when they were not emotionally and/or physically receptive to engaging in the activity.

I might come with a headache or I might not feel too well and like it's the [activity] day today and because I get my joy from the activity you feel obligated to. (Patient 15)

Matching tutors and activities to patient profile

Some participants, particularly those identifying as Black British, argued that an increase in take-up could be achieved by expanding the activity appeal to a wider socioeconomic range of patients. To achieve this, they felt that there needed to be a better match of tutors and activities to the profile of patients in the dialysis units, in particular, taking into account age and ethnicity.

It will depend what the community of patients are. Like the satellite unit at [unit name], in the group that I am in, a lot of the patients are elderly, some of them have a language barrier to understanding… you might basically have a visit there to see the demographic of the people as to what they might or could be offered. (Patient 6)

DISCUSSION

This qualitative study identified positive views from patient participants to the experience of engaging in their chosen arts or creative living activity while receiving HD. Positive experiences of patients on HD participating in arts programmes have been reported in other studies.[9,10,12,13,15] As with Rowe et al.,[13] our findings indicated that a main patient explanation for the positive experience was diversion from the tedium of receiving HD as well as a motivating factor in activity take-up. However, in this study, participants also discussed their positive experience in the context of feeling a sense of achievement in what they accomplished and in discovering unknown skills and talents. They perceived the activities to have therapeutic value not only during HD but also more generally for living as a patient on HD. Longer-term benefits were reported as experiencing a more positive self-identity leading to increased confidence and motivation to take part in other activities and interests. To our knowledge, these findings have not been reported before.

Our appraisal of published evidence identified that only Rowe et al.[12] posited any explanatory theory for the positive responses of patients, an analysis confirmed in a recent realist review.[24] One possible theory suggested by Rowe et al.[12] was that of Csikszentmihalyi's[25] concept of ‘flow’. Csikszentmihalyi argued that optimal human experience was achieved when people were in flow: A state of concentration so absorbing that they described time as passing much faster. The conditions identified as likely to create a state of flow were as follows: The person perceived there to be an opportunity for action (challenge); for stretching their capabilities; and the likelihood of learning new skills. While we concur that this theory has explanatory value for some of the patient-reported positive experiences in this study, we suggest that there may be three alternate explanatory mechanisms that require future investigation. We discuss these in turn.

Our participants' positive experiences, beyond the immediate absorption of the ‘challenging’ activity, could be explained by considering aspects of cognitive adaptation. Taylor[26] argued that people faced with personally threatening events adjusted and coped through three processes: a search for meaning in the experience; attempts at mastery over the event or more generally in life; and attempts to build self-esteem. These processes were described with reference to patients with cancer, although they are likely to apply to patients with other chronic or fatal diseases including patients with ESKD. There has long been evidence of the continuous coping and adjustment challenges faced by patients with kidney failure and the impact of dialysis on self-esteem, particularly in relation to feeling less capable and productive than before kidney failure.[27,28] We theorize that the accounts of more positive self-identity and increased confidence provided by our participants reflected changes in their self-esteem contributing to overall well-being. Several participants also reported distinguishing themselves favourably from other dialysis patients who they perceived as more passive and disengaged because they had chosen not to participate in an activity. Making active self-enhancing comparisons with others in a similar position, to compare positively downwards, was described by Taylor[26] as a method of bolstering self-esteem. It is unknown the extent to which the patient group who accepted the offer of engaging in an activity, and volunteered for the study, were already active in the three areas of cognitive adaption that Taylor[26] described. This requires further investigation in future studies.

An alternative explanatory theory can be found in Goffman's[29] theory of stigma. A stigmatizing condition is characterised by discrediting attributes being assigned to individuals by others. Our findings showed that enhanced self-worth for some participants was linked to positive changes in family members' perceptions of them consequent to engaging in an activity. Changed perceptions appeared to be an affirmation of their identity as one separate from that of a patient on dialysis. We theorize that in undertaking and engaging in the arts and creative activities, the participants disrupted the assignment of discrediting attributes by others and lessened the stigmatizing effect of receiving HD.[29] This also requires further investigation and testing.

A third potential explanatory theory for the positive experiences described by our participants could be the reported therapeutic conversations with some tutors. This programme provided one-on-one tuition at the bedside rather than group activities (as described by most other studies[9,11–14]). There is evidence that cognitive behaviour therapy has beneficial effects for dialysis patients diagnosed with depression.[30] The influence on mood and well-being of one-on-one interactions compared to group activities, which encourage more social interaction, is another area for further examination.

This study also reports that for many participants, having choice was important as to which arts and creativity living activity they engaged in. This is congruent with findings from previous literature on the importance for patients with kidney failure of having choice and control in relation to the timing and delivery of dialysis[31] and support interventions.[32] Greater diversity in activity choice was also recommended, matched to the interests of the socioeconomic profile of dialysis unit patient populations. Participants identifying as Black British particularly emphasized that this improvement to the programme was needed to broaden its appeal. Interestingly, this was the only notable difference in terms of age, ethnic background or dialysis experience in participant responses to the intervention. Additionally, the participant advocacy of peer promotion of the uptake of arts and creative activities is in keeping with other studies reporting the value of peer support for patients with shared lived experience of dialysis.[32]

HD is a challenging, time-consuming therapy due to the lengthy time periods spent on the dialysis machine and the time commitment required to travel to and from dialysis centres. Time spent on machines is viewed as redundant and frustrating. This leads to significant challenges in adherence to the therapy. Poor compliance to HD leads to significant morbidity and mortality as well as increased burden on the NHS. Engaging in a pleasurable activity during dialysis provides a potential incentive to increase dialysis adherence. More broadly, the study findings and theoretical mechanisms for such findings are likely to be of value to policy makers at the national level concerned about how best to support the mental health and well-being of the increasing numbers of people living with chronic and end-stage health conditions, including through participation in the arts.[7] They will also contribute to the evidence base for funding arts-based programmes for these patient groups. The study findings will further be of value to clinicians and decision makers considering specifically how to support the therapeutic needs of patients receiving HD and the contribution that arts programmes can make.

Strengths and limitations

A major strength of the study was PPIE involvement in the design, which prompted and guided consideration of context in understanding participants' experience of undertaking an arts and creative living activity while receiving HD. Theoretical framing of the findings contributed towards an understanding of participants' positive experiences. The study has some limitations. Participants of only one arts programme were recruited, a limitation that can only be addressed by involving more renal centres. However, there are few opportunities currently for patients to participate in such programmes in renal centres in the United Kingdom,[22] and the international experience suggests precarious programme funding. The study used one female interviewer with previous experience of interviewing patients on dialysis, which may have influenced their approach. However, the team approach to analysis and drafting the paper helped mediate against a single interpretation. The study was not funded to translate study materials into different languages or conduct the interviews in languages other than English. Nevertheless, the study participants were diverse in terms of age, ethnicity and dialysis experience, thus increasing the potential transferability of our findings. The study did not actively seek to ask eligible patients who had not participated in the arts programme their reasons for nonparticipation, as there were no records of who had been offered the programme and declined. However, to mitigate this limitation, study participants were asked their views on why other patients might have chosen not to participate in the programme.

CONCLUSION

This study reports positive patient experiences of engaging in a chosen arts or creative living activity while receiving HD, which in turn had a positive influence on the dialysis experience. Irrespective of the activity chosen, participation was perceived to have therapeutic value through improving mood and well-being as well as generating longer-term benefits associated with increased confidence and enhanced self-esteem. This evidence will be of value to policy makers, service commissioners and health professionals considering introducing or supporting such programmes. Our analysis and interpretation suggest theoretical mechanisms for these findings and as such adds both new knowledge to the evidence base and theoretically informs future studies of impacts and outcomes.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

ETHICS STATEMENT

This study was approved by a UK NHS Research Ethics Committee (Reference number 19/WA/0324). Written informed consent was obtained from each interview participant.

AUTHOR CONTRIBUTIONS

Vari M. Drennan and Francesca Taylor conceptualized the study and were responsible for funding acquisition. Vari M. Drennan and Francesca Taylor formulated the methodology. Francesca Taylor, Jeunita Jones, Marie-Louise

Turner and Joyce Popoola contributed to the investigation. Francesca Taylor and Vari M. Drennan carried out the formal analysis. Francesca Taylor was responsible for the first draft of the manuscript; and all authors are in agreement of the final manuscript and its revisions.

DATA AVAILABILITY STATEMENT

Deidentified interview data sets analysed in the current study are available from the corresponding author on reasonable request.

DETAILS

Subject:	Hemodialysis; Motivation; Coping; Hospitals; Creative writing; Boredom; Interviews; Talking; COVID-19; Dialysis; Patients; Quality of life; Research methodology; Patient control; Fatigue; Arts; Stigma; Psychosocial factors; Participation; Research methods; Data collection; Uptake; Trust; Art; Professionals; Identity; Qualitative research; Coronaviruses; Tutoring
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Location:	Ireland; United Kingdom--UK; United States--US
Identifier / keyword:	art; kidney failure; patient preference; qualitative research; renal dialysis; self-concept
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Social network participation towards enactment of self-care in people with chronic obstructive pulmonary disease: A qualitative meta-ethnography

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ProQuest document link

ABSTRACT (ENGLISH)

Background

How people with chronic obstructive pulmonary disease (COPD) engage with supportive social networks to enhance self-care is not understood. The personal rationales for participation in socially directed support have not been addressed in the literature. To determine how people with COPD identify, engage and participate in socially supportive self-care practices, we conducted a systematic review and meta-ethnography of qualitative studies.

Methods

A systematic literature search was conducted between June 2010 and June 2021. Of 3536 articles, 8 fulfilled the inclusion criteria. Using a meta-ethnography approach to the qualitative synthesis, new concepts were derived from the data to identify aligning themes and develop a conceptual model.

Findings

Interpretations from the papers yielded concepts of (1) accountability and personal responsibility in self-care, (2) valued positive relationships with clinicians, (3) understanding of illness through shared and personal experiences and (4) acknowledging social networks in fostering self-care engagement in people with COPD. The independence-experience (Index) model of synthesized (third order) interpretations highlighted the processes of social networks and self-care practices: (a) fear or avoidance of dependency, (b) learning from experiences of adaptive self-care behaviours and (c) including valued practices in self-care. Self-care strategies are formed through illness experiences and relatable social encounters.

Conclusion

The model derived from the third-order interpretations is a framework to describe socially supported self-care and can be used to direct future self-care strategies and target interventions for people with COPD.

Patient or Public Contribution

The findings and model were presented to the long-term conditions patient and public involvement group. The manuscript is coauthored by a public representative.

FULL TEXT

BACKGROUND AND RATIONALE

Self-management interventions[1–3] for people with chronic obstructive pulmonary disease (COPD) have been found to contribute towards reducing the burden of disease, improving quality of life and reducing the risk of hospitalisation.[4] Challenges to enacting self-care in COPD include low health literacy,[5] multi-morbid disease[6] and low self-efficacy[7] in understanding and managing complex, sometimes frightening symptoms.[8] Supportive social networks are recognized as relevant for accessing social resources and enhancing individual capabilities for chronic illness self-management.[9] Social support is a valuable coping mechanism for people with COPD, associated with reduced hospitalisations and fewer exacerbations, and in the general population, insufficient social connections are linked to higher mortality.[3,10–12] Participation in social support networks enables individuals with COPD to embed self-care practices into their personal everyday lives.[3,13] However, this is currently underexplored in the context of COPD.[3,14] There is a need to understand and explain the value of socially supported self-management in people with COPD [14,15] to inform integrated care pathways and community interventions aimed at increasing self-care practices in this population.[16]

Evidence suggests that psychosocial aspects such as addressing anxieties and family dynamics are relevant to supporting behavioural change in people with COPD,[17,18] but are not routinely included in self-management consultations with healthcare professionals.[14,19] Furthermore, evidence suggests that accessing community resources and support from a wide range of social network support[20] enables the maintenance of positive health behaviours and reduces unnecessary contact with health professionals.[21,22] Peer and social network support offers potential support in personal decision making and the maintenance of longer-term health-related activities.[23,24] This review examines how social network participation enables self-care engagement among people with COPD to inform the development of future social network interventions for this population.

Aim (research question)

The aim of this study was to understand the personal and contextual influences of how social self-management support (SSMS) practices are selected and established in the everyday lives of people with COPD.

Objective(s)

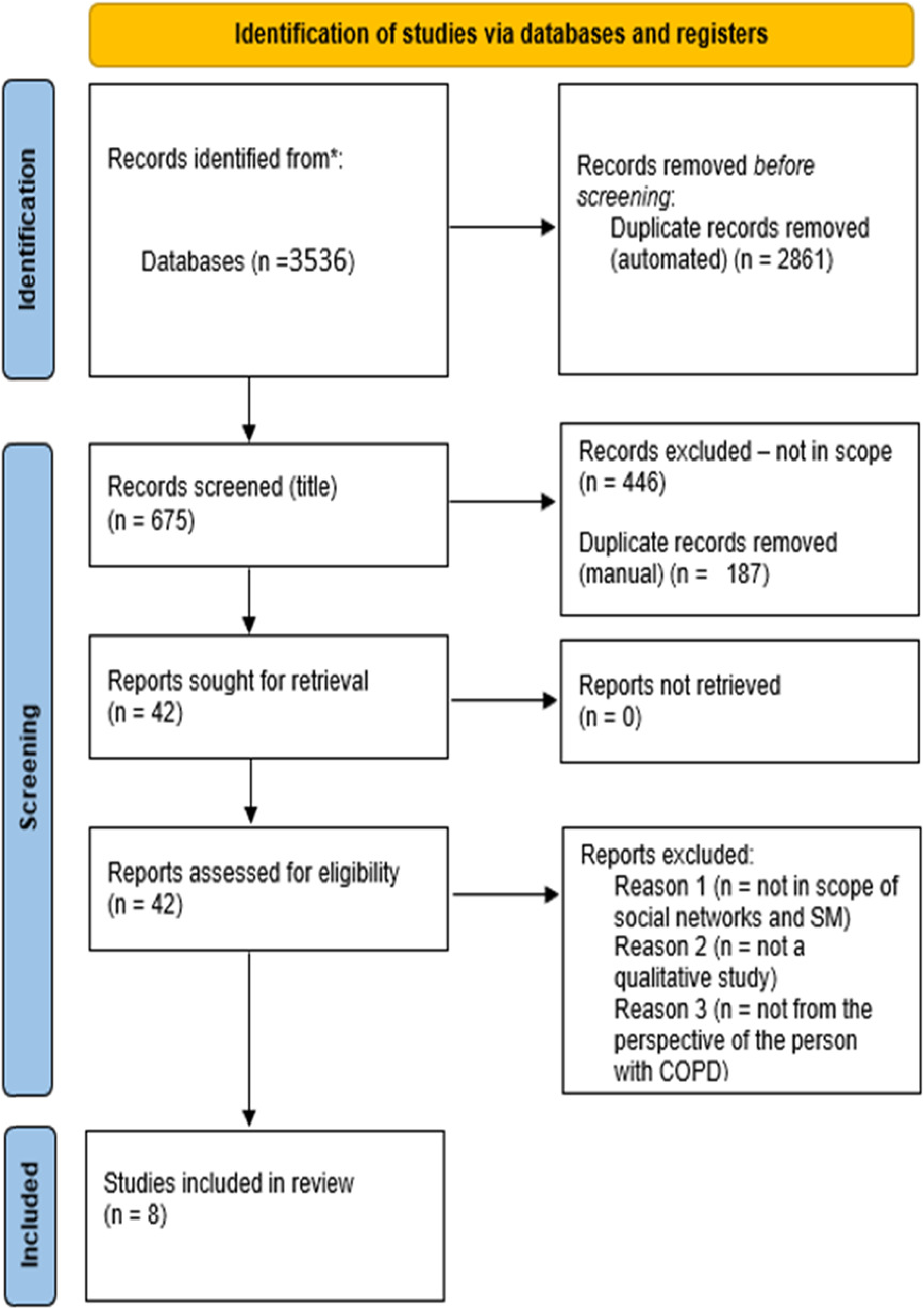
The objectives of this study were to investigate how people with COPD identify, engage and select socially supportive self-care resources and to explore the process of adoption of socially supportive self-care practices in people with COPD.

METHODS

A systematic review and meta-ethnography of qualitative studies was undertaken,[25] using the seven-step method of meta-ethnography, as described by Noblit and Dwight Hare[26,27] and exemplified by Sinnott et al.[28]

In Step 1, we developed a specific research question and its contribution to the field.

In Step 2, a search strategy was devised to ensure that the studies selected would address the research question. The focus of the systematic review and qualitative synthesis was to develop an in-depth understanding of the phenomenon of socially supportive self-management among people with COPD. Search terms were designed to ensure that the qualitative studies selected examined how people with COPD engaged with socially supportive self-management practices. Seven databases were searched: CINAHL, MEDLINE (OVID), APA PsycInfo, Web of Science, PubMed, Cochrane Library and EMBASE. This was supplemented by citation tracking and grey literature searches. The search was limited to English-language papers between June 2010 and June 2021. The search terms used were COPD (and synonyms) AND Chronic Obstructive Pulmonary Disease OR COPD OR Emphysema AND Self-management OR self-care OR self-management support OR social network support AND qualitative studi. Initial titles and abstracts of papers were read by one reviewer (L. W). Full articles of potentially eligible studies were reviewed by two researchers (L. W. and E. S). Inclusion criteria focused on qualitative studies that explored the enactment of socially supported self-management in people with COPD. The quality of the studies included was assessed using a quality appraisal tool developed by the British Sociological Association.[29] This tool has been widely used in similar reviews.[30,31] Quality was not a criterion to exclude studies, but instead provided critical insights into the methods used for data collection and analysis.[28] The selection process of studies is presented in the PRISMA flow diagram (Figure 1).[32]



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Selected studies aligned to the research question on the basis of detailed inclusion and exclusion criteria (Table 1).

Table 1 Inclusion and exclusion criteria

Inclusion criteria	Rationale
Qualitative studies focused on personal narratives and the perspectives of people with COPD	The aim is to integrate and reinterpret qualitative findings
Studies discussing people with COPD	To provide specificity of the long-term condition and the nature of the types of interventional studies
Studies addressing the broad concepts of socially supportive social networks in COPD self-management or engagement and social participation in network support	To understand participation in social supportive self-care or self-management support
Fulfils quality criteria[29]	Guidelines for quality appraisal to ensure that the methods and analysis of the selected studies were rigorous.
Exclusion	Rationale
Non-English Language	Unable to interpret or integrate
Focused on a nuanced area of COPD care delivery (pulmonary rehabilitation or oxygen therapy)	Interventional specificity
Focused on a single self-management intervention (a specific eHealth programme)	Interventional specificity
Not disease-specific	Not specific to the investigational population
If the studies are from the perspective of health professionals or carers alone	Not a personal narrative from a person with COPD

Abbreviation: COPD, chronic obstructive pulmonary disease.

In Step 3, selected studies were read and reread by two authors (L. W. and E. S). Study findings were entered into an extraction table (Table 2). This included both first-order interpretations (views of the participants) and second-order interpretations (views of the authors; Table 3).

Table 2 Data extraction table

Abbreviations: COPD, chronic obstructive pulmonary disease; HCP, health care professional.

Table 3 Analytical framework

Metasynthesis	Ontological positioning	Inclusion	Framework analysis	Indexing	Output
Integrative and interpretive	Interpretivist	All qualitative studies included	Codes clustered around new ideas	Reapplication of the codes	New themes or concepts

		Predefined research question			

In Step 4, we determined how the studies were related to each other by comparing individual study findings. The ontological stance of subjectivism, or interpretivism, was selected.[41]

In Step 5, studies were 'translated into each other', which involved examining the contribution of each study to a key theme or concept. Each theme or concept emerged from individual studies, but was also viewed as relevant to the studies included in the synthesis. The process of data extraction and linking of the concepts is presented in Table 4.

Table 4 Translation of the key concepts through the studies—postdata extraction

Abbreviation: COPD, chronic obstructive pulmonary disease.

Step 6 involved generating third-order interpretations from the main findings of the synthesis. These are new concepts directly derived from the interpretation of second-order concepts (Table 4). To demonstrate this process, an extraction table was used to collate and analyse the qualitative data. This created a visual breakdown of concepts from the studies included, enabling the synthesis of linked concepts across studies[27] (Tables 2 and 4). A line of argument synthesis[27,31] (synthesis refinement) linked common concepts together into new theory, in turn demonstrating that the studies agreed with each other and could be translated back into one another (Table 4).

Finally, Step 7 reports the synthesis. The Supporting Information Tables and the discussion present the stages of synthesis and findings, which were further depicted through the development of conceptual models to illustrate interactions of the phenomenon examined (Tables 3 and 4, Models 2A,B).

RESULTS

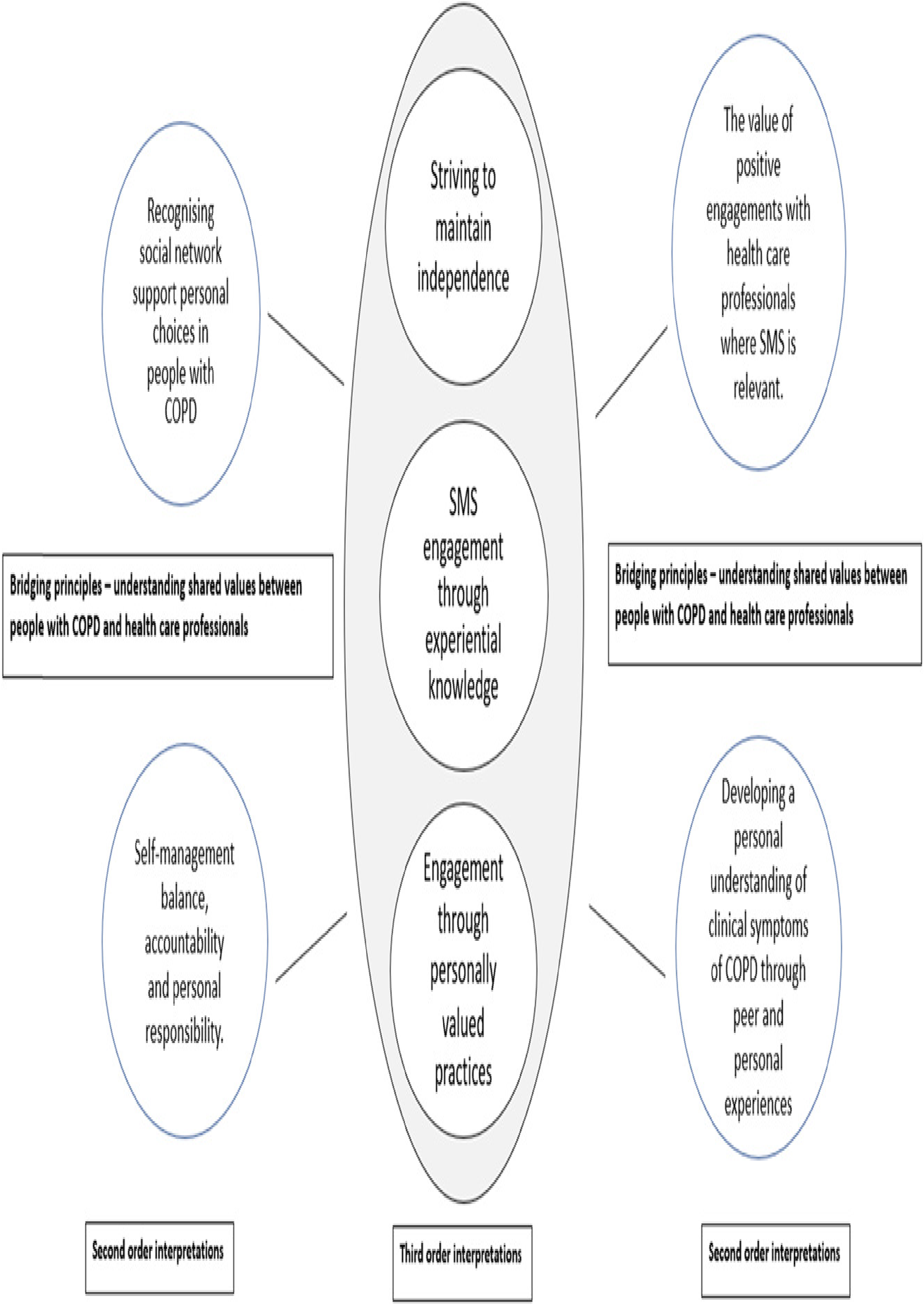
Search outcomes are presented in the PRISMA flow diagram (Figure 1). The searches retrieved 3536 studies, 675 (after removal of duplicates); 42 studies were screened at the full-text stage, of which eight papers were eligible for inclusion in the review.

Qualitative studies were included in the review if they addressed the broad concepts of socially supportive social networks in COPD self-management, engagement and social participation in network support and examined participation through the lens of a person with COPD. Studies were excluded if they focused on a single self-management intervention (a specific eHealth programme), focused on a specific medical treatment of COPD care delivery (e.g., pulmonary rehabilitation or oxygen therapy), perspectives of family carers or health professionals or were not reported in the English language.

Eight studies were included in this review. Slevin et al.,[33] Sheridan et al.,[34] Apps et al.,[35] Fotokian et al.,[36] Franklin et al.,[37] Glenister et al.,[39] Zeb et al.[38] and Willard-Grace et al.[40] reported enactment and engagement in supportive social networks for illness management of COPD using a range of approaches. These were digital health technology (DHT) for symptom assessment and to aid symptom negotiation; experiences of enacting social network support for people from diverse cultural backgrounds; personal perceptions of COPD; managing symptoms of COPD including dyspnoea; and problem solving in older people with COPD and their networks and understanding how people maintain a normal life with disease using social network support. Studies included descriptions of social interventions, including lay health coaching for vulnerable people with COPD, and family support networks.

Studies were conducted in Australia,[39] New Zealand and the Pacific Islands,[34] the United States of America,[40] Iran[36] and Pakistan,[38] and the United Kingdom.[33,35,37]

Key characteristics of the included studies (e.g., sample, methods and findings) were added to a data extraction table (Tables 2 and 4). A concept map, Figure 2, is presented to illustrate the alignments and links of the concepts to justify interpretations. The concept map forms the basis of a conceptual model of engagement and enactment of SSMS in people with COPD.



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Synthesized findings

This meta-ethnography generated four second-order interpretations:

Balancing social network participation with self-care accountability and personal responsibility.

The value of positive engagements with healthcare professionals where socially supported self-care is relevant.

Developing a personal understanding of illness through social participation, shared and personal experiences.

Recognizing social network support to guide and validate personal choices for people with COPD.

These concepts suggest that enactment of self-care practices and social engagement is perceived as challenging due to the everyday uncertainty of the disease and previous negative illness experiences. Individuals living with COPD who were confident in the knowledge of their illness and interpretation of illness symptoms felt more able to engage with supportive social networks, compared to those who had not yet been able to comprehend their own illness experiences or the impact of their symptoms on their daily lives.

- 1.

  Balancing social network participation with self-care accountability and personal responsibility.

  The progression of COPD and mobility limitations caused by increasing breathlessness creates the need to redistribute everyday work, heavy work and family responsibility.[35] People with COPD reported that they would like to balance their illness work with existing habits and understood that they needed to make the ‘right’ choices in terms of lifestyle and self-care. However, the challenges to have the discipline to do this created a perceived conflict of personal accountability for their disease and guilt as they felt responsible for their own illness and unable to control their symptoms.[42]

  ‘I know I have to take the responsibility; it's harmful to me if I don't. This is what the nurse said’ (P19 cited in Franklin[37]).

  People with COPD reported an ‘assumed responsibility’[37]; clinicians and family assume that they are able to make informed choices regarding self-care activities, even though some people report feeling unsure of what types of activity constituted as self-care and adopted personal strategies on more of a ‘trial and error’ basis.

  Self-care practices were often self-initiated as a number of individuals living with COPD understood that they have responsibilities, such as using inhalers correctly, smoking cessation or exercise and attempted to enact these. These enactments are based on personal and peer experiences, experiential constructs fostered by a sense of knowing.[36] This ‘knowing’ is built on experiences, both personal and from comparing their experiences with others, rather than informed or guided by evidence or teaching and professional support from clinicians.

  ‘When I spoke with my friends and relatives and told them that I had this problem, they taught me a lot and have increased my knowledge’ (Participant 1).[36]

  Self-care, therefore, is initiated and developed through behaviours based on personal and shared experiences rather than formal support.[35] Often, peer influences are not considered among individuals with COPD to be self-care practices, but rather more a set of personal behaviours that enabled people to successfully redesign and manage their day-to-day tasks. However, it is acknowledged that this approach often lacked health professional input, based on knowledge derived from experiential constructs that can either positively or negatively influence self-care adoption and participation. Community and peer interactions offered an inclusivity to self-care, providing a prolonged sense of independence, even when the disease was progressing.

  ‘They're great. They lift me up on that thing (disability access ramp) because I've got the oxygen’ (P6[39] in reference to volunteer community transport service).

  However, the failure to perform self-care practices successfully among people with COPD can lead to an increased sense of self-blame. Some felt that personal expectations to manage alone were too high and support was not appropriately tailored to their individual needs, causing personal conflicts in adaptive versus taught self-care practices.[35] DHT has the potential to combine experiential knowledge with health professional-directed support. DHT can offer disease-specific information and advice around specific symptoms, through testimonials, peer and web applications recording and measuring symptoms, reassuring people by finding people with comparable symptoms to build online social support.[33]

•2.

The value of positive engagements with healthcare professionals for initiating socially supported self-care.

In terms of participating in their own care, people with COPD were more willing to engage in consultations when they trusted the healthcare professional and viewed them as investing time in the consultation.[34,36,43]

Quick or rushed interactions were viewed as a disinvestment of health professionals in the personal aspects and experiences of their condition and therefore lay people were less willing to invest in their own care needs. To motivate participation in self-care practices, several people with COPD voiced that being personally valued as an individual would enhance their participation and the ethos of a shared self-care agenda.[33,34,36,37,42]

‘The GP would tell me straightaway “This is not on, my friend” I like this GP a lot as I have the opinion that I can talk opening to him about my problems…. that would not happen if I did not trust the doctor’ (P100 cited in Franklin[37]).

People living with COPD sometimes reported having no recollection of professionally introduced self-care strategies and little understanding of symptom recognition.[34] Self-care participation was viewed as challenging across all studies, requiring trusted and valued relationships with a healthcare professional to successfully incorporate their self-care participation into disease management.[36]

Lay health coaching, which involved using lay people as personal life and health supporters, enabled further development of patient–professional relationships by approaching the condition and other complex health needs from the perspective of the person with COPD.

‘The other thing is that a health coach can be someone who has medical training but they're not a doctor… they can just sit down and have a cup of coffee and talk about our health’ (Participant 42).

DHT was also reported to have the potential to optimize the quality of lay professional consultation experiences. It was considered by most people with COPD to be an empowering experience to facilitate conversations and validate complex symptoms. This was related to having the ability to maintain a clear record of symptoms that could be shared real time with the health professional, and therefore, was not just a verbal report of retrospective symptoms, which participants often found difficult to recall. DHT levelled the balance of power in consultations by providing clear documentary evidence of symptoms, focusing discussions for people with COPD to their experiences of their condition.[33]

‘A lot of time is wasted in consultations talking about things I don't care about. If I was monitoring here at home then there would be plenty to talk about because the information's collected would be about my COPD, about my symptoms, so that wouldn't be a waste of time, it'd be actually something to talk about and try and figure out, say if it was bad at the time’(P127).[33]

•3.

Developing a personal understanding of illness through social participation, shared and personal experiences

The perceived physical and emotional struggle with breathlessness is a defining recurrent issue of living with COPD.[35,44,45] Persistent daily respiratory symptoms limit the ability to engage effectively in self-care practices due to fear, anxiety and fatigue. In turn, these physical and emotional symptoms require adaptation of tasks (pacing) and the need to change behaviours that trigger symptoms.[35]

To be successful at managing COPD, patients must adapt their life to incorporate daily symptoms of breathlessness and fatigue. They are required to manage breathless, fatigue, cough and wheeze and flareups of these symptoms whilst continuing with

- 1. household tasks,
- 2. personal care,
- 3. social activities,
- 4. family responsibilities,
- 5. medical appointments and
- 6. exercise regimes.[46]

People with COPD reported not associating many of these symptoms with COPD, and preferred a trial and error or learning by experience approach to adapting to their symptoms and self-care practices.[35]

The shared validation of these symptoms was welcomed and supported through the validation of the fluctuation and worsening of symptoms in discussions with health professionals or DHT.[33]

‘Imagine after my diagnosis I'd be given a device to help me see the differences in a good day of breathing against a bad day of breathing? I know that would have eased the worry I had about every little change I was feeling. I'm sure plenty do panic at the slightest sign of being breathless’ (Patient 132).[33]

DHT, in this sense, can encourage positive help-seeking and successful feedback from self-initiated self-care behaviours among individuals living with COPD. Even here, there are potential personal conflicts in engaging with the self-care skills taught by healthcare professionals.[35–37,40] People with COPD often seek information about their disease from their peers; through social participation, information is valued to stay abreast of symptoms. However, this may not always be clinically correct.[34,36,38–40]

- 4. Recognizing social network support to guide and validate personal choices in people with COPD

People with COPD preferred to discuss their disease in the context of their social networks in terms of personal narratives related to their condition through stories and experiences.[33,34,36–40] These personal illness narratives can be both in online and offline social networks and are viewed by people with COPD as valued discussions, providing assurances around symptom perceptions and self-care strategies through peer feedback.[33]

Social networks consisted of both peer and family members. Familial groups, extended close family networks (particularly in the case of older people, and people from Iran, Pakistan and the Pacific Islands),[34,36,38] can enable personal choices by providing communication channels to the outside world and providing a conduit for self-care information.[34,36–38] Close family and positive social structures can support the redistribution of personal and social work, such as cooking and cleaning. Positive relationships within social networks can facilitate discussion around the distribution or adaptation of daily tasks to improve the quality of life of someone with COPD.[34–39]

‘People who receive good family support and care from their children get better answers [questionnaire study] are better off than those who live alone; not a hundred percent, but it is less likely. In addition, if [they] do not see or hear well it is not a good relationship with the outside world' (Participant 16).[36]

The reassignment of emotional and family tasks can lead to social displacement or a loss of their usual social role. In turn, a sense of loss is felt for their social position in the family or wider society (i.e., employment loss).[35] The church and faith were viewed as having a positive role in the lives of Pacific Islander and Pakistani groups of people with COPD; these were reported to support emotional needs and family needs, and were hugely valued.[34,36,38]

'All important, spiritual life, if we weren't at Church, I believe we won't be a happy family and be blessed with such obedient children… no one drinks alcohol, no one smokes cigarettes… they will have good futures' (Tongan man, 81 years[34]).

People living with COPD in the Western communities did not value spiritual social participation[38] or being part of a spiritual community to the same extent as the Pakistani, Iranian or Pacific Islander communities. However, all studies noted that people with COPD value social support and seek to reduce dependencies when they can.

Third-order interpretations

Third-order interpretations are the results of the reinterpretation and translation of the second-order interpretations, Figure 2. This section can also be termed *synthesis refinement*.[31]

Experiential knowledge has formed from working through episodes of illness. Illness experience is formed through personal exposure, having the disease and experiencing the symptoms and witnessing the experiences of illness in people with whom they have close relationships, and their peers.[33–36] *Valued practices* are concerned with the practices that people value in their lives, their rituals and activities. In this analysis, these also extend to healthcare professionals and society and the value of people in society beyond illness.[36,37]

People with COPD juggle the looming *inevitability of dependence*, whilst managing the disease and working to retain independence. By seeking, gaining and using experiential knowledge in disease management, people can maintain the balance between dependence and independence.

In these personal experiences with disease, day-to-day management (i.e., I carried less shopping) or in acute fluctuations of disease (i.e., I used my inhaled therapy earlier than I usually do and I didn't get so unwell) enables a process of self-appraisal of disease phenomena. This appraisal draws from narratives or experiences of what has personally worked well in the past. Importantly, 'working well' is what has enabled independence, not necessarily what is deemed to be clinically correct disease management. Therefore, if a personal experience is of a peer (friend or relation) dying shortly after stopping smoking, then this is experiential knowledge.[47] This suggests to people that smoking cessation may contribute to the deterioration of symptoms, lead to the risk of an earlier death and remove a valued activity (smoking). Therefore, people with COPD may dismiss smoking cessation as a viable self-care option due to their experiential knowledge and the enjoyment they get from smoking, not the advice from a health professional.[33,36,38]

These third-order interpretative accounts led to three broader overarching concepts that influence both positive and negative engagement along a continuum.

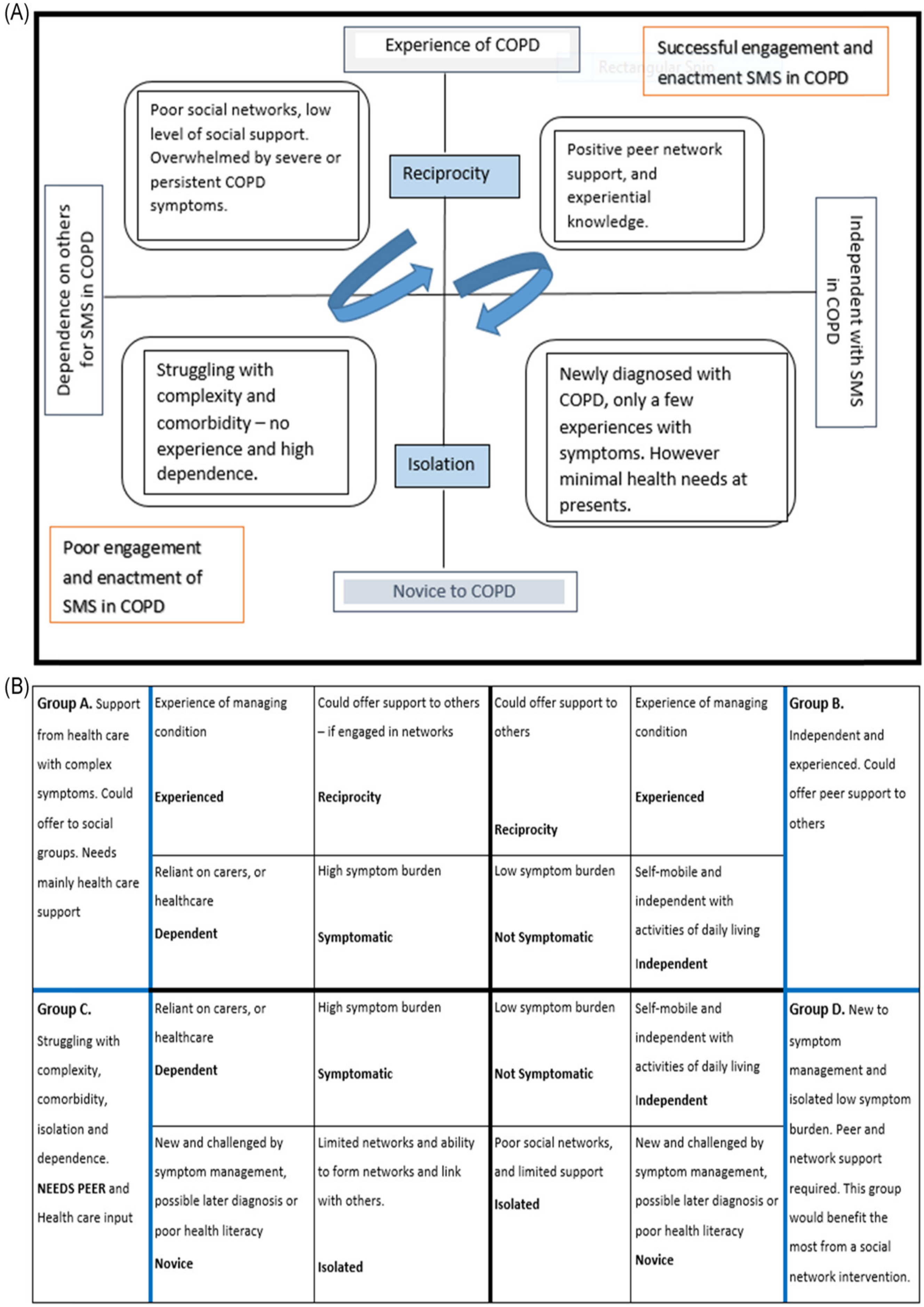
- 1. Experiential knowledge—Learning from the personal successes and failures of adaptive self-care behaviours to inform future self-care practices.
- 2. Inclusion of valued practices in SSMS.

•3.

Inevitability of dependence—The fear or avoidance of the inevitability of dependency.

The personal successes achieved from SSMS with adaptive self-care behaviours can positively inform future self-care practices and choices. Conversely, negative experiences of social self-management can reduce self-efficacy and experiential failures can leave people with a sense of powerlessness, which in turn increases feelings of dependency.

Figure 3A,B shows the Index model that presents the *inde*pendence *ex*perience (Index) continuum. Each person with COPD is either a novice to self-care or has personal experience based on personal knowledge and previous experience of the disease. Individuals living with COPD move both between novice and experience and their own self-care enactment, whilst simultaneously striving to remain as independent as they can for as long as they can.



Group A. Support from health care with complex symptoms. Could offer to social groups. Needs mainly health care support	Experience of managing condition **Experienced**	Could offer support to others – if engaged in networks **Reciprocity**	Could offer support to others **Reciprocity**	Experience of managing condition **Experienced**	**Group B.** Independent and experienced. Could offer peer support to others
	Reliant on carers, or healthcare **Dependent**	High symptom burden **Symptomatic**	Low symptom burden **Not Symptomatic**	Self-mobile and independent with activities of daily living **Independent**	
Group C. Struggling with complexity, comorbidity, isolation and dependence. **NEEDS PEER** and Health care input	Reliant on carers, or healthcare **Dependent**	High symptom burden **Symptomatic**	Low symptom burden **Not Symptomatic**	Self-mobile and independent with activities of daily living **Independent**	**Group D.** New to symptom management and isolated low symptom burden. Peer and network support required. This group would benefit the most from a social network intervention.
	New and challenged by symptom management, possible later diagnosis or poor health literacy **Novice**	Limited networks and ability to form networks and link with others. **Isolated**	Poor social networks, and limited support **Isolated**	New and challenged by symptom management, possible later diagnosis or poor health literacy **Novice**	

Enlarge this image.

The continuum can be influenced positively through peer support structures and positive social networks, but can be influenced negatively when isolated and a novice in COPD.[48,49] Furthermore, poor experiences and/or repetitive failures in self-care or disease complexity can lead to dependency and fear of engagement and enactment in self-care practices.[33,34,36,40]

Patient and public involvement in the synthesis of the findings

Public collaboration was sought to review the language and accessibility of the manuscript and the real-world applicability of the findings. The NIHR ARC Wessex long-term conditions (LTCs) patient and public involvement (PPI) group reviewed the second- and third-order interpretations. The group affirmed the need to address SSMS as relevant aspects of person-centred care. The group highlighted experiential learning in terms of understanding from their own health needs, in particular, valuing positive trusting relationships with healthcare professionals. A group member (A. A.) volunteered to review the manuscript, paying attention to the accessibility, language and jargon of the manuscript. Specific comments from the PPI group are included in Appendix A.

DISCUSSIONMain findings

The aim and objectives of this qualitative meta-ethnography were to focus on participation in social networks to enhance self-care from the perspective of a person with COPD and to explore the process of adoption of socially supportive self-care in people with COPD as targets for future self-care interventions. The findings from this synthesis highlight the complexities involved in social participation linked to self-care practices in COPD. People with COPD are required to understand and negotiate complex health circumstances and across a range of social contexts. These include the following:

•1. day-to-day social work-based negotiations,[16,34–36]

•2. healthcare interactions,[33,35–40]

•3. social negotiations concerned with symptom interpretation and[34,35,38,40]

•4. acceptance of the disease and its limitations by themselves and others.[33,34,36–40,50]

Therefore, engaging with COPD social networks to enhance self-care requires multiple skills of negotiation, personal organisation and opportunities to engage in positive peer interactions to be successful.

COPD has a complex, uncertain trajectory, meaning that the pursuit of clinical and social stability is challenging. The longer people live with COPD, the more opportunity there is to enhance the skills and knowledge of self-care, but these enhanced skills are often against a backdrop of failing health and striving to maintain independence. This study advances COPD self-care beyond taught healthcare professional interactions towards a more complex interplay with personal and peer-acquired knowledge and a perceived fear of dependence.

Through developing an understanding of personally valued practices and developing tailored healthcare encounters, one can improve engagement with socially supportive self-care practices in people with COPD. However, practitioners often prioritize education and information provision over more psychosocial approaches to self-care.[51] Russell et al.[12] undertook a qualitative synthesis of the self-management literature in people with COPD. Our findings agree with those of Russell et al's.[12] study, in that healthcare professionals may not have the skills or confidence to address the psychosocial needs of people with COPD, and this in turn limits the capacity for persons with COPD to engage in their own self-care practices as they do not feel valued. Person-centred healthcare needs to focus on the person as an individual, placing equal importance on addressing personal issues arising from COPD as well as providing clinical treatment. A narrative synthesis of lay understandings of self-management in LTCs, including COPD, found that the time spent with a healthcare professional is often interpreted as positive input into self-care activities.[52] Healthcare professionals who listen and understand personally valued activities can influence self-care practices and health outcomes.[36,42,52] Our findings advance the work of Ambrosio,[53] who described the process of living with chronic illness, suggesting that successful self-care practices can only occur once acceptance and coping have been addressed. Integration of new living patterns is applied before being able to live positively with a chronic illness. Our work on lay perspectives of living with COPD advances Ambrosio et al's.[53] findings and describes the specific issues of dependency and fear, which are heightened in COPD due to persistent and fluctuating breathlessness and fatigue.

Engaging in self-management activities is positively correlated with the length of time living with the condition[53] and was supported by the public review of the findings. This aligns with the conceptual model (Figure 3B) in terms of considering the importance of experiential learning in developing a personal and experiential sense of knowing, which is enhanced over time due to living with COPD.[36] This knowing developed from experiential constructs can, however, both positively and negatively influence participation in SSMS and relies on peer information and a wish on the part of the individual living with COPD to reduce a perceived sense of dependence.[36,37,40] Prompting the broadening of social networks, as in lay coaching, to support interpretation of symptoms and shared decision making,[40] can promote independence in people with COPD, enabled through feeling informed to make decisions about their own care, through peer discussion or valued relationships with healthcare professionals.[48,49]

The conceptual model illustrates the independence and experience continuum of engagement in socially supportive self-care behaviours among people living with COPD. Figure 3A shows the processes of striving for independence, whilst learning self-care practices and management behaviours improves with experience. Figure 3B maps the social continuum against the intensity of COPD symptoms and reciprocal social behaviours, in this way creating a framework to use in clinical practice to direct social participation in people with COPD. It highlights the personal value of social roles and reciprocal relationships.[24,47] Sharing ideas and information within peer networks is part of developing a position in a social group. The exchanges and use of peer knowledge are used to maintain independence, in relation to similar others. This independence operates along a dependence and independence continuum and enables us to further our understanding of how people with COPD engage with social support networks and participate in SSMS and self-care practices.

Implications for future research policy and practice

The conceptual model can be translated into a clinical practice tool. It can be used in clinical consultations to direct social prescribing (linking people to social activities to improve health outcomes) or social support decisions in partnership with healthcare professionals. The Index model could serve to provide a framework to structure patient–healthcare professional interactions[12] and facilitate conversations on the role of social support and networks in supporting SSMS and self-care practices among people with COPD.

Healthcare professionals should consider integrating peer support and lay coaching into existing healthcare pathways to encourage purposefully selected peer encounters to enable supportive, positive self-care practices. Current work to test the conceptual model with healthcare professionals is in progress.

Strengths and limitations

This qualitative meta-ethnography has strength in terms of the scrutiny of the methodology, drawn from several sources,[26,27,31] and review of the analysis by an interdisciplinary team of researchers. This oversight of the formulation of the concepts confers validity to the conceptual models. Further review of the findings was carried out by a PPI representative as an editor of this manuscript. The meta-ethnography is limited by the small number of studies included, although these were robustly selected.

CONCLUSION

This study provides insights into how and why people engage with the principles and practices of socially supportive self-care and the role of participation in social networks in supporting self-care activities and practices from the perspective of people living with COPD. Through mapping the findings of the social continuum with the intensity of COPD symptoms, the Index model has been developed for use in clinical practice to measure the social capacity and direct social participation in people with COPD.

The conceptual model can (i) explain how and why people with COPD understand and engage with social network support to manage their COPD and (ii) provide guidance for healthcare professionals to engage in person-centred conversations relating to valued activities and personal care preferences.

Socially supportive self-care warrants embracing as a fundamental element an encouraging infrastructure of people to assistant in the lives of the person with COPD. In the long term, this can lead to the development of positive cognitive, emotional and physical self-care practices to continually improve health outcomes in people with COPD.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Lindsay Welch designed and delivered the qualitative meta-ethnography, undertook quality appraisal, interpreted the findings, conceptualized the tool and drafted the manuscript. Euan Sadler read the papers, contributed to the analysis and synthesis and reviewed and edited the manuscript for publication. Anne Rogers conceptualized the work, advised on the design process, reviewed and quality-appraised the selected studies and reviewed and edited the manuscript for publication. Anthony Austin reviewed and edited the manuscript from the perspective of a lay user. Anthony reviewed the language and the findings, and commented on the relevance of the findings to user experiences. All the listed authors have read and approved the manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available in the Supporting Information Material of this article.

AAPPENDIX

Comments from the patient and public involvement (PPI) group meeting on 10 December 2020. Permission was obtained from the members of the PPI groups to share their verbatim comments. The findings of the study were presented in diagrammatic form; the group was asked three questions. Each question was discussed in turn. These were the comments from the feedback and the discussion.

Question 1: Do these findings feel 'real'—can you relate them to how people with long term conditions my feel?

Question 2: Do you think they are a fair representation of people with a long-term respiratory condition?

Comments

'Very similar to work on IBD—SM is important, and the collaboration aspect is key—you need to be able to build a relationship with your health professional to make it work' (PPI contributor 1).

'Self-management needs to be INFORMED self-management, it only works if you are informed and understand how to manage yourself. Especially when an adolescent, your views on your illness and your ability to manage your illness differ with age' (PPI contributor 2).

'Having clinicians open to discuss SMS and appreciate patient experiences is important. We are living with the disease. Without the creation of a two-way challenge and dialogue we are likely to fail at SM. We need reciprocal relationships with healthcare' (PPI contributor 3).

*'*As a post-transplant patient, I will always be a patient, so therefore have a long-term condition. I benefit from shared experiences and groups with other transplant patients. Debates and decisions on care, vaccination with a compromised immune system' (PPI contributor 4).

Question 3: Is there a point of finding that you are uncertain about—or does not fit with your thinking and you would like to discuss?

Comments

'Perhaps you are not reflecting access to support at crisis points, and when people are alone. This is the day to day management, discussing the differences when a person is in a crisis—such as a respiratory crisis is important' (PPI contributor 2).

'Anxiety and breathlessness do draw and the work on asthma research' (PPI contributor 5).

'Mention the importance of technological advancements and collaboration with health care and digital' (PPI contributor 1).

The PPI group broadly concur with the findings and the application of the findings in people with long-term conditions and in real-world scenarios. Crisis action plans do have a place and the social network approach could be used to support crisis decision making.

However, more work needs to be completed to understand the role of socially supported self-management at the point of crisis decision making. The PPI group were overall supportive of the conceptual model and particularly valued the core aspects of involvement in care and treatment planning and the inclusion of social or peer influences *(PPI contributors 1, 2, 3)*. Engaging clinical teams in discussing and implementing 'valued activities and a more psychosocial approach to SMS' resonated with the group, therefore this is something to be considered as part of routine care in people with COPD and LTC.

DETAILS

Subject:	Research; Ethnography; Obstructive lung disease; Population; Enactment; Social networks; Ontology; Personal experiences; Medical personnel; Activities of daily living; Oxygen therapy; Chronic illnesses; Avoidance learning; Chronic obstructive pulmonary disease; Citizen participation; Qualitative analysis; Public involvement; Social organization; Learning; Systematic review; Accountability; Social support; Conceptual models; Illnesses; Lung diseases; Professionals; Social interactions; Dependency; Avoidance behavior; Self care
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Thompson, J., Spencer, G., & Curtis, P. (2021). Children's perspectives and experiences of the COVID-19 pandemic and UK public health measures. Health Expectations, 24(6), 2057-2064. doi:https://doi.org/10.1111/hex.13350

BackgroundThe COVID-19 pandemic has had profound impacts on how we live our lives; yet, the implications for children and the effects on children's everyday lives have been relatively underacknowledged. Understanding children's views on COVID-19 and related restrictions on their lives provides an important opportunity to understand how children have responded to the pandemic, including the impacts on their social and emotional well-being.ObjectiveThis study explored the experiences and perspectives of children in relation to the COVID-19 pandemic and related restrictions on everyday life.MethodA qualitative study using semistructured online interviews with participatory drawings was undertaken between May and July 2020. Eighteen children from England and Wales, aged 7–11 years, participated in interviews.FindingsThemes included children's reflections on (1) COVID-19 as a deadly contagion; (2) fears and sadness and (3) social responsibility and opportunities to respond positively.ConclusionsYoung children offer insightful reflections on their experiences during the first wave of the COVID-19 pandemic in the United Kingdom. Children and young people's perspectives must be considered in future public health discourse.Patient or Public ContributionThis work was informed by conversations with my own three primary school-aged children and the children of friends. A formal Patient and Public Involvement (PPI) group was not established due to the speed with which the project was undertaken. Any future research in this area would benefit from formal PPI in the design, methods and questions.

Yao, L., Xiao, M., Luo, Y., Yan, L., Zhao, Q., & Li, Y. (2021). Research on the factors that influence patients with colorectal cancer participating in the prevention and control of surgical site infection: Based on the extended theory of planned behaviour. Health Expectations, 24(6), 2087-2097. doi:https://doi.org/10.1111/hex.13355

BackgroundThe most common and severe type of nosocomial infection in patients with colorectal cancer is surgical site infection (SSI). Patient-related factors are an important components of SSI. So it is necessary to participate in SSI prevention and control. It is important to identify the factors that influence patients' participation behaviour and to explore the mechanism of these effects.MethodsA total of 580 patients with colorectal cancer completed relevant measures. Based on the extended theory of planned behaviour, a structural equation model was used to analyse the relationship among the influencing factors.ResultsThe factors influencing participation of patients with colorectal cancer in SSI prevention and control were participation intention, participation ability, self-efficacy, participation attitude, perceived medical staff support, trust in physicians and social support. The direct effect coefficients of participation intention, participation ability and physician trust on SSI prevention and control behaviour were 0.67, 0.21 and 0.11, respectively. Self-efficacy, participation attitude, perceived medical staff support and social support indirectly affect participation behaviour through participation intention, and their effect values are 0.21, 0.11, 0.11 and 0.08, respectively.ConclusionsBased on the structural equation model developed in this study, targeted intervention measures should be implemented to mobilize the intention and enthusiasm of patients with colorectal cancer to participate in the prevention and control of SSI.Patient or Public ContributionPatients or public contribute to spreading research findings, and promote broad participation in the implementation of policies or strategies.

Clavel, N., Paquette, J., Dumez, V., Claudio, D. G., Djahanchah Philip (Sacha) Ghadiri, Marie-Pascale Pomey, & Normandin, L. (2021). Patient engagement in care: A scoping review of recently validated tools assessing patients' and healthcare professionals' preferences and experience. Health Expectations, 24(6), 1924-1935. doi:https://doi.org/10.1111/hex.13344

BackgroundPatient engagement in care is a priority and a key component of clinical practice. Different approaches to care have been introduced to foster patient engagement. There is a lack of a recent review on tools for assessing the main concepts and dimensions related to patient engagement in care.ObjectiveOur scoping review sought to map and summarize recently validated tools for assessing various concepts and dimensions of patient engagement in care.Search StrategyA scoping review of recent peer-reviewed articles describing tools that assess preferences in and experience with patient engagement in care was conducted in four databases (Ovid Medline, Ovid EMBASE, Cochrane Database of Systematic Reviews, CINAHL-EBSCO). We adopted a broad definition based on the main concepts of patient engagement in care: patient-centredness, empowerment, shared decision-making and partnership in care.Main ResultsOf 2161 articles found, 16, each describing a different tool, were included and analysed. Shared decision-making and patient-centredness are the two main concepts evaluated, often simultaneously in most of the tools. Only four scales measure patient-centredness, empowerment and shared decision-making at the same time, but no tool measures the core dimensions of partnership in care. Most of the tools did not include patients in their development or validation or just consulted them during the validation phase.Discussion and ConclusionThere is no tool coconstructed with patients from development to validation, which can be used to assess the main concepts and dimensions of patient engagement in care at the same time.Patient and Public ContributionThis manuscript was prepared with a patient expert who is one of the authors. Vincent Dumez, who is a patient expert and codirector of the Center of Excellence on Partnership with Patients and the Public, has contributed to the preparation of the manuscript.

Koh, W. M., Abu Bakar, A. I., Hussein, N., Pinnock, H., Su, M. L., Hanafi, N. S., . . . Khoo, E. M. (2021). Sociocultural influences on asthma self-management in a multicultural society: A qualitative study amongst malaysian adults. Health Expectations, 24(6), 2078-2086. doi:https://doi.org/10.1111/hex.13352

BackgroundSupported self-management improves asthma outcomes, but implementation requires adaptation to the local context. Barriers reported in Western cultures may not resonate in other cultural contexts. We explored the views, experiences and beliefs that influenced self-management among adults with asthma in multicultural Malaysia.MethodsAdults with asthma were purposively recruited from an urban primary healthcare clinic for in-depth interviews. Audio-recordings were transcribed verbatim and analysed thematically.ResultsWe interviewed 24 adults. Four themes emerged: (1) Participants believed in the ‘hot and cold’ concept of illness either as an inherent hot/cold body constitution or the ambient temperature. Hence, participants tried to ‘neutralize’ body constitution or to ‘warm up’ the cold temperature that was believed to trigger acute attacks. (2) Participants managed asthma based on past experiences and personal health beliefs as they lacked formal information about asthma and its treatment. (3) Poor communication and variable advice from healthcare practitioners on how to manage their asthma contributed to poor self-management skills. (4) Embarrassment about using inhalers in public and advice from family and friends resulted in a focus on nonpharmacological approaches to asthma self-management practice.ConclusionsAsthma self-management practices were learnt experientially and were strongly influenced by sociocultural beliefs and advice from family and friends. Effective self-management needs to be tailored to cultural norms, personalized to the individuals' preferences and clinical needs, adapted to their level of health literacy and underpinned by patient–practitioner partnerships.Patient and Public ContributionsPatients contributed to data. Members of the public were involved in the discussion of the results.

O'Donovan, B., Mooney, T., Rimmer, B., Fitzpatrick, P., Flannelly, G., Doherty, L., . . . Sharp, L. (2021). Advancing understanding of influences on cervical screening (non)-participation among younger and older women: A qualitative study using the theoretical domains framework and the COM-B model. Health Expectations, 24(6), 2023-2035. doi:https://doi.org/10.1111/hex.13346

BackgroundEffective screening can prevent cervical cancer, but many women choose not to attend their screening tests.ObjectiveThis study aimed to investigate behavioural influences on cervical screening participation using the Theoretical Domains Framework (TDF) and COM-B models of behaviour change.DesignA qualitative study and semistructured phone interviews were conducted with women invited for routine screening tests within the national cervical screening programme in Ireland.Setting and ParticipantsForty-eight women aged 25–65 years were recruited from the national screening register.ResultsSeven core themes were identified that mapped to three COM-B components and 11 TDF domains: (1) knowledge of cervical cancer and screening, (2) coping with smear tests, (3) competing motivational processes—automatic and reflective, (4) cognitive resources, (5) role of social support, (6) environmental influences and (7) perceputal and practical influences. A range of knowledge about screening, perceived risk of cervical cancer and human papillomavirus infection was evident. Factors that influenced screening behaviours may be hierarchical—some were assigned greater importance than others. Positive screening behaviours were linked to autonomous motivation. Deficits in physical and psychological capability (inadequate coping skills) were barriers to screening, while physical and social opportunity (e.g. healthcare professional 'champions') could facilitate participation. Older women raised age-related issues (e.g. screening no longer necessary) and had more negative attitudes to screening, while younger women identified practical barriers.ConclusionsThis study provides insight into screening participation and will aid development of theoretically informed interventions to increase uptake.Patient or Public ContributionWomen invited for screening tests through the national screening programme were interviewed. A Public & Patient Involvement (PPI) Panel, established to provide input into all CERVIVA research projects, advised the research team on recruitment materials and were given the opportunity to review and comment on the interview topic guide. This panel is made up of six women with various cervical screening histories and experiences.

Lin, B., Zhang, Z., Guo, Y., Wang, W., Mei, Y., Wang, S., . . . Cheung, D. (2021). Perceptions of recurrence risk and behavioural changes among first-ever and recurrent stroke survivors: A qualitative analysis. Health Expectations, 24(6), 1962-1970. doi:https://doi.org/10.1111/hex.13335

BackgroundAmong stroke survivors, the risk of stroke recurrence is high, and stroke survivors' perception of the risk of recurrence is crucial to promote healthy behaviours.ObjectivesThis study aimed to explore the perceptions of stroke survivors about their risk of recurrence and healthy behavioural modifications.DesignA qualitative interview study was carried out.ResultsWe interviewed 19 stroke survivors from 3 hospitals. Thematic analysis showed that the perceptions of recurrence risk and healthy behavioural changes differed between first-ever and recurrent stroke survivors. Three themes were generated from the data of first-ever stroke survivors: indifference to and unawareness of the risk of stroke recurrence, the need for professional information support and different awareness of the importance of different healthy behaviours. For first-relapse stroke patients: worry but feel powerlessness towards recurrent event, accurate information is still warranted, regret of unhealthy behaviour patterns. For the survivors suffered two or more times recurrences: perceived severity of recurrences, increased psychological care need, incorrect perceptions of healthy behaviour.Discussion and ConclusionStroke survivors with or without recurrence hold different perceptions towards the risk of recurrence and behavioural changes. The need for information related to warning signs, recurrence risk and risk factors remained consistently unmet. The benefits of healthy behaviours could be a double-edged sword for the prevention of stroke recurrence if the survivors fail to understand these accurately. It is strongly recommended that a specific recurrence risk communication tool and related health education plan be explored on the basis of the number of times patients have experienced stroke recurrence to inform secondary prevention of stroke in the future.Patient/Public ContributionThe patients were involved in the formulation of interview questions and conduct of this study. No public was involved in this study.

Price, E., Lucas, R., & Lane, J. (2021). Experiences of healthcare for people living with multiple sclerosis and their healthcare professionals. Health Expectations, 24(6), 2047-2056. doi:https://doi.org/10.1111/hex.13348

BackgroundMultiple sclerosis (MS) is a chronic inflammatory and neurodegenerative condition of the central nervous system that commonly strikes in young adulthood and has no cure. Many people living with MS (PwMS) will have significant contact with a range of healthcare professionals (HCPs). To achieve optimal health outcomes in MS, it is important to understand factors that contribute to positive or negative healthcare experiences. Previous studies have shown that PwMS want clear communication and in-depth relationships with their HCPs. However, many studies have lacked qualitative feedback from HCPs.ObjectiveThis study aimed to investigate healthcare experiences of PwMS and HCPs and identify areas that are working well and areas that could be improved.MethodsSemistructured interviews with 15 PwMS and 11 HCPs (seven neurologists, four MS nurses) from across Australia were conducted. Interviews were transcribed verbatim and analysed thematically.ResultsBoth PwMS and HCPs valued clear communication, recognized uncertainties associated with MS and highlighted the importance of rapport. PwMS focused on decision-making, understanding roles and expectations, self-directed management and their needs for support. HCPs discussed issues related to medical management, providing hope and reassurance, barriers to healthcare and multidisciplinary care.ConclusionGreater transparency and communication, particularly around the approach to care and the roles played by HCPs, is likely to enhance healthcare experiences and contribute to better health outcomes for PwMS.Public ContributionPwMS and HCPs volunteered to be interviewed, and PwMS assisted with the development of interview content and structure.

Palmer, V. J., Chondros, P., Furler, J., Herrman, H., Pierce, D., Godbee, K., . . . Gunn, J. M. (2021). The CORE study—An adapted mental health experience codesign intervention to improve psychosocial recovery for people with severe mental illness: A stepped wedge cluster randomized-controlled trial. Health Expectations, 24(6), 1948-1961. doi:https://doi.org/10.1111/hex.13334

BackgroundMental health policies outline the need for codesign of services and quality improvement in partnership with service users and staff (and sometimes carers), and yet, evidence of systematic implementation and the impacts on healthcare outcomes is limited.ObjectiveThe aim of this study was to test whether an adapted mental health experience codesign intervention to improve recovery-orientation of services led to greater psychosocial recovery outcomes for service users.DesignA stepped wedge cluster randomized-controlled trial was conducted.Setting and ParticipantsFour Mental Health Community Support Services providers, 287 people living with severe mental illnesses, 61 carers and 120 staff were recruited across Victoria, Australia.Main Outcome MeasuresThe 24-item Revised Recovery Assessment Scale (RAS-R) measured individual psychosocial recovery.ResultsA total of 841 observations were completed with 287 service users. The intention-to-treat analysis found RAS-R scores to be similar between the intervention (mean = 84.7, SD = 15.6) and control (mean = 86.5, SD = 15.3) phases; the adjusted estimated difference in the mean RAS-R score was −1.70 (95% confidence interval: −3.81 to 0.40; p = .11).DiscussionThis first trial of an adapted mental health experience codesign intervention for psychosocial recovery outcomes found no difference between the intervention and control arms.ConclusionsMore attention to the conditions that are required for eight essential mechanisms of change to support codesign processes and implementation is needed.Patient and Public InvolvementThe State consumer (Victorian Mental Illness Awareness Council) and carer peak bodies (Tandem representing mental health carers) codeveloped the intervention. The adapted intervention was facilitated by coinvestigators with lived-experiences who were coauthors for the trial and process evaluation protocols, the engagement model and explanatory model of change for the trial.

Yasuhara, N., Okamoto, S., Hamada, M., Uehara, K., Obana, N., & Imamura, T. (2021). Evaluation of japanese people's perception of risk information for making decisions to receive influenza and rubella vaccinations. Health Expectations, 24(6), 2013-2022. doi:https://doi.org/10.1111/hex.13342

BackgroundGenerally, vaccination uptake in Japan lags behind World Health Organization targets.ObjectiveThis study aimed to understand how risk information and advice affect intention to receive vaccinations.MethodsThis study had a within-subjects design. An online survey based on the Health Belief Model was sent to 2501 Japanese individuals (≧20 years) to assess the intention to be vaccinated for influenza and rubella after receiving minor and severe risk information and hypothetical advice about each vaccine. Regression analysis was used to measure changes in intentions to receive each vaccination after being provided with (1) risk information about each vaccine and (2) hypothetical encouragement and discouragement to be vaccinated.Main OutcomesThe main outcomes included changes in vaccination intentions from baseline.ResultsForty-one percent (N = 1030) of those sent the survey completed it. At baseline, 43% and 65% of the respondents intended to have influenza and rubella vaccinations, respectively. Being provided with information about severe risks and susceptibility increased the intention to have the influenza vaccination among females in their 40s. Receiving inaccurate and discouraging information from one's mother significantly decreased the intention to have the rubella vaccination. Women 50 and older were more likely to intend not to have vaccination for rubella. Severe risk information decreased rubella vaccination intention in all age groups, except women in their 30s and 40s (p < .05).ConclusionFor both vaccinations, older individuals demonstrated vaccine hesitancy. This group requires tailored messaging to help them understand their vulnerability (to influenza) and their role in transmission (for rubella) to encourage uptake of essential vaccinations.Patient or Public ContributionMembers of the Japanese public responded to our online questionnaire on vaccination risk.