Research Topics

Public health in the context of life-limiting illnesses: Patient-centered care in advanced and life-limiting illnesses

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Editorial: Public health in the context of life-limiting illnesses: patient-centered care in advanced and life-limiting illnesses

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palliative care, public health, advanced illness, multimorbidity, life-limiting conditions, patient-centered outcomes

Editorial on the Research Topic
Public health in the context of life-limiting illnesses: patient-centered care in advanced and life-limiting illnesses

Introduction

As global populations age and chronic diseases become more prevalent, public health systems face an increasing need for palliative and end-of-life care. Approximately 60% of individuals dying have prolonged advanced illnesses, necessitating comprehensive strategies to address their complex needs (1). Palliative care, characterized by its holistic and person-centered approach, is becoming an essential component of public health (2).

The COVID-19 pandemic has underscored the critical role of palliative care (3), revealing the intricate link between public health, health promotion, and palliative care services. This editorial explores how public health and palliative care intersect in the context of life-limiting illnesses, highlighting patient-centered care and complex symptom management as two fundamental aspects that palliative care offers.

The growing demand for palliative care

The rising number of individuals living with advanced and life-limiting illnesses represents a significant public health challenge. This trend, driven by demographic shifts and the increasing prevalence of chronic conditions, demands a robust palliative care infrastructure (4). Palliative care aims to alleviate symptoms, manage pain, and improve quality of life for patients with serious illnesses (5). It should be integrated early in the illness trajectory to provide comprehensive support (6, 7).

Palliative care's role in public health

Palliative care is an integral part of public health, essential for developing and implementing comprehensive healthcare services. Public health strategies aim at population-level interventions to promote health, prevent illness, and improve outcomes. Integrating palliative care into these initiatives ensures accessibility, equity, and responsiveness to the needs of diverse populations. The COVID-19 pandemic highlighted the necessity of such integration, revealing healthcare system gaps and underscoring the need for a robust palliative care framework.

In their study on a home health monitoring and education program for complex chronic patients, Soldado-Matoses et al. demonstrate how the primary care nurse led program effectively reduced hospital admissions and emergency department visits. This highlights the pivotal role of primary care nurses in chronic disease management through advanced competencies, showcasing how such initiatives can enhance public health outcomes.

Harrop et al. underscore the urgency of integrating palliative care into public health frameworks. Their longitudinal study on UK residents bereaved between March 2020 and January 2021, revealed high levels symptoms of Prolonged Grief Disorder (PGD). This necessitates strengthened social and specialist support, improved bereavement policies, and enhanced preparedness for future pandemics. Integrating palliative care ensures accessible, equitable, and responsive care, crucial for improving the quality of life for those with advanced and life-limiting illnesses.

Enhancing palliative care access

Despite its benefits, palliative care is underutilized due to several barriers, including lack of awareness, cultural misconceptions, and systemic healthcare issues. Population-level patient-reported outcomes are essential for addressing public health objectives in life-limiting illnesses. Daveson et al., in their case study informed by the Organization for Economic Co-operation and Development's Best-Practice Public Health Framework, illustrated the importance of collecting and analyzing patient-reported data to improve pain management and address equity issues in healthcare delivery.

Shen et al., in their cross-sectional study identified barriers to inpatient palliative care referral among metastatic gynecologic cancer patients, influenced by hospital size, region, and specific cancer types, highlighting disparities in access based on institutional and geographical factors. Effective palliative care interventions require community engagement. Leonard et al. in their article revealed that community-engaged approaches significantly improve person-centered outcomes. The end-of-life needs of Aboriginal and immigrant communities present unique challenges to conventional medical models. Their analysis identified the need for trusted relationships, cultural practices around end-of-life care, and language barriers. The "Compassionate Communities" model emerged as a potential solution to support culturally sensitive care, indicating the necessity for healthcare systems to adapt to diverse cultural contexts.

Reframing palliative care

The COVID-19 pandemic as a global public health emergency highlighted the critical need for policy reforms to support palliative and end-of-life care. Bradshaw et al. identified integration within health and social care systems, digital inclusivity, workforce development, support for care home managers, and addressing disparities of esteem as key policy priorities to equip care homes with the resources, capacity, and expertise needed for high-quality palliative care.

Rehabilitation is an integral part of palliative care (7). Lai et al., in their study on tracheal, bronchus, and lung cancer emphasized the role of rehabilitation in palliative care, and need for comprehensive rehabilitation services. According to projections, the burden of tracheal, bronchus, and lung cancer will continue to rise, particularly among females, necessitating targeted rehabilitation interventions to manage the disease effectively throughout the patient lifecycle.

Conclusions

Integrating palliative care into public health strategies is imperative to address the complex needs of individuals with advanced and life-limiting illnesses. As the global population ages and chronic conditions become more prevalent, the demand for palliative care will continue to grow. Public health initiatives must prioritize the development and implementation of accessible, equitable, and culturally responsive palliative care services. By adopting a holistic, patient-centered approach, healthcare systems can improve the quality of life for patients and their families, ensuring comprehensive care and support throughout the illness trajectory.

Research highlighted in this editorial underscores the multifaceted nature of palliative care and its critical role in public health. From community-engaged interventions to policy reforms and targeted rehabilitation services, to capture of population-level patient-reported outcomes, a comprehensive approach is necessary to meet the diverse needs of patients with life-limiting illnesses. Collaboration across disciplines and community engagement at all stages of care design and implementation can build a more resilient and responsive healthcare system, prioritizing the wellbeing of individuals facing advanced illness.

Author contributions

MH: Conceptualization, Writing – original draft, Writing – review & editing. RS: Writing – original draft, Writing – review & editing. MS: Writing – original draft, Writing – review & editing. RJ: Writing – original draft, Writing – review & editing. RC: Writing – original draft, Writing – review & editing. IH: Supervision, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Shetty P. The parlous state of palliative care in the developing world. *Lancet.* (2010) 376:1453–4. doi: 10.1016/S0140-6736(10)61978-2

2. Higginson IJ, Costantini M. *Palliative Care as a Public Health Issue. Textbook of Palliative Medicine and Supportive Care.* Boca Raton, FL: CRC Press (2021). p. 7–16.

3. Oluyase AO, Hocaoglu M, Cripps RL, Maddocks M, Walshe C, Fraser LK, et al. The challenges of caring for people dying from COVID-19: a multinational, observational study (CovPall). *J Pain Symptom Manage.* (2021) 62:460–70. doi: 10.1016/j.jpainsymman.2021.01.138

4. Bone AE, Gomes B, Etkind SN, Verne J, Murtagh FEM, Evans CJ, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliat Med.* (2018) 32:329–36. doi: 10.1177/0269216317734435

5. Hawley PH. The bow tie model of 21st century palliative care. *J Pain Symptom Manage.* (2014) 47:e2–5. doi: 10.1016/j.jpainsymman.2013.10.009

6. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non–small-cell lung cancer. *N Engl J Med.* (2010) 363:733–42. doi: 10.1056/NEJMoa1000678

7. Bauman JR, Temel JS. The integration of early palliative care with oncology care: the time has come for a new tradition. *J Natl Comprehens Cancer Netw.* (2014) 12:1763–71. doi: 10.6004/jnccn.2014.0177

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Provision of palliative and end-of-life care in UK care homes during the COVID-19 pandemic: A mixed methods observational study with implications for policy

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Introduction: Little consideration has been given to how the provision of palliative and end-of-life care in care homes was affected by COVID-19. The aims of this study were to: (i) investigate the response of UK care homes in meeting the rapidly increasing need for palliative and end-of-life care during the COVID-19 pandemic and (ii) propose policy recommendations for strengthening the provision of palliative and end-of-life care within care homes.

Materials and methods: A mixed methods observational study was conducted, which incorporated (i) an online cross-sectional survey of UK care homes and (ii) qualitative interviews with care home practitioners. Participants for the survey were recruited between April and September 2021. Survey participants indicating availability to participate in an interview were recruited using a purposive sampling approach between June and October 2021. Data were integrated through analytic triangulation in which we sought areas of convergence, divergence, and complementarity.

Results: There were 107 responses to the survey and 27 interviews. *We found that* (i) relationship-centered care is crucial to high-quality palliative and end-of-life care within care homes, but this was disrupted during the pandemic. (ii) Care homes' ability to maintain high-quality relationship-centered care required key "pillars" being in place: integration with external healthcare systems, digital inclusion, and a supported workforce. Inequities within the care home sector meant that in some services these pillars were compromised, and relationship-centered care suffered. (iii) The provision of relationship-centered care was undermined by care home staff feeling that their efforts and expertise in delivering palliative and end-of-life care often went unrecognized/undervalued.

Conclusion: Relationship-centered care is a key component of high-quality palliative and end-of-life care in care homes, but this was disrupted during the COVID-19 pandemic. We identify key policy priorities to equip care homes with the resources, capacity, and expertise needed to deliver palliative and end-of-life care:

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(i) integration within health and social care systems, (ii) digital inclusivity, (iii) workforce development, (iv) support for care home managers, and (v) addressing (dis)parities of esteem. These policy recommendations inform, extend, and align with policies and initiatives within the UK and internationally.

KEYWORDS

care homes, palliative care, end-of-life care, COVID-19, policy, mixed methods, observational

Introduction

Internationally, the burden of COVID-19 deaths fell disproportionately on care homes. The World Health Organization estimated that between March 2020 and February 2021, care home residents made up 41% of all pandemic-related deaths worldwide (1). In the UK, there was a 220% rise in care home deaths during the first pandemic wave, temporarily making them the most common place to die (2), a situation that had not been projected to be reached until 2040 (3).

Within an international context, the term "care home" generally refers to long-term care provision for adults who require 24-h assistance with personal care and daily living activities. The majority of residents are older people (typically over 80) in the last 1 or 2 years of life who live with multiple long-term progressive health conditions, often including dementia (4). Because of this, palliative and end-of-life care is a central element of care provision in care homes (5). This approach to care aims to improve quality of life through the adoption of holistic, person-centered, and multidisciplinary care processes for people with complex long-term, life-limiting, or acute life-threatening conditions (6).

From the start of the COVID-19 pandemic, the high number of deaths occurring in care homes was the subject of intense policy, media, and research scrutiny. This focused on infection prevention/control, including testing for COVID-19, visiting restrictions, and personal protective equipment, as well as the psychological impact of the pandemic on staff, residents, and family carers (7–13). However, research examining the impact of the COVID-19 pandemic on the provision of palliative and end-of-life care in care homes has been limited (14). Research in this area has focused on specific disease types (such as dementia) (15, 16), or on specific elements of palliative care such as anticipatory prescribing (17), early bereavement, (18) advance care planning (19), and the response of care home managers (20). Some of these studies have highlighted how, during the pandemic, care home residents were more likely to have poorer experiences of palliative and end-of-life care compared to other care settings (18, 21).

Developing a more comprehensive understanding of how care homes within the UK responded to and experienced the rapid rise in the need for palliative and end-of-life care during the pandemic is important. This is so that we can identify opportunities for strengthening the provision of this type of care in care homes to meet future demographic challenges. The aims of this study were to: (i) investigate the response of UK care homes in meeting the rapidly increasing need for palliative and end-of-life care for residents during the COVID-19 pandemic and (ii) propose recommendations for strengthening the provision of palliative and end-of-life care within care homes.

Methods

Study design and participant recruitment

This paper presents the results from the CovPall Care Homes study, which was a mixed methods observational study consisting of two work packages: (i) an online cross-sectional survey of UK care home practitioners and (ii) in-depth qualitative interviews with care home practitioners. The rationale for using a mixed methods design was to integrate and triangulate both qualitative and quantitative methods and to explore the research aims in a depth and detail that would not be possible using one approach alone (22).

We used purposive sampling to ensure representation of different sizes, types, and regions from a sampling frame of all UK care homes with or without on-site nursing. Care homes were identified and recruited via our institutional websites, social media, and through working with established national care home practitioner networks. Care home managers or their nominees were invited to complete an online survey, with up to three reminder emails sent (see Figure 1 for recruitment flowchart). Recruitment and distribution of surveys took place between April and September 2021. By completing and submitting the survey, participants provided consent to participate in this study. The survey reporting was in line with the STROBE checklist (23).

For qualitative interviews, care home practitioners who had completed the survey and had agreed to be contacted were purposively sampled (using the same criteria). Additional interviewees were recruited through the study Care Home Expert Panel. Informed consent was confirmed virtually prior to the interview by the researcher (IT, IB, or LB). The researcher talked through each item on the consent form with the interview participant, confirmed verbally that they agreed (or not), marked the responses on the consent form, and recorded the responses in a separate digital file from the interview. A copy of the consent form was emailed to the participant. Participant recruitment and interviews ran concurrently between June and October 2021. Recruitment continued until all networks, avenues, and potential recruitment opportunities had been exhausted.

Data collection

The survey design was informed by a rapid review of evidence on the provision of care in care homes during the pandemic. We tested and refined the survey with our Care Home Expert Panel, Patient and Public Involvement group (most of whom were

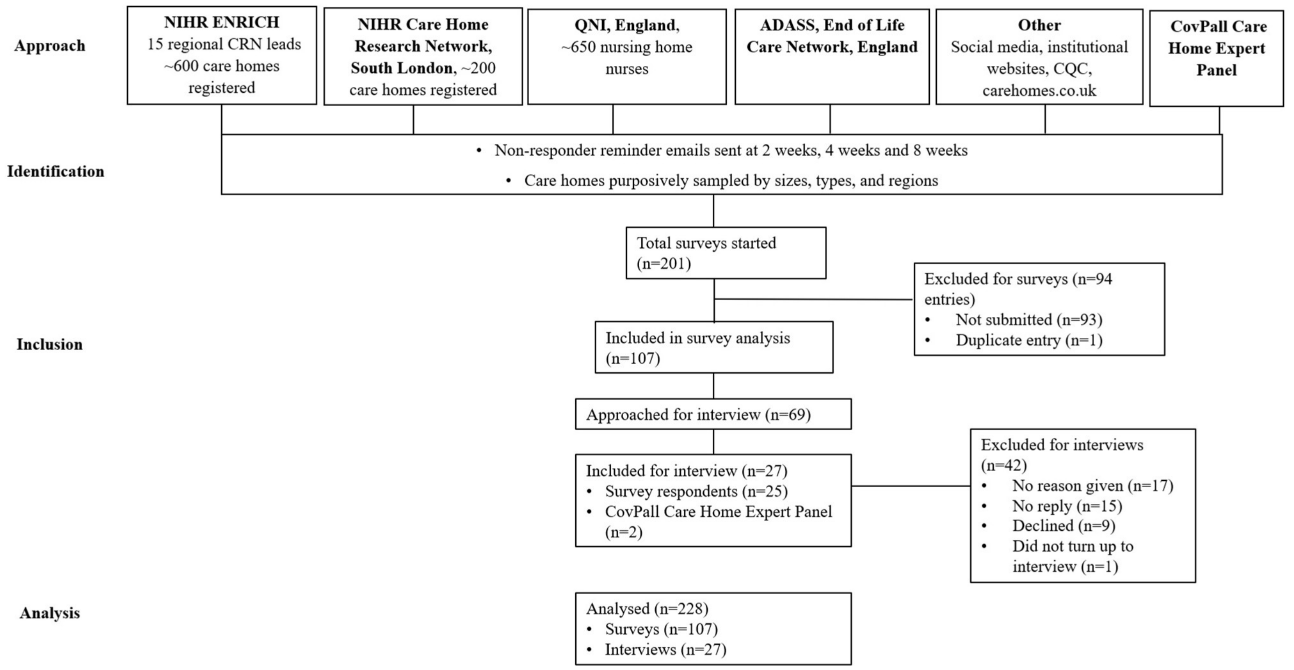


FIGURE 1
Recruitment flow diagram.

family carers with experience of care homes), and Study Steering Committee (comprising care home experts, policy makers, and informal carers). The survey included open- and closed-ended questions that sought information on the respondent role, type of care home, and the impact of COVID-19 on the provision of palliative and end-of-life care (see Supplementary material 1 for the full survey). REDCap was used to securely build and host the survey, which was disseminated and filled in online. Invitations to complete the survey were disseminated via the networks and collaborators outlined in Figure 1 between April and September 2021. Missing/incomplete data were followed up by contacting participants where necessary.

For the second work package, individual semi-structured qualitative interviews were conducted online using Zoom. The interview guide (see Supplementary material 2) was developed using preliminary data from the survey to allow in-depth exploration of the experiences of practitioners in providing palliative care in care homes during the first two waves of the pandemic. The interviews were conducted by three researchers (IT, IB, and LB) and were digitally recorded, anonymized, and transcribed verbatim. On average, they lasted a median of 46 min (range = 22–83 min).

Data analysis

Initially, the different forms of data were analyzed individually. Numerical survey data were analyzed descriptively in SPSS (v27). Qualitative interview transcripts and free-text survey data were analyzed inductively (by SO and AB) using reflexive thematic analysis grounded in a constructionist paradigm (24). The analysis comprised six iterative steps in which SO and AB: (i) familiarized themselves with the data; (ii) generated initial codes by labeling segements of transcripts that aligned with our research aims; (iii) generated intial themes by grouping codes into categories and categories into themes that told us something important about the study aims; (iv) reviewed and revised themes through iterative group discussions with authors and members of the Care Home Expert Panel and Public Study Reference Panel; (v) defined and named themes; and (vi) interpreted data and produced a findings report.

In combining data, we adopted a multiple perspectives approach (25). This entailed integrating and interpreting data through analytic triangulation, in which we sought areas of: (i) convergence, (ii) divergence, and (iii) complementarity. In this way, each form of data enriched the other, becoming more than the sum of their parts, and providing a richer understanding of the study aims (25). During the analytic process, we recognized that Donabedian's (26) model on structures and processes of care provided a useful lens to understand and interpret the findings. We used this model to ask further questions about the data, particularly on how COVID-19 impacted the structures and processes through which pallaitive and end-of-life care could be delivered by staff within care homes.

In contributing to a rigorous analysis, we used Braun and Clarke's assessment tool for quality reflexive thematic analysis to guide the analysis and write-up (27). A key step that we took throughout the analytic process was to draw on the wider research team, the Care Home Expert Panel, Patient and Public Involvement group, and Study Steering Committee as "critical friends" (28). This entailed working collaboratively by meeting regularly to discuss the ongoing data analysis, alongside giving written feedback over numerous iterations of the study findings. Through these processes, findings were constructively challenged, and alternative interpretations of the data were provided and integrated into the data analysis. These processes took place until the research team agreed that the analysis was an accurate reflection of the participants' accounts that addressed the study aims. This spirit of constructive collaboration was also used within a Policy Roundtable, which was convened in November 2021 to discuss the data and potential policy solutions.

The researchers involved in the data analysis also kept reflexive diaries in which they recorded initial "hunches" on what they felt were key messages within the data with regards to the study's aims (29). They also recorded their reflections both introspectively (inward reflections on how they impacted the research process and vice versa) and intersubjectively (reflections on relationships between them and participants) (30). The detail in the reflexive diaries was included in the data analysis as a "springboard for interpretations and more general insight" into the ways through which understandings of the research aim were being co-constructed through the research process (30).

Ethical considerations

Institutional ethical approval was granted by the King's College London Research Ethics committee (LRS-19/20-18541). In this study, we also recognized ethics as a process and engaged in "ethics in practice" (31) as a way to navigate ongoing and potentially unexpected ethical issues that may have arisen throughout the research process. We appreciated that participants were working in an unprecedented context characterized by uncertainty, high pressure, and time limitations. To mitigate this, we worked with the Care Home Expert Panel group to ensure that the survey was concise, asked relevant questions, and used language that was accessible and sensitive.

During interviews, we recognized that there was a potential for participants to become distressed when reflecting on the challenges of the COVID-19 pandemic. There was also a potential for participants not wanting to disclose information that revealed risk or poor practice. To mitigate this, interview guides were developed and conducted in a sensitive and responsive manner, with clear messages that the content of conversations were confidential (unless they posed severe risks to their own or others' wellbeing) and participants' identities would remain anonymous. The research team also collated bereavement and support resources for practitioners that were shared with participants where appropriate.

We also appreciated the potential emotional impact that conducting interviews in this context may have had on researchers. Regular bi-weekly debriefing sessions were held between researchers (IT, IB, and LB) and a senior member of the research team (CE, who has experience in qualitative interviewing in sensitive contexts) in which issues, challenges, or problems that arose in interviews were discussed.

Role of the funding source

The funder of the study, the National Institute for Health and Care Research Policy Research Programme, had no role in the study design, data collection, data analysis, data interpretation, or writing of the report.

Results

A total of 107 participants completed the online survey, and 27 participated in qualitative interviews (out of 69 approached). Table 1 provides an overview of the participants. An overview of the descriptive survey findings can be seen in Table 2. Three themes were constructed following the triangulation of the survey and interview data (Figure 2).

Theme 1: Relationship-centered care

Relationship-centered care was identified as an important feature of care that was vital for providing high-quality palliative and end-of-life care within care homes. It was characterized by staff creating a sense of home and nurturing close relationships with residents and their families; relationships so strong that they were akin to family bonds and extended beyond residents' deaths:

> *"We have a really good rapport with our relatives. One lovely initiative was that as the staff weren't allowed attend the funeral of one of our residents, due to Covid restrictions, the family asked if the funeral cortege could leave from here. That was wonderful, although we all had to socially distance. The hearse drove through in the front of our home and all the residents and staff were able to say goodbye. It was very emotional and a first for us."* [manager, dual residential and nursing home, survey free-text response]

The pandemic disrupted the ability of care home staff to engage in the activities needed to deliver relationship-centered care. In explaining this, qualitative findings converged with the quantitative data in identifying that COVID-19 particularly disrupted the assessment and management of residents' social needs (56, 52.3%) in addition to their physical (17, 15.9%) and psychological (29, 27.1%) needs. Social distancing and visiting restrictions disrupted relationship-centered care as staff were less able to provide emotional support, reassurance, and physical presence when a resident was dying.

Most care homes (84, 78.5%) allowed families to visit residents who were near the end of life. However, visiting restrictions (especially for residents not thought to be dying) and shifts to virtual forms of communication disrupted the ability of families/friends to engage socially and provide emotional support. This had detrimental consequences for both residents and their families (including in bereavement), alongside having a negative impact on the vibrancy and homely atmosphere that usually characterized care homes:

> *"The biggest thing was not having families and friends and volunteers here because the home is very vibrant; we're a really big part of the community, and all of a sudden that didn't happen … We traditionally, up until that time, would have had lots of family involvement … I don't think we can underestimate that, not only from the residents' point of view, but the family's point*

TABLE 1 Survey respondent and interview participant details.

Survey	Number	%	Interviews	Number	%
Total responses			**Total responses**		
	107			27	
Role			**Role**		
Manager	77	72	Manager	16	59.2
Deputy manager	10	9.3	Deputy manager	3	11.1
Registered nurse	8	7.5	Registered nurse	4	14.9
Senior carer/team leader	2	0.2	Other	4	14.9
Other	11	10.3			
Type of care home			**Type of care home**		
Residential	49	45.7	Residential	6	22.2
Nursing	24	22.4	Nursing	10	37.0
Dual-registered for residential and nursing	34	31.7	Dual-registered for Residential and Nursing	11	40.7
Size of care home			**Region**		
Small (≤10 beds)	10	9.3	England	25	93.5
Medium (11–49 beds)	59	55.1	Devolved nations (Scotland, Wales, and Northern Ireland)	2	7.5
Large (50+ beds)	37	34.6	**Gender**		
Missing	1	0.9	Female	21	77.7
Region			Male	6	22.3
England	99	92.5			
Devolved nations (Scotland, Wales, and Northern Ireland)	8	7.5			

> *of view and how they've been able to deal with things afterwards. Because, for some people, it's sort of left them with an unanswered question, or they don't feel that they've come to the end of their journey properly."* [manager, nursing home, interview]

Alongside social distancing, using personal protective equipment (PPE) further disrupted relationship-centered care; it compromised in-person and non-verbal communication and may have contributed to difficulty assessing and managing residents' psychological (29, 27.1%) and spiritual (26, 24.3%) needs:

> *"It was terrible. It was undignified. I would use such a strong word as traumatic for both myself and my staff. It was definitely traumatic for the relatives we know. We don't know how it was for the resident. It was dismal, it was really awful. … the fact that I couldn't care in the way I would like to care. You want to care with someone holding their hands and sitting and playing music and, you know, all of that. There were no frills."* [manager, residential home, interview]

Theme 2: Pillars of relationship-centered care

Care home staff adapted rapidly to preserve as many elements of relationship-centered care as possible in order to uphold the quality of the palliative and end-of-life care that they delivered to residents. Most participants (79, 73.8%) reported that the quality of care for residents at the end of life was maintained despite the many challenges. The ability of care homes to adapt and respond to COVID-19 was contingent on different "pillars" of care being present. Each pillar describes essential structures and/or processes of care that were required to preserve relationship-centered care. Inequities within the care home sector meant that in some services these pillars were compromised, and relationship-centered care suffered.

Pillar 1: Integration within health and social care systems

A key pillar that supported the ability of care homes to provide relationship-centered palliative and end-of-life care was integration with external health and social care services. Quantitative data highlighted that care homes commonly connected with GPs (82, 76.6%) and specialist palliative care teams (83, 77.6%) for advice on palliative and end-of-life care, while residential homes were more likely to integrate with community nursing teams (36, 73.5%).

Qualitative data provided insight into the variability with which care homes were integrated within local health and social care systems. Poor integration with external services led to care home

TABLE 2 An overview of descriptive survey findings.

	Residential (49)	Nursing (24)	Both nursing and residential (34)	Total (107)
Confirmed or suspected outbreak of COVID-19? (*n*, %)				
Yes	25 (51.0%)	19 (79.2%)	28 (82.4%)	72 (67.3%)
No	23 (46.9%)	5 (20.8%)	4 (11.8%)	32 (29.9%)
Missing	1 (2.0%)	0 (0.0%)	2 (5.9%)	3 (2.8%)
Staff shortages				
Yes	17 (34.7%)	13 (54.2%)	18 (52.9%)	48 (45.3%)
No	32 (65.3%)	11 (45.8%)	15 (44.1%)	58 (54.7%)
Missing	0 (0.0%)	0 (0.0%)	1 (2.9%)	1 (0.9%)
During COVID-19 were there issues with:				
Staff turnover	3 (6.1%)	3 (12.5%)	8 (23.5%)	14 (13.1%)
Staff redeployment	1 (2.0%)	3 (12.5%)	6 (17.6%)	10 (9.3%)
Staff absenteeism	15 (30.6%)	13 (54.2%)	18 (52.9%)	46 (43.0%)
Staff stress	31 (63.3%)	17 (70.8%)	27 (79.4%)	75 (70.1%)
Staff Suffering losses	6 (12.2%)	9 (37.5%)	14 (41.2%)	29 (27.1%)
Did your care home allow visitors during the COVID-19 pandemic for people approaching the end of life?				
Yes	37 (75.5%)	21 (87.5%)	26 (76%)	84 (78.5%)
No	11 (22.4%)	3 (12.5%)	7 (20.6%)	21 (19.6%)
Missing	1 (2.0%)	0 (0.0%)	1 (2.9%)	2 (1.9%)
Did staff responsibilities in providing care for people nearing the end-of-life change?				
Yes	15 (30.6%)	5 (20.8%)	16 (47.1%)	36 (33.7%)
No	33 (67.3%)	19 (79.2%)	16 (47.1%)	68 (63.6%)
Missing	1 (2.0%)	0 (0.0%)	2 (5.9%)	3 (2.8%)
Changes in how often agency staff used:				
Yes	20 (40.8%)	12 (50.0%)	17 (50.0%)	49 (45.8%)
No	28 (57.1%)	12 (50.0%)	15 (44.1%)	55 (51.4%)
Total (missing)	1 (2.0%)	0 (0.0%)	2 (5.9%)	3 (2.8%)
During COVID-19 pandemic, were there challenges in assessing and managing:				
Physical needs	8 (16.3%)	3 (12.5%)	6 (17.6%)	17 (15.9%)
Psychological needs	14 (28.6%)	6 (25.0%)	9 (26.5%)	29 (27.1%)
Social, family, or carer needs	20 (40.8%)	16 (66.7%)	20 (58.8%)	56 (52.3%)
Spiritual needs	11 (22.4%)	9 (37.5%)	6 (17.6%)	26 (24.3%)
Cultural needs	5 (10.2%)	4 (16.7%)	3 (8.8%)	12 (11.2%)
Person-centered care	7 (14.3%)	4 (16.7%)	6 (17.6%)	17 (15.9%)
During COVID-19 pandemic, were there challenges managing the following symptoms:				
Agitation	9 (18.4%)	4 (16.7%)	10 (29.4%)	23 (21.5%)
Breathlessness	9 (18.4%)	2 (8.3%)	8 (23.5%)	19 (17.8%)
Fever/shivering	6 (12.2%)	1 (4.2%)	3 (8.8%)	10 (9.3%)
Cough	8 (16.3%)	1 (4.2%)	3 (8.8%)	12 (11.2%)

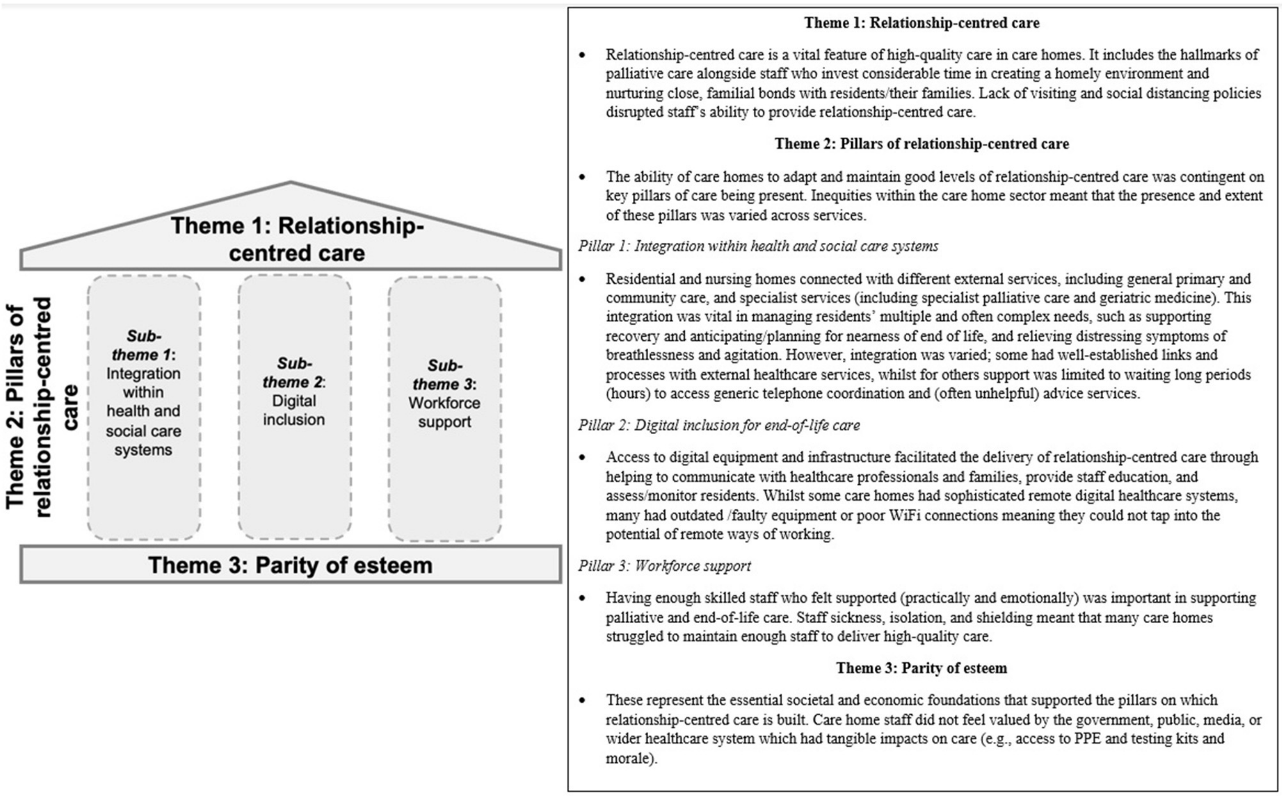
(Continued)

TABLE 2 (Continued)

	Residential (49)	Nursing (24)	Both nursing and residential (34)	Total (107)
Pain	6 (12.2%)	1 (4.2%)	3 (8.8%)	10 (9.3%)
Fatigue	10 (20.4%)	2 (8.3%)	5 (14.7%)	17 (15.9%)
Do you think the quality of care provided to those approaching the end of life fluctuated during the pandemic?				
Yes	8 (16.3%)	8 (33.3%)	10 (29.4%)	26 (24.3%)
No	40 (81.6%)	16 (66.7%)	23 (67.5%)	79 (73.8%)
Missing	1 (2.0%)	0 (0.0%)	1 (2.9%)	2 (1.9%)
During the pandemic, did your care home use any of the following to deliver palliative and end-of-life care:				
End-of-life programme (e.g., Gold Standards Framework, six steps)	11 (22.4%)	14 (58.3%)	14 (41.2%)	39 (36.4%)
National guidance or policies for palliative and end-of-life care	20 (40.8%)	11 (45.8%)	16 (47.1%)	47 (43.9%)
Local guidance or policies for palliative and end-of-life care	22 (44.9%)	16 (66.7%)	19 (55.9%)	57 (53.3%)
Guidance on symptom control (e.g., breathlessness)	12 (24.5%)	11 (45.8%)	15 (44.1%)	38 (35.5%)
Guidance on communication	7 (14.3%)	6 (25.0%)	7 (20.6%)	20 (18.7%)
Electronic palliative care coordination systems (or equivalent)	5 (10.2%)	5 (20.8%)	3 (8.8%)	13 (12.1%)
Other	8 (16.3%)	2 (8.3%)	6 (17.6%)	16 (15.0%)
Since the start of the pandemic, are you using telehealth (e.g., telephone, video calls, use of laptops, tablets) more for palliative and end-of-life care?				
Yes	42 (85.7%)	23 (95.8%)	29 (85.3)	94 (87.9%)
No	6 (12.2%)	1 (4.2%)	3 (8.8%)	10 (9.3%)
Total (missing)	1 (2.0%)	0 (0.0%)	2 (5.9%)	3 (2.8%)
What are you using telehealth for?				
Staff education	28 (57.1%)	13 (54.2%)	19 (55.9%)	60 (56.1%)
Communication with healthcare professionals	44 (89.8%)	23 (95.8%)	27 (79.4%)	94 (87.9%)
Communication with families	38 (77.6%)	20 (83.3%)	25 (73.5%)	83 (77.6%)
Assessment/monitoring of residents	22 (44.9%)	15 (62.5%)	20 (58.8%)	57 (53.3%)
Other	0 (0.0%)	0 (0.0%)	4 (11.8%)	4 (3.7%)
If you need advice about palliative and end-of-life care, who do you usually ask?				
Specialist palliative care and hospice team	31 (63.3%)	22 (91.7%)	30 (88.2%)	83 (77.6%)
Community nurses	36 (73.5%)	3 (12.5%)	8 (23.5%)	47 (43.9%)
Community pharmacist	14 (28.6%)	4 (16.7%)	4 (11.8%)	22 (20.6%)
Other community services (e.g., therapists)	8 (16.3%)	2 (8.3%)	3 (8.8%)	13 (12.1%)
GPs	36 (73.5%)	19 (79.2%)	27 (79.4%)	82 (76.6%)
Geriatricians	2 (4.1%)	1 (4.2%)	3 (8.8%)	6 (5.6%)
Other	3 (6.1%)	0 (0.0%)	1 (2.9%)	4 (3.7%)

staff spending hours trying to access (often unhelpful) generic national or local telephone advice:

> *"Our major source of stress when dealing directly with deteriorating health and end-of-life care was caused by the interminable wait to be able to access NHS24 out of hours [NHS24*–National Health Service urgent care telephone advice] *… Accessing out-of-hours help and support was outrageously difficult. In my daily incident log, I noted one incident: "Contacted 111* [NHS24 urgent care telephone advice] *for help as two ladies were deteriorating. On phone for 40 min. They disconnected us. On again for 45 min, they disconnected us again. Called again'—after another 2 h and 5 min we got through. Eventually got put through to a doctor. The doctor thought*



Theme 1: Relationship-centred care

- Relationship-centred care is a vital feature of high-quality care in care homes. It includes the hallmarks of palliative care alongside staff who invest considerable time in creating a homely environment and nurturing close, familial bonds with residents/their families. Lack of visiting and social distancing policies disrupted staff's ability to provide relationship-centred care.

Theme 2: Pillars of relationship-centred care

- The ability of care homes to adapt and maintain good levels of relationship-centred care was contingent on key pillars of care being present. Inequities within the care home sector meant that the presence and extent of these pillars was varied across services.

Pillar 1: Integration within health and social care systems

- Residential and nursing homes connected with different external services, including general primary and community care, and specialist services (including specialist palliative care and geriatric medicine). This integration was vital in managing residents' multiple and often complex needs, such as supporting recovery and anticipating/planning for nearness of end of life, and relieving distressing symptoms of breathlessness and agitation. However, integration was varied; some had well-established links and processes with external healthcare services, whilst for others support was limited to waiting long periods (hours) to access generic telephone coordination and (often unhelpful) advice services.

Pillar 2: Digital inclusion for end-of-life care

- Access to digital equipment and infrastructure facilitated the delivery of relationship-centred care through helping to communicate with healthcare professionals and families, provide staff education, and assess/monitor residents. Whilst some care homes had sophisticated remote digital healthcare systems, many had outdated /faulty equipment or poor WiFi connections meaning they could not tap into the potential of remote ways of working.

Pillar 3: Workforce support

- Having enough skilled staff who felt supported (practically and emotionally) was important in supporting palliative and end-of-life care. Staff sickness, isolation, and shielding meant that many care homes struggled to maintain enough staff to deliver high-quality care.

Theme 3: Parity of esteem

- These represent the essential societal and economic foundations that supported the pillars on which relationship-centred care is built. Care home staff did not feel valued by the government, public, media, or wider healthcare system which had tangible impacts on care (e.g., access to PPE and testing kits and morale).

FIGURE 2
Overview of integrated findings.

> *hospital at home would not be an option as it's the holidays, and therefore she would look at the use of the ACP* [advance care planning] *medications. I was able to tell her that, actually, not only was hospital at home working despite the bank holiday, I had a phone number of the consultant in charge' … Why do care home managers not have access to the same "hotline" that pharmacists and others have? Why must we be left at the mercy of 111 and pharmacists … this stress could be removed along with the risk of a resident being needlessly in pain".* [manager, residential home, survey free-text response]

Qualitative data complemented quantitative data in providing a deeper understanding of the key ingredients needed for integrated working throughout the pandemic. This was conveyed by a care home nurse who summarized that good integration was based on "*excellent relationships through professional networking; mutual trust and respect; professionalism"* [manager, nursing home, survey free-text response].

Integration between services during the pandemic was strengthened by pre-existing and explicit ways of working, alongside robust relationships with external healthcare professionals. Processes that facilitated these relationships were care homes having direct lines of communication, such as a single point of contact, "a hot-line" to access support/advice, and regular case note reviews of residents in multidisciplinary team meetings. Whilst for some care homes these forms of integration existed before the pandemic, others were able to use COVID-19 as a springboard for their development. Participants perceived that these processes helped to prevent hospital admissions, ensure timely access to care and treatments (including medications), improve clinical assessment of residents, facilitate advance care planning and after-death care, and allow care home staff more time to focus on relationship-centered care to meet residents' needs:

> *"We had a lot of support from the district nurses. We have a lot of support from the community matrons... We're not like a medical nursing home; we're a residential home. There was a lot of things that we couldn't do without district nurse input. So, I think, like, administering end-of-life drugs and things like that. We have a lot of input from the community matrons, which was so helpful to us."* [other, residential home, interview]

Pillar 2: Digital inclusion for end-of-life care

Almost all (94, 87.9%) care homes reported increased use of remote consultations to provide palliative and end-of-life care. Telehealth was used for communication with healthcare professionals (94, 87.9%) and residents' families (83, 77.6%), staff education (60, 56.1%), and for the assessment and monitoring of residents (57, 53.3%).

Qualitative data illuminated how participants' experiences of and views on using digital resources to support relationship-centered care were affected by existing infrastructure. For some, using digital technology was an effective way of accessing skilled clinical support, preserving connectivity with residents and their families, and supporting integration. For others, there was a lack of basic equipment and/or Wi-Fi, meaning the potential benefits of digital technology could not be harnessed. This was detrimental to the provision of relationship-centered care, as it limited integration and restricted emotional involvement/contact between residents, their families, and staff:

> *"We had one lady who was end of life, not from COVID, but was end of life and had been for a little while, and her daughter, before the pandemic, used to come in and read her a book. They would read a book together; they would do a chapter together each time she came in. So, she carried on doing that, but did it with the iPad next to her. And that was really something that was really comforting for her daughter, because she still felt that bit of involvement, although she physically couldn't be there."* [manager, nursing home, interview]
>
> *"We have atrocious internet here. So, yes, we have used emails, but we're not able to get things like Skype, hence me being on the phone… I think the lack of Skype, etc., did impact on the emotional support for be it staff, residents, and relatives. You know, the emotional contact between relatives and their loved ones."* [deputy manager, nursing home, interview]

While many recognized the potential value of using digital technology in facilitating palliative and end-of-life care, others voiced concerns that it was difficult and distressing for some patients to use (especially those with dementia), alongside sometimes detracting from important in-person elements of relationship-centered care:

> *"… people with dementia, there wasn't a void for them particularly, because it was filled with something else. They didn't always get the face timing and the video calls. So, sometimes we had to make a bit of a call on that to say, actually, it's really distressing, because they don't know why you're not there, although you appear to be there."* [manager, nursing home, interview]

Pillar 3: Workforce support

The third pillar that impacted the ability of care homes to provide palliative and end-of-life care was having a sufficiently supported workforce. This meant staff having the capacity to provide relationship-centered care with sufficient time and both practical and emotional support. Staff shortages (48, 45.3%), stress (75, 70.1%), and absenteeism (46, 43%) had a cumulative effect on the ability of staff to provide care. Sickness and shielding/isolation resulted in increased workloads placed on smaller numbers of staff. This had physical and psychological impacts on staff, meaning that they had less capacity to deliver palliative and end-of-life care to the standard that they wanted:

> *"Because our workload had increased due [to] other residents being sick at the same time, we weren't able to give the level of care to the residents that we would normally give during their last hours of life … you're not giving your normal five-star service, and you know that, and you know that person is at their end of life, but there are other people who need your assistance – and because we were short of staff, because they were off either isolating, household isolating, self-isolating".* [manager, nursing home, interview]

The survey data showed that 45.8% of care homes hired agency staff to support their workforce. Qualitative data expanded on this by highlighting participants' concerns that use of agency staff could impair relationship-centered care for people approaching the end of life because of having more limited skills in end-of-life care, as well as insufficient knowledge of residents and their preferences:

> *"We had up to 50 staff off sick or shielding at one time. Only essential care was the priority due to staff numbers. Agency staff were employed, though these rarely turned up. This all impacted end-of-life care—the ability to closely monitor residents and react appropriately.… The home was using staff who were not familiar with the residents, unlike our own staff who knew their plans for end of life and would respond to palliative concerns".* [manager, dual residential and nursing home, survey free-text response]

These workforce pressures occurred in a context of an "infodemic". After an initial dearth of information, care home staff felt inundated by information that was confusing and changed rapidly. The time it took to make sense of, disseminate, and act on this meant that the staff's focus shifted away from relationship-centered care toward more logistical/administrative duties and maintenance of essential care:

> *"Care home staff have had a horrendous time over the last 15 months … as the pandemic continued, we were inundated with documentation issuing directives and guidance from so many bodies it became overwhelming and still is. The information to be disseminated needs to be summarized and bullet pointed for ease of access and legibility, especially for small care homes and providers who do not have a huge HR department to sieve through and highlight the most relevant requirements".* [manager, dual residential and nursing home, survey free-text response]

Theme 3: Parity of esteem

Parity of esteem captures the societal and economic foundations that are essential for supporting the different pillars of care needed for high-quality relationship-centered care. Despite making significant contributions to providing palliative and end-of-life care throughout the pandemic, participants felt their efforts and expertise went unrecognized and were undervalued by the government, media, public, and wider healthcare system.

There was a common misperception that care homes served as a "*dumping ground for old people who are not able to do things for themselves*" [manager, nursing home, interview] or a place where other settings of care could discharge people testing positive for COVID-19. Many felt excluded from national gestures (i.e., public clapping for the National Health Service) and positive media stories regarding the work of the NHS, which affected the morale of an already stretched and tired workforce:

> *"Staff got really tired because they were doing really long shifts and not wanting to leave staff at the care home, because they were short of staff as well . . . And it was horrendous. It was distressing. Even though the work they've done is unbelievable, I don't think the government or society has particularly placed any massive accolade on the work that the care home staff have done, who are predominantly untrained healthcare assistants. And I think they don't feel that valued, and I think that contributes to poor mental health. They've done a brilliant job."* [registered nurse, nursing home, interview]

While many participants perceived a lack of media support during the pandemic, others felt the media actively targeted, blamed, and spread misinformation about care homes in relation to COVID-related deaths:

> *"I've also got to say, the NHS staff were lauded as if they were supernatural beings. They were angels and heroes and all that. And then you've got the health and social care staff, and stories starting to appear in your daily rags about scandals at nursing homes. We had reporters at the front, guys with cameras, and guys trying to speak, trying to locate relatives [in incidents where residents] had died to try and get dirt on the place, you know? Aye, it happened. So, then you look at an article, and it's actually about your place and about people in the wider MDT that you're working with that you know, for a fact, have done their absolutely utmost, and the thing would have been twice as bad if you didn't have them. And their actual practices are getting brought into question by somebody that can't put a few paragraphs together in a way that makes journalistic sense. . . That's in print."* [deputy manager, nursing home, interview]

This disparity of esteem had tangible impacts on the ability of care home staff to provide palliative and end-of-life care safely and confidently throughout the pandemic. Some participants felt as though care homes had been deprioritised or abandoned by government authorities and health services in the distribution of adequate PPE and testing kits:

> *"I don't think that the health authority phoned us once. . . The health service was not supportive as such, and it was upsetting when we'd phone our regular suppliers for PPE or things like that and we're being told: 'Oh, it has to be directed to the NHS', like we were nothing. And you just felt that care homes were kind of left out in the cold."* [manager, nursing home, interview]

Discussion

The aims of this study were to investigate the response of UK care homes in meeting the rapidly increasing need for palliative and end-of-life care during the COVID-19 pandemic and to propose recommendations for strengthening the provision of palliative and end-of-life care within care homes. The novelty and contributions of this study lie in the adoption of a mixed methods approach, in which we triangulated closed-ended and free-text survey responses with in-depth qualitative interview data. As such, this study contributes to a more thorough and contextualized understanding of how and why the delivery of palliative and end-of-life care in care homes was affected by the COVID-19 pandemic, and how policy changes may support its provision both now and in the future.

The findings demonstrate that relationship-centered care is crucial to high-quality palliative and end-of-life care within care homes. Relationship-centered care is already a well-established concept in the health and social care literature, referring to how the quality of relationships between residents, their families, and practitioners influences processes and outcomes of care (32). Despite the disruptions to relationship-centered care (predominantly due to visiting restrictions and social distancing policies), the majority of participants in this study reported that the quality of care for residents at the end of life was maintained. These findings contrast with recent research conducted with bereaved relatives, in which studies found that those who died in care homes during the COVID-19 pandemic were more likely to experience poorer outcomes before death compared to other settings of care (e.g., hospice, home, and hospital) (18, 21). These differences may be explained by the extent to which the "pillars of relationship-centered care" were present across services and how this affected the ability of care homes to uphold the provision of high-quality palliative and end-of-life care in the context COVID-19.

One of these pillars was good integration with health and social care services. Previous studies have highlighted the importance of integration within health and social care (20, 33) and palliative and end-of-life care (34). Care home-specific research has also demonstrated that services that provide "wraparound care" that is not reliant on single practitioners and value care homes as partners in the care of older people are more likely to lead to improved resident and system outcomes (35, 36). Our findings highlight how care home staff drew on "meso" forms of integration (34) to support high-quality palliative and end-of-life care through creating new (or strengthening already existing) connections with primary, specialist palliative, and community care services. Previous research has identified "key ingredients" for successful integrated healthcare (33, 34). Our findings extend these by showing the importance of mutual trust, a sense of partnership, and strong community ties underpinning integration between care homes and external services. They also show that inequities in integration existed, which impacted on patient care. Whilst some care home services already had well-established integration with external services, and others were able to forge these networks during the pandemic, others did not. Instead, some services relied on generic, slow, and unhelpful advice for residents at the end of life, impacting the quality of care that they were able to deliver. Future research, resources, and policy changes are needed to address this and understand how to optimize integration between care homes and external services to support the provision of high-quality palliative and end-of-life care in care homes.

Our study demonstrates how the "digital divide" was another pillar of care that impacted the ability of care homes to harness the potential benefits of digital technology in the provision of relationship-centered care. In line with previous work (37), where the necessary infrastructure and equipment was accessible and used effectively, this could preserve some elements of relationship-centered care and facilitate integration with external services. However, these were not always in place, and participants did not always feel supported or able to work in these ways. Moreover, video consultations could sometimes be difficult to use, distressing and confusing for some patients (especially those with cognitive impairments), and detract from important elements of relationship-centered care. Careful consideration of these issues—including a more systematic evaluation of the benefits and limitations of digital technology in this context (37)—is needed (alongside policy and service developments) to embed digital technology within care homes in ways that optimize relationship-centered care.

This study supports previous research that highlights the key role that care home managers play in supporting their team to deliver high-quality palliative and end-of-life care, but it also highlights how the pressures of the pandemic had profound physical and psychological impacts on staff that undermined their ability to do this (9, 10, 20). These impacts were cumulative and disrupted the capacity of care home staff to deliver care to the standards that they wanted. The gradual accumulation of physical, emotional, and psychological distress experienced by healthcare professionals throughout the pandemic has been well-documented, including across palliative care settings (38–40). These experiences are situated within a workforce crisis in the UK adult health and social care sector, characterized by low pay, high staff turnover, and difficulty in recruiting and retaining staff (41). The recruitment and retainment of skilled staff within care homes relies on them feeling valued and adequately supported in the delivery of care (including palliative and end-of-life). This includes providing care home managers with adequate emotional and practical support so that they can support their teams, alongside ensuring care home staff have sufficient resources and time to deliver high-quality care. Moreover, it is important that the burden and pressures of developing these support strategies and solutions are not placed solely on individuals. Governments and organizations have a duty of care and ethical responsibility to mitigate workforce shortages, maintain staff wellbeing, and ensure that adequate structures and processes of care are in place to support staff and services in the delivery of high-quality palliative and end-of-life care in care homes (38, 42).

However, despite the extensive contribution of care homes in meeting the rapid rise in the need for palliative and end-of-life care throughout the pandemic, participants felt that their role was often unrecognized and undervalued. This had tangible impacts on the provision of palliative and end-of-life care, including not being prioritized in the distribution of PPE or testing kits. Rather than providing them with the support and resources needed, there was a prevailing sense among practitioners that the government in England failed to protect their (and their patients') health throughout the pandemic (43), with a High Court judgement concluding that insufficient equipment was the result of unlawful policy decisions by the government (44).

Implications for policy

During the first weeks of the pandemic, care homes became the most common place of death in England, reaching the levels projected for 2040 (2, 3). The COVID-19 pandemic, therefore, has provided a "stress test" in which lessons can and should be learned for the future provision of palliative and end-of-life care in care homes. In contributing to this, we identify key policy priorities for strengthening these provisions (see Table 3). These priorities should be considered by policymakers to ensure that care homes are equipped with the resources, capacity, and expertise needed to deliver high-quality palliative and end-of-life care, and ameliorate serious health-related suffering for an aging population with an increasing prevalence of frailty, dementia, and multimorbidity globally (45).

The policy recommendations suggested here inform, extend, and align with already existing policies and initiatives. Internationally, this includes the World Health Assembly 2014 declaration on strengthening the integration of palliative care as an essential service within universal health coverage (46), and the Worldwide Hospice Palliative Care Alliance call to build integrated palliative care programmes and services, including in care homes (47). Within the UK, the NHS England 2019 Long Term Plan, which includes the Framework for Enhanced Health in Care Homes (48), is a policy example pursuing integrated approaches that prioritize care centered on individual residents, their families, and care staff, with care needs met through a whole-system, collaborative approach.

Strengths and limitations

Through combining survey and qualitative interview data over different time points, this study provides an in-depth understanding of how COVID-19 affected the provision of palliative and end-of-life care in care homes. Survey respondents and interview participants were sampled across care home size, type, and region, enhancing the generalisability of the findings. Whilst the survey was only offered in the English language and distributed to care homes within the UK, we anticipate that many of these findings, alongside their policy implications, also resonate with and have relevance to care home/long-term residential facilities internationally.

We recognize that a limitation of this study is that, despite the effort to maximize recruitment for the survey, the final sample is relatively small. We sought to maximize the data by purposively over-recruiting in the qualitative interviews, targeting areas of underrepresentation in the survey, such as smaller care homes. Another limitation of this study is that survey and interview data predominantly represent the voices/perspectives of care home managers. These may not accurately reflect the views of other professionals/staff (e.g., nurses, healthcare assistants, and care workers/assistants) who provided palliative and end-of-life care within these organizations throughout the pandemic. Moreover, beyond the input from our Patient and Public Involvement group, the perspectives of the residents and their families/carers were not included in this study. Future research focused on these perspectives will help to further our understanding of the impact of COVID-19 on the provision of palliative and end-of-life care in care homes, and how we can learn from these to better practice in the future.

TABLE 3 Policy priorities for the provision of palliative and end-of-life care in care homes.

Policy priorities	Policy implications	Ways to action this
1. Integration within health and social care systems	**'Spirit of partnership': integration with health and social care services**: Care homes should be well-integrated with external services so that they can receive timely access to support and specialist advice that helps with the delivery of palliative and end-of-life care. This may be through strengthening already established links across the health and social care sector or creating new ones.	• Palliative care representation within multidisciplinary team meetings in care homes to provide specialist advice that supports decision-making. • Universal representation of care homes within local governance systems (such as integrated care systems in England).
2. Digital inclusion for end-of-life care	**Digital inclusivity** An equity-centered approach to future digital policies—in which care homes keep up with technological advancements in healthcare—is crucial. This must include ensuring that all care homes have access to the resources (including equipment and infrastructure) needed to tap into the potentials of digital ways of working to support palliative and end-of-life care.	• Including care homes in national digital healthcare strategies and agreeing on a minimal level of I.T. support, training, and infrastructure that is needed to support palliative and end-of-life care in care homes. • Supporting integrated working through putting interoperable electronic systems (e.g., electronic patient records that can be easily shared and accessed across services and settings) at the heart of any digital healthcare policy/strategy.
3. Workforce development	**Workforce development, training, and support in delivering palliative and end-of-life care:** Staff working in care homes should feel confident, skilled, and supported in the delivery of palliative and end-of-life care, including assessing and managing physical, psychosocial, spiritual, and cultural needs. Training in palliative and end-of-life care should be accessible and tailored to care home staff.	• To address the social care workforce crisis, career pathways and opportunities must be created that attract and retain staff into care home roles, including graduate nurses and healthcare assistants. Better conditions of work for all, including pay and continuing professional development funding, is also essential.
4. Support for care home managers	**Support for care home managers**: Care home managers play an integral role in supporting their teams to deliver high-quality palliative and end-of-life care. Ensuring that care home managers have adequate emotional and practical support to do this is crucial.	• Initiatives that foster collaborations between care home managers, alongside creating alliances with hospices, may better support care home managers through facilitating the sharing of best practice, skills and capabilities, knowledge, support, and advice. Care home managers should also be included in the development of policy and guidance that directly affect the sector.
5. Address (dis)parity of esteem	**Valuing the role of care homes and care home staff:** Care homes and their staff play a key role in the delivery of high-quality palliative and end-of-life care both during and outside of pandemics. These contributions should be recognized and valued by the government, media, public, and wider healthcare system.	• Within policy and planning, care homes should be positioned as equal partners within the health and social care system through better funding, staffing, and representation to influence policy decision-making at local, regional, and national levels.

Conclusion

This study not only highlights the vital role of relationship-centered care when providing palliative and end-of-life care in care homes, but also how this aspect of care was disrupted during the COVID-19 pandemic due to visiting restrictions, social distancing measures, and staff shortages. The ability of care homes to adapt and provide relationship-centered care was dependent on different "pillars" of care being present. These included integrated working with health and social care providers, having access to the equipment and infrastructure needed to take advantage of digital ways of working, and feeling practically and emotionally supported. Although care home staff made significant contributions in providing palliative and end-of-life care during the pandemic, they felt that these went unnoticed and undervalued. These findings inform key policy priorities that should be considered by policymakers to ensure that care homes are equipped with the resources, capacity, and expertise needed to deliver palliative and end-of-life care both now and in the future. This is especially relevant given the known, escalating need for this type of care in care homes over the next 20 years.

Data availability statement

Applications for use of the survey data can be made for up to 10 years and will be considered on a case-by-case basis on receipt of a methodological sound proposal to achieve aims in line with the original protocol. The study protocol is available on request. All requests for data access should be addressed to the Chief Investigator via the details on the CovPall website (https://www.kcl.ac.uk/cicelysaunders/research/evaluating/covpall-study/covpall-care-homes and palliativecare@kcl.ac.uk) and will be reviewed by the Study Steering Group.

Ethics statement

Institutional ethical approval was granted by King's College London Research Ethics Committee (LRS-19/20-18541). The patients/participants provided their written informed consent to participate in this study.

Author contributions

KS and CE are grant holders, joint chief investigators, and were responsible for study conceptualization and development of the study protocol, with critical input from grant co-applicants. IH, CG, SB, and CE-S are co-applicants for funding. IT and IB co-ordinated data collection with the assistance of KS and CE-S. Data analysis was led by SO and ABr. ABr, KS, and CE drafted the original manuscript. All authors had access to all study data, discussed the interpretation of findings, take responsibility for data integrity and analysis, contributed to the analysis plan, and provided critical revision of the manuscript for important intellectual content.

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Conflict of interest

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The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

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References

1. Comas-Herrera A, Zalakaín J, Lemmon E, Henderson D, Litwin C, Hsu A, et al. *Mortality Associated with COVID-19 in Care Homes: International Evidence*. LTC Responses to COVID-19 (2021). Available online at: https://ltccovid.org/2020/04/12/mortality-associated-with-covid-19-outbreaks-in-care-homes-early-international-evidence/

2. Bone AE, Finucane AM, Leniz J, Higginson IJ, Sleeman KE. Changing patterns of mortality during the COVID-19 pandemic: population-based modelling to understand palliative care implications. *Palliat Med.* (2020) 34:1193–201. doi: 10.1177/0269216320944810

3. Bone AE, Gomes B, Etkind SN, Verne J, Murtagh FEM, Evans CJ, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliat Med.* (2018) 32:329–36. 2017/10/11. doi: 10.1177/0269216317734435

4. Moore DC, Payne S, Keegan T, Van den Block L, Deliens L, Gambassi G, et al. Length of stay in long-term care facilities: a comparison of residents in six European countries. Results of the PACE cross-sectional study. *BMJ Open.* (2020) 10:e033881. doi: 10.1136/bmjopen-2019-033881

5. Froggatt KA. Palliative care and nursing homes: where next? *Palliat Med.* (2001) 15:42–8. doi: 10.1191/026921601671222652

6. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *Lancet.* (2018) 391:1391–454. doi: 10.1016/S0140-6736(17)32513-8

7. Sizoo EM, Monnier AA, Bloemen M, Hertogh CMPM, Smalbrugge M. Dilemmas with restrictive visiting policies in dutch nursing homes during the COVID-19 pandemic: a qualitative analysis of an open-ended questionnaire with elderly care physicians. *J Am Med Dir Assoc.* (2020) 21:1774–81.e1772. doi: 10.1016/j.jamda.2020.10.024

8. Haj ME, Altintas E, Chapelet G, Kapogiannis D, Gallouj K. High depression and anxiety in people with Alzheimer's disease living in retirement homes during the covid-19 crisis. *Psychiatry Res.* (2020) 291:113294. doi: 10.1016/j.psychres.2020.113294

9. Nyashanu M, Pfende F and Ekpenyong MS. Triggers of mental health problems among frontline healthcare workers during the COVID-19 pandemic in private care homes and domiciliary care agencies: lived experiences of care workers in the Midlands region, UK. *Health Soc Care Community.* (2022) 30:e370–e376. doi: 10.1111/hsc.13204

10. Gordon AL, Goodman C, Achterberg W, et al. Commentary: COVID in care homes—challenges and dilemmas in healthcare delivery. *Age Ageing.* (2020) 49:701–5. doi: 10.1093/ageing/afaa113

11. Dyer AH, Fallon A, Noonan C, Dolphin H, O'Farrelly C, Bourke NM, et al. Managing the impact of COVID-19 in nursing homes and long-term care facilities: an update. *J Am Med Dir Assoc.* (2022). 23:1590–602. doi: 10.1016/j.jamda.2022.06.028

12. Jones K, Schnitzler K, Borgstrom E. The implications of COVID-19 on health and social care personnel in long-term care facilities for older people: an international scoping review. *Health Soc Care Community.* (2022) 30:e3493–e3506. 20220813. doi: 10.1111/hsc.13969

13. Beattie M, Carolan C, Macaden L, Maciver A, Dingwall L, Macgilleeathain R, et al. Care home workers experiences of stress and coping during COVID-19 pandemic: a mixed methods study. *Nurs Open.* (2022) 10:687–703. doi: 10.1002/nop2.1335

14. Spacey A, Porter S, Board M, Scammell J. Impact of the COVID-19 pandemic on end of life care delivery in care homes: a mixed method systematic review. *Palliat Med.* (2021) 35:1468–79. doi: 10.1177/02692163211029806

15. Bolt SR, van der Steen JT, Mujezinović I, Janssen DJA, Schols JMGA, Zwakhalen SMG, et al. Practical nursing recommendations for palliative care for people with dementia living in long-term care facilities during the COVID-19 pandemic: a rapid scoping review. *Int J Nurs Stud.* (2021) 113:103781. doi: 10.1016/j.ijnurstu.2020.103781

16. Hanna K, Cannon J, Gabbay M, Marlow P, Mason S, Rajagopal M, et al. End of life care in UK care homes during the COVID-19 pandemic: a qualitative study. *BMC Palliat Care.* (2022) 21:91. doi: 10.1186/s12904-022-00979-4

17. Antunes B, Bowers B, Winterburn I, Kelly MP, Brodrick R, Pollock K, et al. Anticipatory prescribing in community end-of-life care in the UK and Ireland during the COVID-19 pandemic: online survey. *BMJ Palliat Care.* (2020) 10:343–9. doi: 10.1136/bmjspcare-2020-002394

18. Selman LE, Farnell D, Longo M, Goss S, Seddon K, Torrens-Burton A, et al. Risk factors associated with poorer experiences of end-of-life care and challenges in early bereavement: results of a national online survey of people bereaved during the COVID-19 pandemic. *Palliat Med.* (2022) 36:717–29. 20220217. doi: 10.1177/02692163221074876

19. Spacey A and Porter S. Understanding advance care planning in care homes throughout the COVID-19 pandemic: a critical realist review and synthesis. *Palliat Med.* (2022) 2022:2692163221137103. doi: 10.1177/02692163221137103

20. Marshall F, Gordon A, Gladman JRF, Bishop S. Care homes, their communities, and resilience in the face of the COVID-19 pandemic: interim findings from a qualitative study. *BMC Geriatr.* (2021) 21:102. doi: 10.1186/s12877-021-02053-9

21. Yildiz B, Korfage IJ, Witkamp EF, Goossensen A, van Lent LG, Pasman HR, et al. Dying in times of COVID-19: experiences in different care settings–an online questionnaire study among bereaved relatives (the CO-LIVE study). *Palliat Med.* (2022) 36:751–61. doi: 10.1177/02692163221079698

22. Doyle L, Brady A-M, Byrne G. An overview of mixed methods research. *J Res Nursing.* (2009) 14:175–85. doi: 10.1177/1744987108093962

23. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Lancet.* (2007) 370:1453–7. doi: 10.1016/S0140-6736(07)61602-X

24. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc.* (2019) 11:589–97. doi: 10.1080/2159676X.2019.1628806

25. Vogl S, Schmidt E-M, Zartler U. Triangulating perspectives: ontology and epistemology in the analysis of qualitative multiple perspective interviews. *Int J Social Res Methodol.* (2019) 22:611–24. doi: 10.1080/13645579.2019.1630901

26. Donabedian A. Evaluating the quality of medical care. *Milbank Mem Fund Q.* (1966) 44:166–206. doi: 10.2307/3348969

27. Braun V, Clarke V. *One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qualitative Research in Psychology.* (2021) 18:328–52. doi: 10.1080/14780887.2020.1769238

28. Smith B, McGannon KR. Developing rigor in qualitative research: problems and opportunities within sport and exercise psychology. *Int Rev Sport Exerc Psychol.* (2018) 11:101–21. doi: 10.1080/1750984X.2017.1317357

29. Parkinson S, Eatough V, Holmes J, et al. Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qual Res Psychol.* (2016) 13:109–29. doi: 10.1080/14780887.2015.1119228

30. Finlay L. Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qual Res.* (2002) 2:209–30. doi: 10.1177/146879410200200205

31. Sparkes A, Smith B. *Qualitative Research Methods in Sport, Exercise & Health From Process to Product.* London: Routledge. (2014). doi: 10.4324/9780203852187

32. Soklaridis S, Ravitz P, Adler Nevo G, et al. Relationship-centred care in health: a 20-year scoping review. *Patient Expe J.* (2016) 3:130–45. doi: 10.35680/2372-0247.1111

33. Briggs AM, Valentijn PP, Thiyagarajan JA, de Carvalho IA. Elements of integrated care approaches for older people: a review of reviews. *BMJ Open.* (2018) 8:e021194. doi: 10.1136/bmjopen-2017-021194

34. Payne S, Hughes S, Wilkinson J, Hasselaar J, Preston N. Recommendations on priorities for integrated palliative care: transparent expert consultation with international leaders for the InSuP-C project. *BMC Palliat Care.* (2019) 18:32. doi: 10.1186/s12904-019-0418-5

35. Goodman C, Davies SL, Gordon AL, Dening T, Gage H, Meyer J, et al. Optimal NHS service delivery to care homes: a realist evaluation of the features and mechanisms that support effective working for the continuing care of older people in residential settings. *Health Serv Res.* (2017) 5. doi: 10.3310/hsdr05290

36. Gordon AL, Goodman C, Davies SL, Dening T, Gage H, Meyer J, et al. Optimal healthcare delivery to care homes in the UK: a realist evaluation of what supports effective working to improve healthcare outcomes. *Age Ageing.* (2018) 47:595–603. doi: 10.1093/ageing/afx195

37. Seifert A, Batsis JA and Smith AC. Telemedicine in long-term care facilities during and beyond COVID-19: challenges caused by the digital divide. *Front Public Health.* (2020) 8:601595. doi: 10.3389/fpubh.2020.601595

38. Bradshaw A, Dunleavy L, Garner I, Preston N, Bajwah S, Cripps R, et al. Experiences of staff providing specialist palliative care during COVID-19: a multiple qualitative case study. *J R Soc Med.* (2022) 115:220–30. doi: 10.1177/01410768221077366

39. Hanna JR, Rapa E, Dalton LJ, et al. Health and social care professionals' experiences of providing end of life care during the COVID-19 pandemic: a qualitative study. *Palliat Med.* (2021) 35:1249–57. doi: 10.1177/02692163211017808

40. Fish EC, Lloyd A. Moral distress amongst palliative care doctors working during the COVID-19 pandemic: a narrative-focussed interview study. *Palliat Med.* (2022) 36:955–63. doi: 10.1177/02692163221088930

41. Skills for Care. *The State of the Adult Social Care Sector and Workforce in England.* Leeds: Skills for Care (2022). Available online at: https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2022.pdf

42. Harrison KL, Dzeng E, Ritchie CS, Shanafelt TD, Kamal AH, Bull JH, et al. Addressing palliative care clinician burnout in organizations: a workforce necessity, an ethical imperative. *J Pain Symptom Manage.* (2017) 53:1091–6. doi: 10.1016/j.jpainsymman.2017.01.007

43. Institute of Public Policy Research. *Care Fit for Carers: Ensuring the Safety and Welfare of NHS and Social Care Workers During and After COVID-19.* London: Institute for Public Policy Research (2020). Available online at: https://www.ippr.org/files/2020-04/1587632465_care-fit-for-carers-april20.pdf

44. Gardner and Harris vs. Secretary of State for Health and Social Care and Ors. London: Royal Court of Justice. (2022).

45. Sleeman KE, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Global Health.* (2019) 7:e883–92. doi: 10.1016/S2214-109X(19)30172-X

46. World Health Asembly. *Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course.* Geneva: World Health Organisation. (2014).

47. Gomez-Batiste XSC. *Building Integrated Palliative Care Programs and Services Catalonia: Worldwide Hospice Palliative Care Alliance.* Catalonia: Worldwide Hospice Palliative Care Alliance (2017). Available online at: https://kehpca.org/wp-content/uploads/2020/06/Go%CC%81mez-Batiste-X-Connor-S-Eds.-Building-Integrated-Palliative-Care-Programs-and-Services.-2017-b.pdf

48. National Health Service. *The Framework for Enhanced Health in Care Homes.* England: NHS England (2020). Available online at: https://www.england.nhs.uk/wp-content/uploads/2020/03/the-framework-for-enhanced-health-in-care-homes-v2-0.pdf

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Transition of care from hospital to home for older people with chronic diseases: a qualitative study of older patients' and health care providers' perspectives

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Background: Transitional care is a critical area of care delivery for older adults with chronic illnesses and complex health conditions. Older adults have high, ongoing care needs during the transition from hospital to home due to certain physical, psychological, social, and caregiving burdens, and in practice, patients' needs are not being met or are receiving transitional care services that are unequal and inconsistent with their actual needs, hindering their safe, healthy transition. The purpose of this study was to explore the perceptions of older adults and health care providers, including older adults, about the transition of care from hospital to home for older patients in one region of China.

Objective: To explore barriers and facilitators in the transition of care from hospital to home for older adults in China from the perspectives of older patients with chronic diseases and healthcare professionals.

Methods: This was a qualitative study based on a semi-structured approach. Participants were recruited from November 2021 to October 2022 from a tertiary and community hospital. Data were analyzed using thematic analysis.

Results: A total of 20 interviews were conducted with 10 patients and 9 medical caregivers, including two interviews with one patient. The older adult/adults patients included 4 men and 6 women with an age range of 63 to 89 years and a mean age of 74.3 ± 10.1 years. The medical caregivers included two general practitioners and seven nurses age range was 26 to 40 years with a mean age of 32.8 ± 4.6 years. Five themes were identified: (1) attitude and attributes; (2) better interpersonal relationships and communication between HCPs and patients; (3) improved Coordination of Healthcare Services Is Needed; (4) availability of resources and accessibility of services; and (5) policy and environment fit. These themes often serve as both barriers and facilitators to older adults' access to transitional care.

Conclusions: Given the fragmentation of the health care system and the complexity of care needs, patient and family-centered care should be implemented. Establish interconnected electronic information support systems; develop navigator roles; and develop competent organizational leaders and appropriate reforms to better support patient transitions.

KEYWORDS

older patients, chronic diseases, transitional care, health care providers, qualitative research

Introduction

With the rapid development of population aging, chronic health problems in the older adults are becoming more prominent and the coexistence of multiple diseases is becoming more serious, and the global burden of chronic diseases is increasing dramatically (1, 2). In China, the world's largest developing country, data from the seventh census show that the population aged 60 years and older is about 264 million, accounting for 18.7% of the total population (3), and nearly 3/4 of the older people suffer from one or more chronic diseases (4). Older adults with multiple chronic conditions often have more complex needs, requiring multiple health care providers to provide a wide range of medical and geriatric care facilities in multiple care settings, and often requiring transitions between hospitals and the older adult's own home (5). Several studies have shown that the transition from hospital to home can be a complex, risk-filled process. Approximately one in five patients experience adverse events during this transition, including unplanned readmissions within a month of discharge, medication errors, and even death (6–8). And shorter hospital days may exacerbate this problem and consume even more health care resources, as older adults discharged from the hospital to their homes may have complex health problems, ongoing treatment and care needs (9). Improving the safety and quality of care transitions is an important way to improve patient outcomes and increase the efficiency of health care resource utilization, and has become one of the global concerns (10, 11).

Transitional care is defined as the set of measures taken to ensure that patients receive timely, safe, and continuous health care services, including discharge planning, referrals, follow-up, medication management, and self-education, during the period when patients need to be transferred between sites (hospital-community or hospital-home) or switch between levels of care at the same site (from ICU to general ward) due to changes in their condition (5, 12). *Performance measurement: accelerating improvement:* accelerating improvement identifies patient-centered transition of care from hospital to home as one of the three priority areas for measuring performance measurement (13). Previously Naylor et al. and Coleman et al. reported the significant role of transitional care in reducing readmission rates and improving quality of life in older patients with chronic diseases, among others (14–16), as an important strategy to ensure the safety and meet the ongoing care needs of older patients (17).

However, many problems remain for older adults in the transition from hospital to home, and patient needs are not yet being met (18, 19). With the onslaught of person-centered health care ideology, especially for older patients with higher care needs or complex health problems, health care providers have a responsibility to provide follow-up services and health coaching to bridge system disparities and ensure their continuity of care across levels of care or locations (20, 21). However, the provision of such care depends largely on organizational or system requirements rather than on helping patients or family caregivers achieve individualized goals of care, potentially resulting in patients receiving care that is not aligned with actual needs during the transition or some perceived differences in priorities between health care providers and patients (22, 23). Health transitions in older adults depend on effective self-management, and health care providers need to provide care that promotes sustained and effective self-management in older adults rather than promoting patient dependence. A key challenge in transitional care is the need to provide patients with medical care that is adapted to independent, self-directed needs, i.e., their own perceived, rather than professional-defined needs (24). Although there is a scale developed by Coleman et al. (12) to assess the quality of transitional care services for older patients after discharge, this assessment tool assesses more the overall quality of transitional care and lacks indicators to assess the quality of the structure and process of transitional care services (25). It is also incomplete to understand the patient's perception of transitional care only from his or her perspective. Health care providers (HCP), especially nurses, as the primary implementers and providers of transitional care, interact with other health care professionals to assess patients' biological, psychological, social, and emotional needs, provide community care services including outpatient and home health care, and identify barriers to providing follow-up services and care (26–28). Their perceptions and attitudes about care transitions also influence the safety and quality of transitions (26, 27).

In China, transitional care from hospital to home usually includes verbal health education before discharge and telephone follow-up after discharge, as well as home visits by family physicians and transitional nurses at the request of patients or caregivers. Under a tiered system, family physicians or their teams generally obtain information about and provide follow-up care to older patients during their transition of care from the hospital to their own homes, including medication administration and wound care. However, this model remains challenging due to limitations in primary health care facilities and transitional care hiring staff (29). There is a growing body of qualitative research on the problems and unmet needs of older patients and the ineffectiveness of transitional care (30–32). However, the development of transitional care strategies is influenced by health care resources and cultural differences, and localized policy development needs to be combined with standardization. The perceptions of transition of care among older patients with chronic diseases and healthcare professionals in China have not been adequately described in previous studies. In order for older adults to successfully transition from hospital to home, there is a need to understand the experiences and perceptions of care transitions from both patient and provider perspectives to identify gaps and optimize care transition processes to improve care practices related to this highly relevant area.

The purpose of this study was to explore the perceptions and experiences of transition of care among older patients with chronic diseases and healthcare professionals in a Chinese context to identify potential areas for future interventions to improve the practice of care with this highly relevant transition.

Methods

Study design

This qualitative study used semi-structured interviews to explore the perspectives of older patients with chronic conditions and health care providers on transitions of care to understand barriers and facilitators of transitions of care for older patients.

Ethical approval

The study was approved by the Human Ethics Committee of Zhengzhou University, and verbal consent or written informed consent was obtained from all patients and medical caregivers involved in the study.

Participants and setting

Participants in this study included older patients and medical caregivers from a tertiary care hospital and a community health facility. A purposive sampling method was used for this study. The inclusion criteria for older adults were: age ≥60 years; coping with at least two chronic diseases (e.g., diabetes, coronary heart disease, chronic obstructive pulmonary disease, stroke); having experienced at least one transfer from hospital to home or undergoing a transition from hospital to home within the past 30 days; and being able to communicate verbally in Chinese (i.e., no language impairment or aphasia). Health care worker inclusion criteria included nurses and general practitioners working in community health care settings involved in the transition of care from hospital to home for older patients with chronic conditions.

Collection process

Qualitative data collection was conducted between November 2021 and October 2022. Qualitative data collection took place between November 2021 and October 2022. For the recruitment of older adult/adults patients, we explained the purpose of the study and obtained consent from older adult/adults patients 2–3 days before their discharge from the hospital, left their basic information at the time of discharge, and interviewed the patients by phone or at follow-up visits or in the community within 1 month. For health care providers, we contacted the relevant hospital or community agency directors in advance to inform them of the purpose and content of the study, to obtain a list of health care providers willing to participate, and invited health care providers to participate. The interview guide was developed by the researcher team based on the local medical culture and with reference to relevant transitional care researches (33–36). See Table 1 for interview guide. All interviews were recorded and interviewed in Chinese by a team of experienced graduate students, five of whom were Master of Nursing students who had systematically studied and successfully passed the relevant qualitative research program, and two researchers piloted the interview guide to verify its applicability and feasibility. In addition, professionals in the field of qualitative research were invited to revise the interview questions and provide guidance on the interview process. Interviews ranged from 15 to 90 min in length, with notes taken during the interview for initial interpretation. Verbatim notes were taken during the 24 h of data collection. When researchers repeatedly heard similar descriptions in the analysis was no new categories were found that were relevant to the study topic, consider whether the study reached data saturation, and stop collecting data when the research team reached consistency regarding the saturation of the data.

TABLE 1 Interview topic guide of the older patients and HCPs.

The patient interview guide	The HCPs interview guide
① What was your experience with care transitions like?	① How did you plan for the older adult's discharge from the hospital?
② How do you feel healthcare organizations provide transitional care to older adults?	② What were some of the challenges and hardships faced in transition of care?
③ What difficulties and barriers did you face during your care transition?	③ How did you cope with them?
④ How did you cope with the transition of care?	④ How do you think care could be improved?

Theoretical framework

To understand the barriers and facilitators that influence older adults during care transitions, this study applied an ecological perspective. This perspective incorporates knowledge from a broader context, including social, economic, political, and cultural factors (37). The theory has been previously applied to studies of transitional care for older adults in the United States (33) and Canada (38). By adopting an ecological or whole-systems perspective to the study of health system issues, interconnectedness across the health care system can be achieved, supporting patients and health care providers to work together to adaptively manage and mitigate challenges in their health care settings (39).

Data analysis

The data was transcribed and analyzed using Nvivo 12 software and traditional Microsoft Word software. Thematic analysis is used for recording analysis (40). Thematic analysis helps to identify, analyze, and report themes in the data, which is an iterative process where codes and types are compared and analyzed to derive themes (41, 42). Two researchers read the transcripts individually for analysis until a consensus was reached between coding and analysis. The report of this study complies with the Consolidated Reporting Standards for Qualitative Research (COREQ) guidelines (43).

Results

A total of 20 interviews were conducted between November 2021 and October 2022 with 10 patients and nine medical caregivers, two of which were with the same patient. Ten older patients had a mean age of 74.3 ± 10.1, with an age range of 63–89 years, of whom four were male and six were female. The average age of the medical caregivers was 32.8 ± 4.6, with an age range of 26–40 years, and an average experience of 10.0 ± 6.6, including two general practitioners and seven nurses. Statistical data are detailed in Table 2.

Attitude and attributes

Attitude and attributes are both important facilitators and barriers to transition of care for older adults. The active

TABLE 2 Demographic characteristics of the older patients and HCPs.

Demographic information of older patients (*n* = 10)	*n* (%)	Demographic information of HCPs (*n* = 9)	*n* (%)
Gender		Gender	
Male	4 (40%)	Male	1 (11.1%)
Female	6 (60%)	Female	8 (88.9%)
Age, mean (SD)	74.3 (10.1)	Age, mean (SD)	32.8 (4.6)
Marital status		Job experience, mean (SD)	10.0 (6.6)
Married	5 (50%)	Profession	
Single/widowed	5 (50%)	General physicians	2 (22.2%)
Living alone		Nurses	7 (78.8%)
Alone	2 (20%)	Place of work	
With spouse	5 (30%)	Tertiary hospitals	4 (44.4%)
With other family	3 (50%)	Community medical institutions	5 (55.6%)

participation of some older adults in care transitions and their confidence that they can have a bright future at home is a sign of their positive attitudes.

> "I came home without any problems, and if it wasn't for the coronavirus, I would have been out traveling again, haha." (P8)
>
> "The community institution is very close to my house, a few minutes walk away … The doctors and nurses also call me regularly, the community often conducts medical consultations, there are doctors' phone numbers saved, and we have a family bed … Home will make I feel safer." (P3)

Despite the fact that the conditions at home are not as good as those in a skilled nursing facility, older people still choose to return to their families. This has to do with the influence of traditional Chinese culture, where the idea of filial piety and raising children for old age is deeply rooted.

> "I suggested a referral to a professional nursing home, and he refused." (HCP4)
>
> "I have children, I am not going into a nursing home. To let the older people live in a nursing home is to have children who are not filial and will be spit upon by others." (P9)

When certain symptoms appear, some older people participants will first manage the symptoms based on their past experiences, and then seek medical help as a last resort when their self-tries fail. This is related to the financial income of the der persons, the taboo to seek medical help, and the fear of "covering their ears."

> "Nowadays, older people are bound to live and die with chronic diseases, and it makes sense that the old saying 'a long illness becomes a good doctor.' Like I've been diabetic for so many years, I know what to do when my blood sugar is high … I think I'm capable of dealing with some unexpected situations and don't have to come to the hospital for everything." (P7)
>
> "Wheezing when you hurry to sit down and rest … breathing poorly the first reaction should be to find medicine and oxygen equipment … when taking medicine also does not work, I can only go back to the old place again, although I reluctantly hospitalized, but no way I do not want to die yet." (P4)
>
> "They always endured until they could not endure before they came to the hospital, I asked why they did not come earlier, some of them would justifiably reply: I used to come over like this, it is not a very serious matter, it became complicated to come to the hospital, I do not want to come to the hospital … seems very open-minded, but in fact the fear of the hospital, which has to do with their stubborn perceptions, which is hard to change." (HCP1)

To further achieve independence at home after discharge from the hospital, some participants learned new skills, including blood glucose monitoring, injections, and oxygen, complex medication management, and rehabilitation-related care, in addition to having positive thoughts, in an effort to improve self-management, learn self-care skills, and take personal responsibility for self-care.

> "There are many people who have had their hands and feet cut off because of diabetes. Our neighbor, who had a bad heart and diabetes, cut off a toe, and the palm of her foot (wound) did not grow easily, it festered, and (the surface of the foot) ran through. It will bring trouble to my son, I usually pay more attention now, I don't eat anything sweet!" (P3)
>
> "You are the first person in charge of your health, don't think about other people reminding you, relying on others won't work." (P9)

Yet transition is a process of transformation across organizational settings, and as older adults faced a transition from a medical facility to an unstructured home environment, some participants expressed a sense of uncertainty and concern about in-home care. They exhibited fear, depression, loneliness, and even despair, all of which are barriers to transitional care. This negative perception of transition was associated with symptoms that had not yet disappeared, negative experiences of past transitions, and knowledge skill gaps in dealing with physical changes and managing adverse reactions.

> "I don't want to be discharged home, I don't feel cured, I can't talk or walk easily now, what if I fall, what if a blood vessel ruptures again? Will I still be able to run away from Hades." (P9)

Better interpersonal relationships and communication between HCPs and patients

The conventional wisdom is that discharge from the hospital represents the end of the relationship with the hospital. During the care transition journey, patients fear abandonment by their medical caregivers due to unresolved illness, desire lasting interpersonal relationships and connections with them for follow-up appointments and timely follow-up care, and affirm the role family caregivers play in facilitating and coordinating communication between each other.

Older adults require frequent travel between the hospital and home due to recurring, migratory non-healing chronic conditions. Some participants emphasized the desire to continue contact with medical caregivers after discharge from the hospital so that problems can be responded to quickly.

> "It would be nice to have a contact number for the doctor or nurse so that I can call if there is a problem." (P1)
>
> "Provide the phone number of the department so that when I have a problem it can be dealt with promptly, preferably the supervising doctor." (P6)

Several participants reported the importance of maintaining long-term, trusting relationships with medical caregivers. There is no doubt that this provides a better opportunity for medical staff to help patients transition as well.

> "I come to Dr. Jia every time I have a problem, I trust her, she understands my situation, I don't reject a new doctor to reach me, but the new doctor prescribes medication that is not consistent with what I had before and I can't maintain trust in it . . . ." (P3)
>
> "I can't know every patient like the back of my hand, it takes time and frequent contact, and when the conversation is accurate and I tell her [the patient] background, her condition, I think she will open up." (HCP3)

Communication between the HCP and the patient was seen as a barrier when medical diagnoses or discussions of conditions were not delivered in a way that the patient could understand or when too much medical jargon was used, and limited the trust and relationship that some older participants had with the medical staff.

> ". . . Not everyone is a medical student, when they say medical terminology words, I know they are talking about my condition, but it sounds as if it is a pipe dream, they tell me that a certain indicator on my labs is high and I might have a sudden brain attack, but what do I know? . . . ." (P6)

In addition, the tone and attitude of care providers' speech and workload were daunting to patients.

> "The doctors and nurses are very busy, taking time out for meals, in and out of . . . I know they are here, I made several trips to the doctor's office and couldn't find them . . . ." (P4)
>
> "I went for a follow-up appointment and he looked at my report card and simply said two words and called the next person without even looking up at me . . . I understand that they are busy, but I felt lost inside, like an assembly line job with no emotion." (P10)

It is clear that older adults and HCPs recognize the important supportive role that family caregivers play in building, maintaining, and communicating with each other and even in the transition of care for older adults. Older adults who are confused about discharge instructions and follow-up plans due to memory, comprehension, or mobility limitations require family caregivers to be involved in discharge education or counseling about medical decisions and matters. Whereas communication and contact among healthcare professionals is not real-time and fluid, family caregivers facilitate the transfer and sharing of patient care information among different healthcare providers.

> "It's better to have a family member there who will provide additional information, such as previous visits, medication information and test reports, etc. The more detailed I know, the better I can treat the patient." (HCP4)

An interesting phenomenon is the transformation of family caregivers from supportive supporters to surrogates and advocates for care decisions, and the closeness of the relationship between health care workers and family caregivers even more than patients, which are mutually understood and commonplace.

> "When I had mobility problems, I would ask my children to contact Dr. Jada by phone, and they had WeChat between them for easy contact." (P3).
>
> "I would explain some precautions, let's say you have diabetes and you need to control . . . on your diet, and the patient would have family members come along to participate. . . ." (HCP6)
>
> "It's important to educate the caregiver about health and the family needs to understand which symptoms are present and they need to come to the hospital quickly and not delay at home." (HCP3)

In contrast, for older adults who live alone or not with a younger caregiver, health care providers are selective in their coverage and patient education, which is related to their level of health literacy and acceptance of health education.

> "Explaining so much they (he and his older partner) can't understand. I would prefer to have the younger caregiver around, and they are sorry it's not mandatory. A lot of times I will say something in layman's terms and in layman's terms depending on his education level, so that you don't intermittently ask you questions when you tell him something to do." (HCP2)

Improved coordination of healthcare services is needed

Care coordination refers to the coordination of care providers between different health care facilities or within a health care facility. A coordinated health care delivery system is an important facilitator of care transitions. Poor coordination among health care providers leads to difficulties in effective communication and information transfer, and thus inconsistent and underserved care delivery.

Older adults have detailed records of their visits during hospitalization, but after discharge patients have to repeat their health information and medication details to other health care providers, and even repeat some medical tests. This caused dissatisfaction and frustration among patients and health care providers, and expressed the need for a well-developed electronic system to avoid duplication or inaccurate transmission of verbal information to patients as well as to facilitate advance knowledge of patients, facilitate knowledge transfer of diseases, and what steps to take to complete care planning.

One participant indicated,

> "When you leave the hospital, the hospital should pass on the information to community agencies. This is correct. But in reality, the hospital doesn't do that, and the community agency doesn't know that you've been discharged; they don't know anything. You had to repeat the process… They didn't do a good job of bridging the gap." (P2)
>
> "My CT report should be shared between hospitals instead of wasting money on re-testing." (P5)
>
> "We belong to different systems and we can only see information about the patient's treatment within the same tissue, and they (patients) also often complain that we have taken imaging tests at other hospitals and suspect that we are getting money from them …, when in fact we don't get their details." (HCP3)

Increased collaboration among care providers can be beneficial to patient transition. Older adults and HCPs expressed the need for a role model to navigate the health care system during care transitions. Patients don't understand how the health care system works, and they want a dedicated person to interface with community agencies or family physicians for information prior to discharge and to be able to contact for help if they are overwhelmed after discharge.

> "I hope the hospital and community [agencies] complete the docking … for good symptomatic management," adding further, "There is no point of contact between the clinical staff and the community health care providers, and our community is not affiliated with this hospital. The hospital should have a dedicated person to help us find the docking community organization." (P6)

Although medical caregivers also agreed with having coordinators to navigate care transitions, there was disagreement about who should serve. Most patients felt that there should be their own supervising physician or nurse who was familiar with them. Nursing staff, on the other hand, felt that a dedicated person should be set up to coordinate and that it should not be the busy front-line clinical staff doing this job.

> "… In the hospital it would be just treating acute symptoms and more importantly home regimen … In this gap, despite the follow up, it does not seem to meet the patient's needs… .... We should create a professional team with dedicated staff to do this and create a docking organization between the department and community organizations or home care. Let's say a patient is discharged from our ward and we notify him a day in advance and say come on, here's a patient who needs to be discharged …." (HCP8)

In reality middle-aged and chronically ill patients often have more complex care needs, fragmented health systems and limited availability of resources, and health care workers have to make more efforts to coordinate care transitions and rely more on positive personal traits. Yet some participants indicated that imperfect financial incentives and regulatory measures may further increase the care coordination gap.

> "… on care transition coordination is more on the individual, there is no mandatory system that says you have to do it, I do the work and I don't have any performance income, and I would struggle with guilt and busy work if I didn't make the effort for it." (HCP9)

Availability of resources and accessibility of services

Older patients are discharged from the hospital with unresolved illnesses and high levels of need for follow-up care information and resources during the transition of care, and then there are systemic barriers to care transitions due to the lack of a holistic transition of care plan in the health care system, resulting in a lack of available medical resources and expression of service accessibility after discharge.

Returning home represents the end of the medical journey, and participants report a lack of follow-up ongoing follow-up and a sense of isolation and abandonment in the transition of care.

> "No one cares about you after you leave the hospital, the doctors don't call, the nurses don't," the participant further explained, "When you go home you are on your own, you don't know who to call if something goes wrong." (P2)

For participants in remote or rural areas, they reported that there were no available medical teams and resources, especially when mobility was limited and transportation was difficult, and more effort had to be made to ensure the transition.

One older participant said

> "It was a particularly small clinic, with only one staff member doing both doctor and nurse work. And there were no rehabilitation facilities. I had no choice but to municipal hospital, the one side of my body had paralyzed, which was troublesome for me and required a lot of stuff to bring, just like moving." (P9)

Although providers could identify patients' needs, staff shortages prevented them from providing appropriate care.

> "Caregivers ask us for home infusions, and I know that's their expectation, but it's unrealistic." (HCP3)

In addition, there is limited training on mental health issues and needs of older adults, and health care providers are more focused on addressing somatic symptoms.

> "… he appears mildly depressed, we'll just have to comfort and reassure, I can't inject drugs into his psyche." (HCP7)

And with the pandemic outbreak of the coronavirus epidemic, the implementation of some prevention and control measures has made follow-up appointments and home visits challenging.

> "My neighbor he got infected and the community told me I needed to stay out for 7 days, I was supposed to go to the hospital to review my heart, but there was no way I could do that, I had to wait until the unblock." (P5)

Healthcare organizations have introduced Internet-based digital communication technologies to protect staff safety and reduce face-to-face care services, but the availability of supportive resources and the accessibility of services remain limited, which may be related to the e-health literacy of older adults and the infrastructure of community agencies.

Policy and environment fit

China's 13th Five-Year Plan emphasizes continuity of care, although the state has introduced a series of incentives to facilitate transitions of care for older adults. However, current policies still lack specificity and certainty, making transitional care for older adults fraught with opacity and immaturity.

> "I know the Health Care Commission has a policy, but that's too big and I need more detailed rules to implement …." (HCP5)

Stable, competent leaders play an important role in policy planning and guidance for care transitions for older adults.

> "The central government sets the documented policy and the hospital has to implement it, but you can't implement it blindly, you have to understand the plight of older adults, and the key is to rely on a handful of people, depending on the ability and also the level of dedication." (P6)

In addition, one nurse expressed the need to consider the medical cultural environment when implementing transitional care.

> "Transitional care is in a limbo, many aspects are not perfect, our health care system is different, we can't simply copy foreign countries, the care environment we are in is very different …." (HCP8)

Discussions

Progress in transitional care has been made in China since 2011.But the continuum of management of older patients with chronic conditions after discharge from hospital remains fragmented (44). To improve continuity of care for older adults with chronic conditions, we explored older adults' and health care providers' perceptions and experiences of transition care and identified five themes: attitudes and posture, better interpersonal relationships and communication between health care providers and patients, need for improved care coordination, availability of resources and accessibility of services, and policy and environmental adaptations. These themes are often both barriers and facilitators that affect the care of older adults in transition. For example, at the individual level, positive beliefs of the older person and coping strategies to address stressors between the individual and the environment are considered valuable; at the interpersonal level, relationship continuity based on trust enhances patient confidence in transition; and at the policy level, competent organizational leaders are important enablers of transition care development. However, there appears to be a disconnect in post-hospital follow-up care support. For example, there is a lack of available medical resources, a lack of clear accountability and incentive systems, and neglected cultural attributes. Among these factors, consistent with the broader international literature, are family caregiver advocacy, care coordination, and relationships between patients and providers (33, 34, 45).

Our study found that patients' personal attributes and posture play an important role in care transitions. Complex emotional responses in older adults are associated with confidence in home care, coping with outcomes, and ongoing health status. This is consistent with studies Hestevik et al. (24) and by Dolu et al. (34), in which older patients are experiencing insecure transitions due to symptoms that have not disappeared after discharge, personal loss of control over their lives, and self-management difficulties, where safety and stress are intertwined in care transitions. Despite the unstructured nature of the home environment, influenced by filial ideology, older chronically ill patients choose to transition at home and struggle to find ways to take control of their lives and coping strategies to stay at home for as long as possible, which is a sign of both positive attitudes and barriers to the use of formal care for older adults. Coping strategies emerge under the influence of personal beliefs, and coping outcomes in turn influence patients' experiences and confidence in care transitions. According to Lazarus, the primary function of coping is to address interpersonal stress and emotional regulation by doing something to address the person's environment, and people who master a sense of control may be better able to cope with their environment and stress. In our study, the coping styles of older patients with chronic illnesses included symptom management according to pre-existing experiences and learning self-care skills, which are positive, problem-oriented coping strategies. This is consistent with Backman et al. (33) and Allen et al. (35) studies, where older adults developed self-management skills by actively adapting health behaviors and skills to better manage their illness. This is a result of the free choice of people with chronic conditions to decide how to live with dignity and cope with their current situation. This has clinical implications in a system that promotes the acquisition of feelings of helplessness and dependency in older adults who use health care services. For example, health care professionals may listen to patients' stories to better understand the personal meaning and different ways that people with chronic illnesses cope with daily life, helping them to identify when their coping style may not be in their best interest or the transitional impairment it causes. Thus, there is a need to see others as "people" rather than as groups and "objective" data, and to be sensitive and responsive and adaptable to their specific personal characteristics in transitional situations.

Patient and family involvement in care is central to global health care. We found that both patients and healthcare providers recognize the value of including family caregivers in the care transition circle, which is consistent with previous studies (46, 47). Prior literature has focused on the need for patients and families to receive information (48), and we also highlight the important role family caregivers play in providing information to healthcare providers, which supports the study by Baxter et al. (21). Family caregivers providing information to medical staff to proactively bridge system gaps is an effective way to support safety and quality of care, especially in a context of dysfunctional communication systems and changing organizational structures (49). Furthermore, in addition to patient and family caregiver efforts in care transitions, health care providers should abandon their paternalistic medical authority style (24), such as the use of professional jargon and distant attitudes when talking (50). Thus, for health care providers, care decisions need to be made based on the background, preferences, and values of older adults (51), which is consistent with the basic principles of patient-centered care (32). Otherwise, care can become authoritarian, invasive and oppressive to the patient, and detrimental to the establishment of a trusting relationship.

Care coordination is an area of current focus for improvement to achieve cross-organizational and cross-professional integration. In our survey, older adults described disruptions in care delivery when transitioning from hospital to home, and disconnects between tertiary hospitals, community-based organizations, and home were associated with the occurrence of adverse events, and medication errors (52, 53). In line with Baxter et al. (21), technology can be used as a way to improve safety during the transition. Therefore the use of relatable information support systems in holistic care is essential to support the seamless transfer of electronic medical records and prior visit records between hospital, community, and home care for care coordination (54). In addition, consistent with previous research, the navigator role needs to be introduced in "siloed" systems as a link between patients, informal caregivers, and health care providers during transitions in the health care system (55). The navigator typically advocates, empowers, motivates, and helps to identify, anticipate, and mitigate barriers that patients encounter during transitions of care, reducing readmission and emergency department return rates (56, 57). However, it is worth noting that whether clinical frontline staff or specialized agency staff navigate care transitions more cost-effectively and economically needs to be further explored.

The imbalance in care resources during the transition from the hospital to the unstructured home and the poor availability of services do not meet the needs of older patients with chronic diseases for home rehabilitation. Previous studies have similarly shown that this unbalanced relationship may affect the successful achievement of established care goals. In China, universal health coverage has been actively pursued after the reform of the healthcare system, but due to the size of the population and geographic distribution, significant differences in healthcare resource availability, staffing, and accessibility of services between urban and rural areas have been identified as barrier factors to transitional care (36). It can be a challenging task for care providers to prioritize their needs and make decisions. Some health care services and medical teams, require patients to travel to the inner city to receive care. And financial subsidies are not available to cover the various non-direct care-related costs that older adults incur to access health care, so there may be additional structural financial barriers to accessing care for older adults living in regional and rural areas. Health systems are the ultimate drivers of care practices for patient populations. In the West, the practice of transitional care is dependent on the appropriate medical resources and health care systems. The Affordable Care Act in the United States (58), the evolution of government-funded outpatient and subacute care models in Australia (59), and the development of the Medicare Trust model in the United Kingdom (60) have made transitional care for older adults cost-effective and cost-efficient. The future Chinese healthcare system may need to consider transitional care for older adults and make appropriate adjustments.

> With the COVID-19 pandemic, limited contact between older adults and their families and healthcare providers has facilitated the widespread use of telemedicine (61, 62). Despite the fact that older adults are largely digitally illiterate, studies have found that older adults find tele-rehabilitation acceptable, improving access to health care (63). This is

especially true when telemedicine offers the possibility of medication reconciliation and regular visits for patients who would not otherwise receive post-discharge follow-up or who have mobility and transportation limitations, as well as frailty. However, the first thing that needs to be addressed are the barriers to acceptability and implementation of telemedicine for older adults in order to improve the achievement of the target system. Otherwise, these digital interventions may not only exacerbate any problems that older people already face when trying to access health and social care services. It could also, in turn, affect the workload of primary care, and health care providers must take greater responsibility for ensuring that this important population receives the care they need (64).

In addition, our findings suggest that effective care transitions require strong leaders in addition to organizational and system changes. This is consistent with previous research that having a person or team within an organization that supports transitional care delivery can be a powerful catalyst for change (65).

Limitation

The study conducted interviews with older patients with chronic conditions and frontline health care providers, and future interviews could be conducted with health system leaders and older family members with chronic conditions about their experiences during the transition from hospital to home care and their perceptions of improving the transition of care process. The final study was limited to one city in central China and cannot be fully transferred to other urban settings; more research is needed to determine the generalizability of the results to develop and formulate patient-centered transitional care interventions.

Conclusion

We explored older adults' and health care providers' perceptions of care transitions with enabling factors including positive personal attributes, coordination of services across organizational settings, effective communication among health care providers, provision of resources, and policies that are compatible with cultural environments. Identifying these barriers and enablers provides an opportunity to improve the complex needs of patient care in a fragmented health care system while maintaining a patient and family focus. This provides strategic options for improving access to care in complex systems.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

This study was approved by the Ethics Committee of Zhengzhou University in China (approval number: ZZUIRB2021-78). The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

MS conceived the study, collected the data, and conceived the first draft. MS and JW developed the interview guide and performed the transcription and data analysis. YQ refined the theme, participated in the writing of some of the first drafts, and was responsible for the revision and finalization of subsequent manuscripts. LL approved the guide. MZ and TX provided support. LL and RR performed quality control of this study and critically revised the manuscript for important intellectual content. All authors have read and approved the final manuscript.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. The Lancet. GBD 2017: a fragile world. *Lancet.* (2018) 392:1683. doi: 10.1016/S0140-6736(18)32858-7

2. Islam MM, Valderas JM, Yen L, Dawda P, Jowsey T, McRae IS. Multimorbidity and comorbidity of chronic diseases among the senior Australians: prevalence and patterns. *PLoS ONE.* (2014) 9:e83783. doi: 10.1371/journal.pone.0083783

3. National Bureau of Statistics. *Bulletin of 7th China National Population Census.* Available online at: http://www.stats.gov.cn.zzulib.vpn358.com/tjsj/tjgb/rkpcgb/qgrkpcgb/202106/t20210628_1818824.html (accessed May 10, 2022).

4. Wang LM, Chen ZH, Zhang M, Zhao ZP, Huang ZJ, Zhang X, et al. [Study of the prevalence and disease burden of chronic disease in the elderly in China]. *Zhonghua Liu Xing Bing Xue Za Zhi.* (2019) 40:277–83. doi: 10.3760/cma.j.issn.0254-6450.2019.03.005

5. Coleman EA, Boult C. Improving the quality of transitional care for persons with complex care needs. *J Am Geriatr Soc.* (2003) 51:556–7. doi: 10.1046/j.1532-5415.2003.51186.x

6. Forster AJ, Murff HJ, Peterson JF, Gandhi TK, Bates DW. The incidence and severity of adverse events affecting patients after discharge from the hospital. *Ann Intern Med.* (2003) 138:161–7. doi: 10.7326/0003-4819-138-3-200302040-00007

7. Tsilimingras D, Schnipper J, Duke A, Agens J, Quintero S, Bellamy G, et al. Post-discharge adverse events among urban and rural patients of an urban community hospital: a prospective cohort study. *J Gen Intern Med.* (2015) 30:1164–71. doi: 10.1007/s11606-015-3260-3

8. Forster AJ, Clark HD, Menard A, Dupuis N, Chernish R, Chandok N, et al. Adverse events among medical patients after discharge from hospital. *CMAJ.* (2004) 170:345–9. doi: 10.1053/cmaj.1040215

9. Hardicre NK, Birks Y, Murray J, Sheard L, Hughes L, Heyhoe J, et al. Partners at care transitions (PACT) -e xploring older peoples' experiences of transitioning from hospital to home in the UK: protocol for an observation and interview study of older people and their families to understand patient experience and involvement in care at transitions. *BMJ Open.* (2017) 7:e018054. doi: 10.1136/bmjopen-2017-018054

10. World Health Organisation. *Transitions of Care: Technical Series on Safer Primary Care*. Geneva: WHO (2016).

11. Digital N. *Hospital Admitted Patient Care Activity, 2015–16*. London: Government Statistical Service, NHS Digital UK (2016).

12. Coleman EA, Mahoney E, Parry C. Assessing the quality of preparation for posthospital care from the patient's perspective: the care transitions measure. *Med Care.* (2005) 43:246–55. doi: 10.1097/00005650-200503000-00007

13. Ring JC, Chao SM. *Performance Measurement: Accelerating Improvement*. Washington, DC: Institute of Medicine (2006).

14. Naylor MD, Brooten DA, Campbell RL, Maislin G, McCauley KM, Schwartz JS. Transitional care of older adults hospitalized with heart failure: a randomized, controlled trial. *J Am Geriatr Soc.* (2004) 52:675–84. doi: 10.1111/j.1532-5415.2004.52202.x

15. Parry C, Min SJ, Chugh A, Chalmers S, Coleman EA. Further application of the care transitions intervention: results of a randomized controlled trial conducted in a fee-for-service setting. *Home Health Care Serv Q.* (2009) 28:84–99. doi: 10.1080/01621420903155924

16. Coleman EA, Parry C, Chalmers S, Min SJ. The care transitions intervention: results of a randomized controlled trial. *Arch Intern Med.* (2006) 166:1822–8. doi: 10.1001/archinte.166.17.1822

17. Hirschman KB, Shaid E, McCauley K, Pauly MV, Naylor MD. Continuity of care: the transitional care model. *Online J Issues Nurs.* (2015) 20:1. doi: 10.3912/OJIN.Vol20No03Man01

18. Hughes AK, Woodward AT, Fritz MC, Swierenga SJ, Freddolino PP, Reeves MJ. Unmet needs of US acute stroke survivors enrolled in a transitional care intervention trial. *J Stroke Cerebrovasc Dis.* (2020) 29:104462. doi: 10.1016/j.jstrokecerebrovasdis.2019.104462

19. Gerson LD, Rose LE. Needs of persons with serious mental illness following discharge from inpatient treatment: patient and family views. *Arch Psychiatr Nurs.* (2012) 26:261–71. doi: 10.1016/j.apnu.2012.02.002

20. World Health Organization. *WHO Global Strategy on People-Centred and Integrated Health Services: Interim Report.* Geneva: World Health Organization (2015).

21. Baxter R, Shannon R, Murray J, O'Hara JK, Sheard L, Cracknell A, et al. Delivering exceptionally safe transitions of care to older people: a qualitative study of multidisciplinary staff perspectives. *BMC Health Serv Res.* (2020) 20:780. doi: 10.1186/s12913-020-05641-4

22. Chen L, Xiao LD, Chamberlain D, Newman P. Enablers and barriers in hospital-to-home transitional care for stroke survivors and caregivers: a systematic review. *J Clin Nurs.* (2021) 30:2786–807. doi: 10.1111/jocn.15807

23. Olsen CF, Debesay J, Bergland A, Bye A, Langaas AG. What matters when asking, "what matters to you?" - Perceptions and experiences of health care providers on involving older people in transitional care. *BMC Health Serv Res.* (2020) 20:317. doi: 10.1186/s12913-020-05150-4

24. Hestevik CH, Molin M, Debesay J, Bergland A, Bye A. Older persons' experiences of adapting to daily life at home after hospital discharge: a qualitative metasummary. *BMC Health Serv Res.* (2019) 19:224. doi: 10.1186/s12913-019-4035-z

25. Shi X, Geng G, Hua J, Cui M, Xiao Y, Xie J. Development of an informational support questionnaire of transitional care for aged patients with chronic disease. *BMJ Open.* (2020) 10:e036573. doi: 10.1136/bmjopen-2019-036573

26. Lima M, Magalhães AMM, Oelke ND, Marques GQ, Lorenzini E, Weber LAF, et al. Care transition strategies in Latin American countries: an integrative review. *Rev Gaucha Enferm.* (2018) 39:e20180119. doi: 10.1590/1983-1447.2018.20180119

27. Hesselink G, Zegers M, Vernooij-Dassen M, Barach P, Kalkman C, Flink M, et al. Improving patient discharge and reducing hospital readmissions by using Intervention Mapping. *BMC Health Serv Res.* (2014) 14:389. doi: 10.1186/1472-6963-14-389

28. Camicia M, Lutz BJ. Nursing's role in successful transitions across settings. *Stroke.* (2016) 47:e246–9. doi: 10.1161/STROKEAHA.116.012095

29. National Bureau of Statistics. *China Health Statistics Yearbook 2019*. Available online at: http://www.stats.gov.cn/sj/ndsj/ (accessed May 19, 2022).

30. Allen J, Hutchinson AM, Brown R, Livingston PM. User experience and care integration in transitional care for older people from hospital to home: a meta-synthesis. *Qual Health Res.* (2017) 27:24–36. doi: 10.1177/1049732316658267

31. Foust JB, Vuckovic N, Henriquez E. Hospital to home health care transition: patient, caregiver, and clinician perspectives. *West J Nurs Res.* (2012) 34:194–212. doi: 10.1177/0193945911400448

32. Kraun L, De Vliegher K, Vandamme M, Holtzheimer E, Ellen M, van Achterberg T. Older peoples' and informal caregivers' experiences, views, and needs in transitional care decision-making: a systematic review. *Int J Nurs Stud.* (2022) 134:104303. doi: 10.1016/j.ijnurstu.2022.104303

33. Backman C, Stacey D, Crick M, Cho-Young D, Marck PB. Use of participatory visual narrative methods to explore older adults' experiences of managing multiple chronic conditions during care transitions. *BMC Health Serv Res.* (2018) 18:482. doi: 10.1186/s12913-018-3292-6

34. Dolu I, Naharci M, Logan PA, Paal P, Vaismoradi M. A qualitative study of older patients' and family caregivers' perspectives of transitional care from hospital to home. *Res Theory Nurs Pract.* (2021) 35:168–88. doi: 10.1891/RTNP-D-20-00067

35. Allen J, Hutchinson AM, Brown R, Livingston PM. User experience and care for older people transitioning from hospital to home: patients' and carers' perspectives. *Health Expect.* (2018) 21:518–27. doi: 10.1111/hex.12646

36. Dolu I, Naharci M, Logan PA, Paal P, Vaismoradi M. Transitional 'hospital to home' care of older patients: healthcare professionals' perspectives. *Scand J Caring Sci.* (2021) 35:871–80. doi: 10.1111/scs.12904

37. Edwards N, Mill J, Kothari AR. Multiple intervention research programs in community health. *Can J Nurs Res.* (2004) 36:40–54.

38. Graham CL, Ivey SL, Neuhauser L. From hospital to home: assessing the transitional care needs of vulnerable seniors. *Gerontologist.* (2009) 49:23–33. doi: 10.1093/geront/gnp005

39. Richard L, Potvin L, Kishchuk N, Prlic H, Green L. Assessment of the integration of the ecological apporach in health promotion programs. *Am J Health Promot.* (1996) 10:318–28. doi: 10.4278/0890-1171-10.4.318

40. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* (2006) 3:77–101. doi: 10.1191/1478088706qp063oa

41. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* (2005) 15:1277–88. doi: 10.1177/1049732305276687

42. Vaismoradi M, Jones J, Turunen H, Snelgrove S. Theme development in qualitative content analysis and thematic analysis. *J Nurs Educ Pract.* (2016) 6:100–10. doi: 10.5430/jnep.v6n5p100

43. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* (2007) 19:349–57. doi: 10.1093/intqhc/mzm042

44. Lin S, Wang C, Wang Q, Xie S, Tu Q, Zhang H, et al. The experience of stroke survivors and caregivers during hospital-to-home transitional care: a qualitative longitudinal study. *Int J Nurs Stud.* (2022) 130:104213. doi: 10.1016/j.ijnurstu.2022.104213

45. Stolee P, Elliott J, Byrne K, Sims-Gould J, Tong C, Chesworth B, et al. A framework for supporting post-acute care transitions of older patients with hip fracture. *J Am Med Dir Assoc.* (2019) 20:414–9.e1. doi: 10.1016/j.jamda.2019.01.147

46. Ward-Griffin C, McKeever P. Relationships between nurses and family caregivers: partners in care? *ANS Adv Nurs Sci.* (2000) 22:89–103. doi: 10.1097/00012272-200003000-00008

47. Backman C, Cho-Young D. Engaging patients and informal caregivers to improve safety and facilitate person- and family-centered care during transitions from hospital to home - a qualitative descriptive study. *Patient Prefer Adherence.* (2019) 13:617–26. doi: 10.2147/PPA.S201054

48. Glenny C, Stolee P, Sheiban L, Jaglal S. Communicating during care transitions for older hip fracture patients: family caregiver and health care provider's perspectives. *Int J Integr Care.* (2013) 13:e044. doi: 10.5334/ijic.1076

49. O'Hara JK, Aase K, Waring J. Scaffolding our systems? Patients and families 'reaching in' as a source of healthcare resilience. *BMJ Qual Saf.* (2019) 28:3–6. doi: 10.1136/bmjqs-2018-008216

50. Perry MA, Hudson S, Ardis K. "If I didn't have anybody, what would I have done?": experiences of older adults and their discharge home after lower limb orthopaedic surgery. *J Rehabil Med.* (2011) 43:916–22. doi: 10.2340/16501977-0874

51. Hvalvik S, Reierson I. Striving to maintain a dignified life for the patient in transition: next of kin's experiences during the transition process of an older person in transition from hospital to home. *Int J Qual Stud Health Well-being.* (2015) 10:26554. doi: 10.3402/qhw.v10.26554

52. Coleman EA. Falling through the cracks: challenges and opportunities for improving transitional care for persons with continuous complex care needs. *J Am Geriatr Soc.* (2003) 51:549–55. doi: 10.1046/j.1532-5415.2003.51185.x

53. Davis MM, Devoe M, Kansagara D, Nicolaidis C. Englander H. "Did I do as best as the system would let me?" Healthcare professional views on hospital to

home care transitions. *J Gen Intern Med.* (2012) 27:1649–56. doi: 10.1007/s11606-012-2169-3

54. Shannon B, Shannon H, Bowles KA, Williams C, Andrew N, Morphet J. Health professionals' experience of implementing and delivering a 'Community Care' programme in metropolitan Melbourne: a qualitative reflexive thematic analysis. *BMJ Open.* (2022) 12:e062437. doi: 10.1136/bmjopen-2022-062437

55. Toscan J, Mairs K, Hinton S, Stolee P. Integrated transitional care: patient, informal caregiver and health care provider perspectives on care transitions for older persons with hip fracture. *Int J Integr Care.* (2012) 12:e13. doi: 10.5334/ijic.797

56. Manderson B, McMurray J, Piraino E, Stolee P. Navigation roles support chronically ill older adults through healthcare transitions: a systematic review of the literature. *Health Soc Care Community.* (2012) 20:113–27. doi: 10.1111/j.1365-2524.2011.01032.x

57. Kokorelias KM, Shiers-Hanley JE, Rios J, Knoepfli A, Hitzig SL. Factors influencing the implementation of patient navigation programs for adults with complex needs: a scoping review of the literature. *Health Serv Insights.* (2021) 14:11786329211033267. doi: 10.1177/11786329211033267

58. Naylor MD, Aiken LH, Kurtzman ET, Olds DM, Hirschman KB. The care span: the importance of transitional care in achieving health reform. *Health Aff.* (2011) 30:746–54. doi: 10.1377/hlthaff.2011.0041

59. Australian Government Department of Health. *Transition Care Programme Guidelines*. Available online at: https://www.health.gov.au/resources/publications/transition-care-programme-guidelines (accessed January 19, 2022).

60. Winfield A, Burns E. Let's all get home safely: a commentary on NICE and SCIE guidelines (NG27) transition between inpatient hospital settings and community or care home settings. *Age Ageing.* (2016) 45:757–60. doi: 10.1093/ageing/afw151

61. Rupa J, Laver K, Harvey G, McNamara C, Crotty M, Lynch EA, et al. 'plethora of services' but a lack of consistency: a qualitative study of service providers' perspectives about transitioning from hospital to home for older South Australians. *Australas J Ageing.* (2022) 41:e371–e8. doi: 10.1111/ajag.13080

62. Smolić Š, Blaževski N, Fabijančić M. Remote healthcare during the COVID-19 pandemic: findings for older adults in 27 european countries and Israel. *Front Public Health.* (2022) 10:921379. doi: 10.3389/fpubh.2022.921379

63. Murukesu RR, Singh DKA, Shahar S, Subramaniam P. Physical activity patterns, psychosocial well-being and coping strategies among older persons with cognitive frailty of the "WE-RISE" trial throughout the COVID-19 movement control order. *Clin Interv Aging.* (2021) 16:415–29. doi: 10.2147/CIA.S290851

64. Kunonga TP, Spiers GF, Beyer FR, Hanratty B, Boulton E, Hall A, et al. Effects of digital technologies on older people's access to health and social care: umbrella review. *J Med Internet Res.* (2021) 23:e25887. doi: 10.2196/25887

65. Shortell SM, Zukoski AP, Alexander JA, Bazzoli GJ, Conrad DA, Hasnain-Wynia R, et al. Evaluating partnerships for community health improvement: tracking the footprints. *J Health Polit Policy Law.* (2002) 27:49–91. doi: 10.1215/03616878-27-1-49

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The Death Literacy Index: translation, cultural adaptation, and validation of the Chinese version

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Objective: Applying public health approaches to address palliative care allows for a broader perspective. The Death Literacy Index (DLI) is a novel instrument designed to assess the knowledge and skills required to access, comprehend, and make informed decisions regarding end-of-life care. Translation of the DLI could strengthen the capacity to build desirable services and policies regarding dying and death. It could also help to identify the barriers to services and future advocacy efforts.

Methods: The DLI was forward translated into Chinese and backward translated through two panels. Two rounds of cognitive interviews and a pilot test were conducted before the survey. A sample of 3,221 participants was recruited via an online survey in five cities in southern China (Guangzhou, Zhuhai, Jiangmen, Hong Kong and Macao) to evaluate the factor structure, validity and reliability of the translated DLI. Additionally, multi-group confirmatory factor analyses (MGCFA) were performed to examine measurement invariance across genders and the experiences of parental death.

Results: Exploratory factor analysis showed a six-factor structure for the translated DLI, and confirmatory factor analysis confirmed the structure. The overall scale and subscales had high internal consistency and satisfactory validity. The results from MGCFA showed that death literacy was adequately invariant for different genders and experiences of parental death.

Conclusion: The Chinese DLI is a reliable and valid instrument for measuring death literacy among people in southern China, and therefore can be used for both research and community practice.

KEYWORDS

death literacy, Death Literacy Index, validity, reliability, factor analysis

1. Introduction

In addition to social systems such as health and education, death has a unique system of its own. Kastenbaum initially proposed the concept of the death system in 1977. It consists of five elements: people, places, times, objects, and symbols (1). It is common to consider death and dying as the end result of medical intervention, which involves the dying person, his or her family, medical personnel, the hospital and those responsible for handling the after-death arrangements. Through aggressive and sometimes futile treatments, dying has become medicalized part of the public sphere. In particular, dying is mostly categorized as a matter of concern in the healthcare sector. Palliative care has been endorsed as a means of combating the medicalization of dying and ensuring dignity for the dying (2). Kellehear connected palliative care to public health (3), enabling the possibility of a health promotion approach to dying. In such health promotion discourses, people who are dying have the right and responsibility to control their treatments and information acquisition, which are often delegated to their family (4, 5). The World Health Organization (WHO) also recognized the importance of integrating palliative care into public health systems (6). People who are dying, healthcare professionals with different specialties, and the entire community are connected to death and dying with strong social ties. For instance, health care is provided to the dying person by professionals according to the person's values and preferences, and to help the family cope with challenges associated with the end of life. The dying process may happen at home if it is the preference of the dying person. In that case, a person's social network is also changed.

The aging population is increasing rapidly around the globe (7). This results in an increased number of deaths and rising demand for palliative care services (8, 9). However, Chinese society faces a number of barriers with regard to end-of-life care as well as public awareness of end-of-life care, including inadequate educational and clinical resources and, lack of support from the national health system (10). The quality of death in China ranks low compared with other countries (11). Although the concept of palliative care was introduced in mainland China in the 1990s, its development has been very slow (12). In 2017, National Health and Family Planning Commission issued guidelines on hospice care and piloted the service in some regions for 2 years (13). This was a milestone in promoting the development of hospice care in mainland China at the policy level. However, healthcare professionals have low awareness regarding end-of-life care and inadequate skills and knowledge to provide such care (14). Although 87% of older adults in China died at home over the past 20 years (15), the general public in China is relatively unaware of end-of-life care. In a survey investigating the awareness of palliative care, approximately 90% of respondents had no prior knowledge of the service (10). Almost 90% of older adults received care from family members rather than professional caregiver before death, and 40% of them died in pain (15). This reflects a significant blank of community end-of-life services, and showed a considerable gap in China to achieve the goal of high-quality death. With limited resources and a rapidly growing aging population, the public's need for end-of-life care is expected to increase.

In contrast, Hong Kong has the longest history of palliative care and offers the most comprehensive end-of-life care in China (16). Its quality of death ranks 22nd among 80 countries (11). In spite of this, Hong Kong faces a number of barriers to palliative care development, including barriers related to politics, economics, sociocultural issues, technological advancements, environmental, and legal issues (17, 18). Although over 30% of Hong Kong people preferred to die at home, over 90% death happened in hospitals (19). In terms of service targets, local palliative care services are limited to patients with cancer, end-stage renal disease, chronic obstructive pulmonary disease, advanced heart failure, and neurological disorders. This disease-oriented palliative care policy results in fragmented services and poor collaboration between hospitals and communities, and between the medical and social sectors (17, 20). Consequently, such policies inhibit the capacity of clinical service delivery as well as public awareness of needs and preferences in terms of these services. Clinicians therefore continue to advocate for the government to develop palliative care policy that is locally appropriate (16).

Macao is still in the early stages of developing end-of-life care. While the first palliative care unit was established in Macao in 2000 with 20 beds to provide care for terminal cancer patients and their families, only 35 hospice beds have been added since then (21, 22). However, the demand for palliative care services outweighs the supply, as evidenced by the number of deaths per year increasing 1.7 times, from 1,338 to 2,320, between 2000 and 2021 (23, 24). In terms of policy regarding end-of-life care and death, the Macao SAR government implemented a 10-year action plan for services for older adults in 2016 (25). While end-of-life care was mentioned in the action plan, only brief references were made regarding strengthening education to raise awareness and expand end-of-life services. Moreover, there is no report of the effectiveness, nor is there any baseline data of the action plan that would help to explain what society's current status is. This raises questions about whether the services provided are adequate and meet the needs of the public. The provision of palliative care in Macao is only available in inpatient setting (21). However, a considerable amount of people would like to be cared at home during the end of life (26). While end-of-life care is included in the government's healthcare agenda, primarily through education and inpatient palliative care, there is a significant gap between the needs of the public and existing services.

As with health literacy, Leonard et al. (27) stated that "death literacy is the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and death care options". Death involves an extensive public health system that is often overlooked as merely a result of medical treatments. The development of services that meet the needs of citizens requires a comprehensive understanding of the current situation. Through the lens of public health, death literacy plays an important role in policy and service development. On the one hand, the level of death literacy of community residents can specifically reflect the level of relevant knowledge as well as the presence of community services that can provide specific guidance for public policy development. On the other hand, death literacy is shaped by personal experiences of interaction with end-of-life care services. Therefore, the promotion of death literacy requires proactive engagement from every sector (28). A measurement tool for death literacy that is applicable to China is urgently needed.

The Death Literacy Index (DLI) was developed to measure the death literacy among the general public in communities or countries, and to provide insight into further intervention development (29). It can inform the healthcare system about education, service provision, and community development to provide support for people who are dying and their families. The DLI is a novel instrument and has only been evaluated in Australia, Turkey, the UK and Sweden (29–32). In the original development (29), the 29-item DLI was identified as having a four-factor structure; two of these factors contained two subscales, resulting in six subscales. All subsequent studies also identified 6 factors that had good internal consistency with the overall scale

(Cronbach's alpha = 0.90–0.94) and subscales (Cronbach's alpha = 0.68–0.94) (30–32).

Since the DLI was designed for intervention assessment, it can be used to compare changes before and after the development of the death system, and the public's awareness of death-related information and services (27). It may also assist in identifying barriers to the provision of death services and in developing future advocacy strategies. The Greater Bay Area of China is being promoted by the Chinese government with the aims of facilitating interaction and communication in daily life, and collaboration in economic development in Guangdong Province, Hong Kong, and Macao. Therefore, the objective of this study was to translate the DLI into Chinese and evaluate its applicability in southern Chinese sociocultural contexts, including Macao SAR, Hong Kong SAR, Guangzhou, Zhuhai, and Jiangmen. These cities of southern China share a similar historical and cultural context but have different levels of economic and medical service development. The applicability of the DLI in cities with disparities in medical service accessibility can also be observed.

2. Methods

2.1. Study design

Using a cross-sectional online survey design, this study recruited residents from five cities in southern China, including Macao, Hong Kong, Guangzhou, Zhuhai, and Jiangmen.

2.2. Translation and cultural adaptation of the DLI

The DLI includes four subscales with 29 items in total. The four subscales are practical knowledge, experiential knowledge, factual knowledge, and community knowledge. All items are measured on a five-point Likert scale. A person's practical knowledge refers to the perception of how well he or she can communicate with friends and family about death. This subscale comprises 8 items that include talking support and hands on support (1 point = not at all able, 5 points = very able). The experiential knowledge subscale measures a person's wisdom and skills gained from direct experiences with caring for someone at the end-of-life or death education. Participants were asked to recall their previous loss experience with 5 items (1 point = very untrue of me, 5 points = very true of me). The factual knowledge subscale assesses the understanding of the death system and information required for good planning for the end of one's life using 7 items (1 point = strongly disagree, 5 points = strongly agree). There are 9 items in the community knowledge subscale, which measures a person's knowledge of accessing support for people who are dying and their caregivers (1 point = strongly disagree, 5 points = strongly agree). There are no reverse-coded items. Scores are calculated by summing items and scaling the number of items in a subscale (with a range of scores between 0 and 10). Authorization to its use was obtained from the authors.

The translation process of the DLI followed WHO translation guidelines (33), including forward translation, expert panel back-translation, pretesting and cognitive interviewing. Forward translation was conducted by two independent, bilingual, fluent Cantonese and English local translators. The translators were instructed to use plain and conceptually equivalent language to translate. After forward translation, a panel was convened to discuss the differences between the two translations and between the translators and the research team, and a consensus was reached. Panel members included the two translators, the principal investigator (WIN), and three other research members (SLC, XL, and MZ). During the panel, there were discussions about cultural applicability regarding specific words, such as "emotional strength" in Item 9, "compassionate" in Item 12, and "cemetery staff" in Item 20. All disagreements were resolved during the panel. The members decided to change "cemetery staff" to "cemetery/funeral staff". Most deceased persons are not currently buried in a cemetery, but are kept in a shrine after cremation. Additionally, "culturally appropriate support" in Item 24 was modified to "support in line with Chinese culture". In addition, Hong Kong and Macao use traditional Chinese, while mainland China uses simplified Chinese. Therefore, two different versions of the questionnaire were used. Furthermore, the word "quality" used in Mainland China and in Hong Kong and Macao is different, so we applied the equivalent words in traditional and simplified Chinese versions. After the translated version was finalized, two other translators were invited to conduct back-translation using the same approach as forward translation.

Cognitive interviews were used to identify phrases or terms that could lead to ambiguity (34). Two rounds of cognitive interviews were conducted in October 2022 after the translated DLI was finalized, with 10 participants in each round. The cognitive interviewees were recruited through acquaintances of the research team, to ensure the diversity of the participants. The inclusion criteria for the cognitive interviews were Chinese individuals aged 18–74 years who lived in Macao, Hong Kong, Guangzhou, Zhuhai, or Jiangmen. The recruited participants had diverse backgrounds, included both males and females, and of different ages, education levels and occupations. In practice, the research team members held a consensus meeting regarding the interview protocol before the interviews, to agree on the interview outline and to align the cues for follow-up questions. Individual interviews were performed by the research team for each participant. The interviews began with the collection of basic demographic information. Concurrent verbal probing was administered following the interview guide which created by the research team (35). Participants were asked to verbally describe their interpretation after they answered each item. When the interviewee's description differs from the original intention of the item, it will be recorded on paper along with the suggestions for modification. Modification of the items was made before the second round of cognitive interviews that took into account the feedback from the first round. Interview protocol was not adjusted after the first round.

The cognitive interviews resulted in the modification of words on Items 11, 15, 19, and 20. In Item 11, the word "developed" was changed to "increased" because participants stated that wisdom cannot be developed. In Item 15, participants suggested that "planning" should be changed to "preparing" because "planning for death" might remind people of "planning for suicide" in the context of the Chinese language. In Item 19, participants found it difficult to connect "illness trajectory" at the beginning and "quality of end of life" at the end since not all illnesses are life-threatening. A conditional sentence was therefore added to indicate the situation of being seriously ill. In Item 20, the participants' opinion was that the word "contribution" implied too much credit, so it was changed to "help" (Supplementary material 1 provides the original and Chinese version).

After the cognitive interviews, the research team conducted a pilot test to examine the feasibility of the translated DLI and to identify possible alternative expressions in the Chinese population. A minimum sample size of 30 from the population of interest is generally recommended for a pilot study (36). Participants were purposively recruited in the five cities through acquaintances of the research team. Fifty-three participants aged 22–74 years (41.0 ± 15.0) were recruited in the pilot test. Cronbach's alpha of the translated DLI was 0.88 for the total scale. The final translated version of the DLI contained the same number of items as the original version.

2.3. Questionnaire and participant recruitment

Survey data were collected using a structured online questionnaire. The questionnaire contained the translated DLI and sociodemographic characteristics of participants, including their age, gender, level of education, marital status, religious beliefs, occupation, whether they had children and siblings, and whether their parents were alive.

Inclusion criteria were people who were residing in the abovementioned five cities at the time of the survey implementation and who identified themselves as Chinese, were aged 18–74, were able to give consent and understood written Chinese. Participant recruitment and data collection were conducted from October to November 2022. A sample size of ten respondents was calculated for each item in the DLI (37). Therefore, the target number of recruitments was at least 290 participants. Convenience and snowball sampling methods were applied via online advertisements and social media platforms. Posters with traditional and simplified Chinese, a short description of the study, and the link to the questionnaire were distributed to various local social service organizations and colleges via social media platforms such as Facebook, WhatsApp and WeChat. Potential participants could click on the link to provide informed consent and proceed with the questionnaire. After completing the questionnaire, participants were encouraged to distribute the study information to their friends and others who were interested.

2.4. Statistical analysis and scale evaluation

Raw data were coded using Microsoft Office Excel 2013, confirmatory factor analysis (CFA) was performed using Amos (version 22.0), and Statistical Package for the Social Sciences Version 22 (SPSS, version 22) was utilized for data manipulation and other analyses. Analyses were restricted to respondents who completed the full questionnaire ($n = 3{,}221$). The threshold for statistical significance was set to $p < 0.05$.

All demographic characteristics were categorized and were calculated as frequencies and percentages. Item analysis was conducted to examine the quality of the DLI items. A distribution analysis was conducted to determine interpretability (median, range, interquartile range). To discriminate participants with the

TABLE 1 Socio-demographic characteristics ($n = 3{,}221$).

Variable	*n*	%
Gender		
Male	671	20.8
Female	2,550	79.2
Age (year)		
18–34	2,338	72.6
35–54	734	22.8
55–74	149	4.6
Education level		
Primary school or below	36	1.1
Secondary school	257	8.0
College or above	2,928	90.9
Marital status		
Not married	2,124	65.9
Married/cohabited	996	30.9
Separated/divorced	82	2.5
Widowed	19	0.6
Children		
Yes	909	28.2
No	2,312	71.8
Siblings		
Yes	2,636	81.8
No	585	18.2
Religious beliefs		
Yes	867	26.9
No	2,354	73.1
Occupation		
Medical (assistant) professional	767	23.8
Student	1,702	52.8
Other	587	18.2
Not employed	165	5.1
Experience of parental death		
Both parents alive	2,616	81.2
At least one parent died/ don't know	605	18.8

TABLE 2 Item analysis of the translated DLI ($n = 3,221$).

Item	Mean	SD	Skewness	Item discrimination	Cronbach's α if item deleted	Corrected item-total correlation coefficients
1. Talk about death, dying or grieving to a close friend	7.5	2.35	−1.13	-17.66^{***}	0.94	0.34
2. Talk about death, dying or grieving to a child	6.9	2.63	−0.86	-21.07^{***}	0.94	0.36
3. Talk to a newly bereaved person about their loss	5.0	3.15	−0.04	-24.43^{***}	0.94	0.34
4. Talk to a GP about support at home or in their place of care for a dying person	7.5	2.26	−1.13	-18.25^{***}	0.94	0.35
5. Feeding a person or assisting them to eat	8.3	1.81	−1.22	-16.92^{***}	0.94	0.38
6. Bathing a person	7.6	2.26	−1.03	-22.31^{***}	0.94	0.41
7. Lifting a person or assisting to transfer them	8.0	2.02	−1.21	-19.57^{***}	0.94	0.41
8. Administering injections	7.2	2.74	−0.97	-22.55^{***}	0.94	0.39
9. Increased my emotional strength to help others with death and dying processes	7.2	2.20	−0.85	-30.51^{***}	0.94	0.57
10. Led me to re-evaluate what is important and not important in life	7.6	2.01	−0.97	-23.26^{***}	0.94	0.48
11. Increased my wisdom and understanding	7.5	2.05	−0.91	-28.43^{***}	0.94	0.55
12. Made me more compassionate toward myself	7.6	2.03	−0.97	-26.78^{***}	0.94	0.54
13. Provided me with skills and strategies when facing similar challenges in the future	7.4	2.08	−0.88	-30.19^{***}	0.94	0.58
14. I know the law regarding dying at home	5.6	2.74	−0.30	-45.40^{***}	0.94	0.64
15. I feel confident in knowing what documents you need to complete in preparing for death	5.8	2.73	−0.40	-46.63^{***}	0.94	0.66
16. I know how to navigate the health care system to support a dying person to receive care	6.5	2.56	−0.75	-46.40^{***}	0.94	0.70
17. I know how to navigate funeral services and options	6.2	2.66	−0.57	-46.98^{***}	0.94	0.68
18. I know how to access palliative care in my area	6.0	2.70	−0.48	-49.64^{***}	0.94	0.69
19. When I am seriously ill, I have sufficient understanding of illness trajectories to make informed decisions around medical treatments available and how that will shape quality of end of life	7.1	2.28	−0.98	-31.40^{***}	0.94	0.59
20. I know what the cemetery staff/ funeral staff can help at end of life	6.7	2.40	−0.86	-38.57^{***}	0.94	0.66
21. Access community support	6.2	2.60	−0.56	-58.02^{***}	0.94	0.75
22. Provide day to day care for the dying person	6.3	2.55	−0.66	-53.96^{***}	0.94	0.74
23. Access equipment required for care	6.3	2.57	−0.62	-54.70^{***}	0.94	0.75
24. Access appropriate support in line with Chinese culture	6.2	2.60	−0.57	-52.33^{***}	0.94	0.72
25. Access emotional support for myself	6.5	2.46	−0.77	-45.98^{***}	0.94	0.72
26. People with life threatening illnesses	6.2	2.62	−0.64	-44.56^{***}	0.94	0.67
27. People who are dying	6.2	2.64	−0.62	-44.67^{***}	0.94	0.66
28. Carers for people who are dying	6.2	2.65	−0.62	-44.17^{***}	0.94	0.66
29. People who are grieving	6.2	2.64	−0.61	-42.76^{***}	0.94	0.65
Total DLI	6.7				0.94	

$^{***}p < 0.001$.

All items ranged 0–10.

TABLE 3 Distribution analysis of the translated DLI ($n = 3{,}221$).

Subscales	Mean (SD)	Median	IQR	Floor and ceiling effect	
				Lowest possible total score n (%)	Highest possible total score n (%)
Practical knowledge	7.25 (1.58)	7.50	1.88	10 (0.3%)	175 (5.4%)
Talking support	6.73 (1.99)	7.50	1.88	35 (1.1%)	272 (8.4%)
Doing hands on care	7.78 (1.86)	7.50	2.50	20 (0.6%)	792 (24.6%)
Experiential knowledge	7.45 (1.79)	7.50	2.00	17 (0.5%)	526 (16.3%)
Factual knowledge	6.27 (2.07)	6.79	2.50	24 (0.7%)	205 (6.4%)
Community knowledge	6.26 (2.26)	7.50	2.50	43 (1.3%)	242 (7.5%)
Accessing help	6.29 (2.36)	7.50	2.50	67 (2.1%)	293 (9.1%)
Support groups	6.21 (2.54)	7.50	2.50	109 (3.4%)	341 (10.6%)
DLI total	6.74 (1.50)	6.90	1.81	5 (0.2%)	80 (2.5%)

SD, Standard deviation; IQR, interquartile range.
All items ranged 0–10.

TABLE 4 Correlation matrix of six-factor translated DLI ($n = 3{,}221$).

	F1	F2	F3	F4	F5	F6
F1: Talking support	1					
F2: Doing hands on care	0.35**	1				
F3: Experiential Knowledge	0.47**	0.47**	1			
F4: Factual Knowledge	0.32**	0.29**	0.44**	1		
F5: Accessing help	0.19**	0.22**	0.35**	0.73**	1	
F6: Support groups	0.10**	0.17**	0.25**	0.59**	0.72**	1

**$p < 0.01$.

highest or lowest possible score for the item, floor and ceiling effects were evaluated, which indicated whether 15% of respondents scored the lowest or highest possible (38, 39).

Exploratory factor analysis (EFA) was implemented to test dimensionality and internal consistency, and CFA was used to confirm whether the factor structure of the translated DLI matched the EFA results. The dimensionality of EFA was set to extract factors with eigenvalues > 1 using principal component analysis (PCA) with varimax rotation. Rotated factor loadings loaded on the primary factor > 0.4 were considered satisfactory (40). Parallel analysis (PA) was performed to compare the eigenvalues. To assess the suitability of the data for factor analysis, Kaiser-Meyer-Olkin (KMO) measurement and Bartlett's test of sphericity were used. The dataset was considered appropriate for PCA when KMO was over 0.70 and Bartlett's test of sphericity was significant ($p < 0.05$) (37). The internal consistency was examined by Cronbach's alpha and McDonald's omega, and composite reliability (CR) and average of variance extracted (AVE) were examined to confirm discriminant and convergent validity. Model with CR > 0.7 and AVE > 0.5 were considered adequate (41).

Regarding CFA, the goodness of fit and acceptability of the model were assessed by indicators such as the comparative fit index (CFI), goodness-of-fit index (GFI), non-norm-fitting index (Tucker-Lewis Index, TLI), root mean square error of approximation (RMSEA), and standardized root mean square residual (SRMR). The model was considered to have reasonable fit and acceptability if the CFI > 0.9, GFI > 0.9, TLI > 0.9, RMSEA < 0.08, and SRMR < 0.09, using the maximum-likelihood method (42). Studies have reported that there are differences in death anxiety and coping strategies between genders and whether the individuals have had loss experiences (43, 44). Also, the research team assumed that with the experience of parental death, the individual would have more interaction with community services and health system regarding end-of-life care. Therefore, after the measurement model was confirmed, multi-group confirmatory factor analysis (MGCFA) was performed to investigate validity across different genders and experiences with parental death. Three levels of measurement invariance were tested, i.e., configural measurement invariance, metric invariance, and scalar measurement. If the changes in CFI (ΔCFI), TLI (ΔTLI), RMSEA (ΔRMSEA) and SRMR (ΔSRMR) were <0.01, the model was considered acceptable (45).

2.5. Ethical approval

Ethical approval for the study was granted by the Research Management and Development Department of Kiang Wu Nursing College of Macau (reference: 2021DEC02). All participants were informed about the purpose of the study and their right to withdraw from the study at any time. Informed consent was obtained from all participants who agreed to participate.

3. Results

3.1. Participant characteristics

There were 3,221 valid responses in the questionnaire survey study. The majority were female (79.2%) and, aged 18 to 34 (72.6%) with a mean age of 28.3 ± 12.4 years (range 18–74). Most of them were students (52.8%), had an education level of college or

TABLE 5 Exploratory factor analysis and convergent validity of the six-factor translated DLI (*n* = 3,221)*.

	Factor Loading						Communalities
	F1	F2	F3	F4	F5	F6	
15. I feel confident in knowing what documents you need to complete in preparing for death	0.80						0.75
17. I know how to navigate funeral services and options	0.79						0.75
14. I know the law regarding dying at home	0.74						0.69
16. I know how to navigate the health care system to support a dying person to receive care	0.72						0.70
18. I know how to access palliative care in my area	0.69						0.68
20. I know what the cemetery staff/ funeral staff can help at end of life	0.54						0.55
19. When I am seriously ill, I have sufficient understanding of illness trajectories to make informed decisions around medical treatments available and how that will shape quality of end of life	0.53						0.49
27. People who are dying		0.88					0.94
28. Carers for people who are dying		0.88					0.94
26. People with life threatening illnesses		0.86					0.91
29. People who are grieving		0.85					0.90
22. Provide day to day care for the dying person			0.77				0.87
23. Access equipment required for care			0.77				0.88
24. Access appropriate support in line with Chinese culture			0.76				0.85
25. Access emotional support for myself			0.75				0.80
21. Access community support	0.41		0.71				0.83
11. Increased my life wisdom and understanding				0.85			0.81
12. Made me more compassionate toward myself				0.84			0.79
13. Provided me with skills and strategies when facing similar challenges in the future				0.82			0.79
10. Led me to re-evaluate what is important and not important in life				0.77			0.70
9. Increased my emotional strength to help others with death and dying processes				0.72			0.67
7. Lifting a person or assisting to transfer them					0.85		0.80
5. Feeding a person or assisting them to eat					0.83		0.80
6. Bathing a person					0.81		0.71
8. Administering injections					0.72		0.59
2. Talk about death, dying or grieving to a child						0.82	0.73
1. Talk about death, dying or grieving to a close friend						0.79	0.71
4. Talk to a GP about support at home or in their place of care for a dying person						0.70	0.63
3. Talk to a newly bereaved person about their loss						0.60	0.49
Eigenvalues	4.61	3.97	3.84	3.83	3.03	2.45	
% of Variance	15.91	13.69	13.25	13.21	10.44	8.44	
% of Cumulative Variance	15.91	29.60	42.85	56.05	66.49	74.93	
Cronbach's alpha (α)/ McDonald's omega (ω)	0.91/0.91	0.97/0.97	0.96/0.96	0.91/0.91	0.85/0.85	0.76/0.76	0.94/0.94
Construct Reliability (CR)	0.91	0.97	0.96	0.92	0.87	0.79	0.98
Average of variance extracted (AVE)	0.58	0.90	0.81	0.69	0.63	0.49	0.68

*Only loadings ≥ 0.40 in the items are shown in the table.

F1, Factual Knowledge; F2, Community support group; F3, Accessing help; F4, Experiential Knowledge; F5, Hands on support; F6, Talking support.

TABLE 6 Confirmatory factor analysis between full sample and sub-groups.

	CFI	GFI	TLI	RMSEA (90% CI)	SRMR
Full sample ($n = 3{,}221$)	0.956	0.915	0.952	0.055 (0.053, 0.056)	0.0531
Male ($n = 671$)	0.937	0.864	0.931	0.066 (0.063, 0.070)	0.0650
Female ($n = 2{,}550$)	0.954	0.910	0.949	0.056 (0.054, 0.058)	0.0522
Both parents alive ($n = 2{,}616$)	0.957	0.912	0.953	0.055 (0.053, 0.057)	0.0554
At least one parent died/ don't know (n=605)	0.931	0.872	0.924	0.064 (0.060, 0.068)	0.0583

above (90.9), were not married (65.9%), and had siblings (81.8%) but did not have children (71.8%) or religious belief (73.1%) (Table 1).

3.2. Item and distribution analysis

The item discrimination test showed positive discrimination for all of the items (46) (Table 2). The result of distribution analysis showed that the mean score of each subscale and the DLI total mean score represented the possible ranges. Applying the criterion of 15% of participants scoring the lowest or highest possible score, the DLI total mean score did not show any floor or ceiling effects. In terms of subscales, a ceiling effect was demonstrated in the "doing hands on care" and "experiential knowledge" subscales, with over 15% of participants obtaining the highest possible score (Table 3).

3.3. Exploratory factor analysis

The KMO was 0.948, and Bartlett's test of sphericity was significant ($\chi^2_{406} = 80{,}632.31$; $p < 0.001$), suggesting that the matrix was suitable for factor extraction. PA suggested five factors, instead of six factors in the original development and later adaptation studies. However, all of the items in the "support groups" subscale (Items 21–25) showed cross-loading on "factual knowledge" and on "community knowledge". It has been reported that the result of PA may not be satisfactory when factors are highly correlated (47). Correlation analysis was then performed on all six subscales and showed that "accessing help" had strong correlation with "support groups" and "factual knowledge" (Table 4). Additionally, the CFA of the five-factor structure suggested that it was a poor-fitting model [$\chi^2_{367} = 15{,}015.058$ ($p < 0.001$), CFI = 0.818, GFI = 0.656, TLI = 0.801, RMSEA = 0.111, SRMR = 0.111]. Therefore, the research team continued the subsequent analysis using the six-factor structure.

In the six-factor structure, Item 21 "access community support" loaded at 0.41 on the "factual knowledge" and "accessing help" factors. The research team decided to keep it on "accessing help" since it had stronger loading on "accessing help". The items accounted for a cumulative variance of 74.93%. The overall Cronbach's alpha coefficient of the translated DLI was 0.94, while the subscales were 0.76–0.97, with similar results of Omega coefficients, suggesting good internal consistency (Table 5).

3.4. Confirmatory factor analysis

In the CFA results, the model fit for the six-factor structure of the translated DLI was as follows: $\chi^2_{367} = 3{,}889.860$ ($p < 0.001$), CFI = 0.956, GFI = 0.915, TLI = 0.952, RMSEA = 0.055 (90% C.I. = 0.053–0.056) and SRMR = 0.0513 (Table 6). All scales had CR > 0.7 and AVE > 0.4, indicating adequate discriminant and convergent validity. The factor loading of the items in CFA ranged from 0.44 to 0.97. The path diagram for the CFA model is shown in Figure 1. In MGCFA, the results showed good fit in the values of CFI, TLI, RMSEA and SRMR for both comparisons of gender and experience of parental death (Table 7).

4. Discussion

The Chinese version of the DLI demonstrated a satisfactory measure of validity and reliability for assessing the Chinese general public living in southern China. To our knowledge, this is the first study to validate the DLI in Asia and to translate the DLI into Chinese. Another validation effort is underway in northern China (Beijing).

The lowest loading items were informed decisions (Item 19), cemetery staff (Item 20), and talking to newly bereaved (Item 3). The low homogeneity of the results on the informed decisions item suggested that people may be less aware of the importance of the illness trajectory, which may be the focus of future education. In the translation process, "funeral workers" was added to the cemetery staff item, and "help" rather than "contribution" was suggested in cognitive interviews. Funeral practitioners have been stigmatized and marginalized in Chinese culture (48), and after-death rituals are diversified between ethnic groups. Therefore, people might have different impressions of the contribution and benefits of bereavement outcomes that funeral practitioners can bring to the family (49). Furthermore, the barriers to discussing life-threatening illnesses and bereavement may also be influenced by traditional Chinese sociocultural factors, such as "family determination" and "death as taboo" (50). Both family members and healthcare professionals tend not to involve patients in the clinical decision-making process (51, 52). Despite this, the internal consistencies of factual knowledge and talking support were good.

In the six-factor structure, item 21 showed cross-loading in EFA on the "factual knowledge" and "accessing help" subscales. This might be caused by the fact that when people need information to access community resources, the information is a kind of fact. However, because the loading only just meets the threshold of 0.4, this is unlikely to be a significant concern. Regarding internal

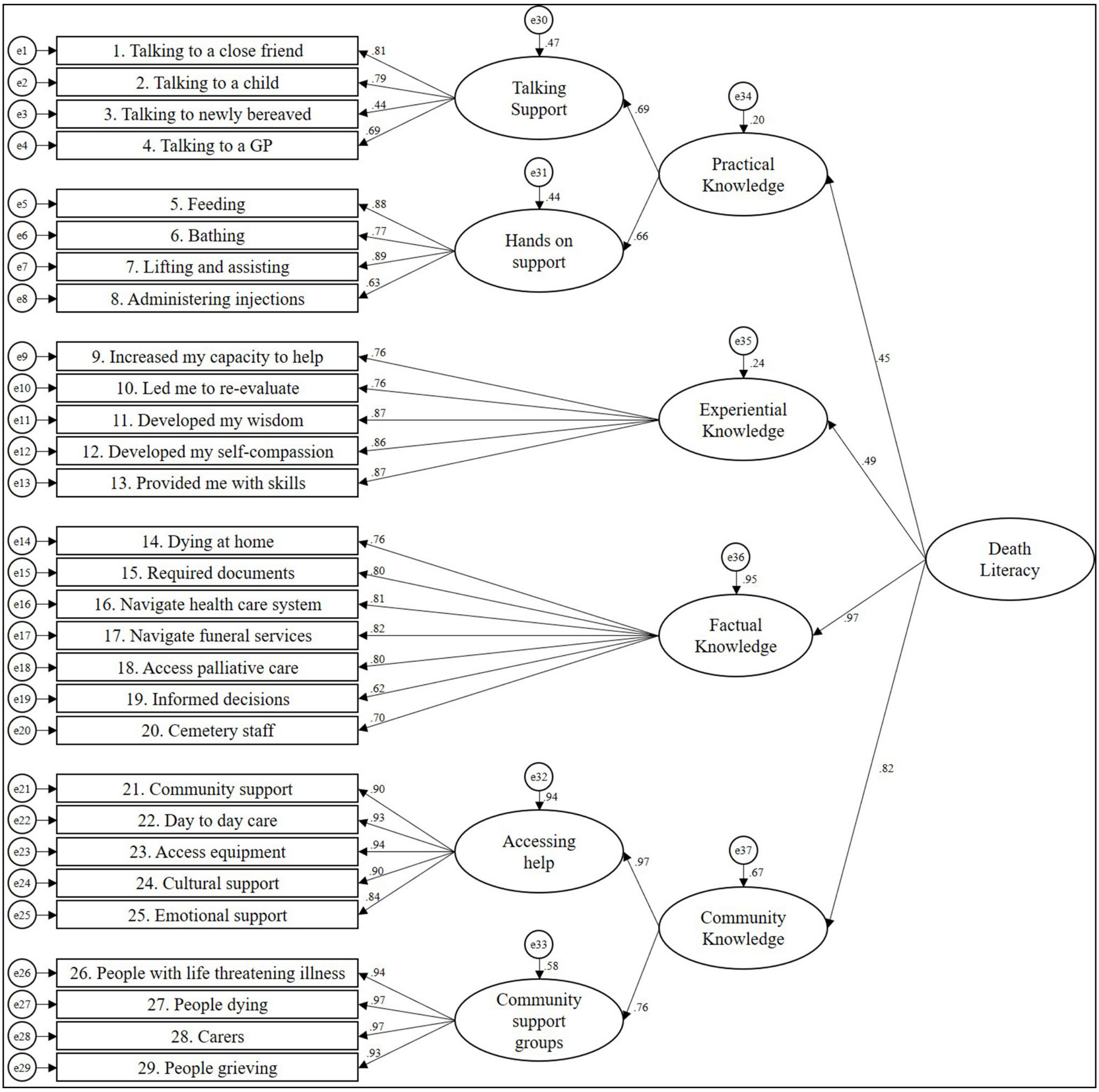

FIGURE 1
Structural equation model for the fitting model for the Chinese translated Death Literacy Index.

reliability, although the AVE in the "talking support" subscale was <0.5, it is still considered to have adequate convergent validity if the CR is higher than 0.6, as suggested by Fornell and Larcker (41).

The mean scores of the DLI scales and subscales in the current study were consistently higher than those in the Australian and UK populations (27, 30). This suggests that the levels of death literacy reported in the Chinese population were higher. One prominent difference is that the sample in this study was significantly younger than that in the UK study. Studies have found that older age and more knowledge of end-of-life care are associated with more positive death attitudes (53). The younger generation is believed to have less experience and knowledge of death. However, the younger generation was reported more death anxiety compare to the middle-aged (54), this might have led to more information seeking. There is a need to clarify the relationship between age and death literacy, as well as other influencing factors. Furthermore, considering this study was conducted during the COVID-19 pandemic in China, most people were probably confronted with their own mortality more than before the pandemic. With new death cases reported every day, people might have become alarmed by the impermanence and fragility of life. As a coping strategy for facing the fear of death, people would increase their motivation of health information-seeking behaviors (55, 56). It can be assumed that increased exposure to death might also increase

TABLE 7 Multi-group confirmatory factor analysis for different sub-groups.

	CFI	TLI	RMSEA (90% CI)	SRMR	Model compare	ΔCFI	ΔTLI	ΔRMSEA	ΔSRMR	Decision
Gender										
M1: Configural invariance	0.950	0.945	0.041 (0.040, 0.042)	0.0650						
M2: Metric invariance	0.950	0.946	0.041 (0.040, 0.042)	0.0648	M1	0	0.001	0	−0.0002	Accept ($\Delta < 0.01$)
M3: Scalar invariance	0.949	0.947	0.041 (0.039, 0.042)	0.0648	M2	−0.001	0.001	0	0	Accept ($\Delta < 0.01$)
Experience of parental death										
M4: Configural invariance	0.953	0.948	0.040 (0.039, 0.041)	0.0554						
M5: Metric invariance	0.953	0.949	0.040 (0.039, 0.041)	0.0548	M4	0	0.001	0	−0.0006	Accept ($\Delta < 0.01$)
M6: Scalar invariance	0.951	0.950	0.040 (0.038, 0.041)	0.0547	M5	−0.002	0.001	0	−0.0001	Accept ($\Delta < 0.01$)

motivation to learn about death, contributing to the high score on the DLI.

Interpretability was found to be good, but a ceiling effect was observed in two subscales, i.e., "doing hands on care" and "experiential knowledge". The two subscales were also found to have the highest mean scores, suggesting that participants had the most confidence in performing such care, which can be attributed to instrumental support being viewed as filial behaviors when parents are at the end of their lives (57). This kind of reciprocal relationship is appreciated in Chinese communities (58, 59). The "support groups" subscale scored the lowest on the DLI, suggesting that people consider support groups to be inaccessible, and peer support services to be inadequate. The lack of awareness of support groups in the community might also contribute to the low score on the support group subscale. There are sociocultural barriers to the acceptance of peer support groups, and Chinese are reported to be more conservative in regard to self-disclosure (60, 61). Despite this, a variety of community-based peer support models are being developed in China (62, 63), and locally developed peer support groups are becoming more acceptable to Chinese people (64). Because it is difficult to determine the cause of the low score on the "support group" subscale simply by the items of the scale, it may be necessary to include items that reflect community resources in subsequent research. On the other hand, it is worth noting that participants considered death to be positive and purposeful for one's life; this contradicts with traditional Chinese philosophy, which sees death as bad fortune (65). Previous studies have shown that loss experiences could decrease death anxiety, and gender differences can also affect death anxiety and coping strategies (43, 44). By applying MGCFA, this study assessed the measurement invariance of the DLI across genders and the experiences of parental death and showed sufficient invariance. This information allows us to interpret and compare the mean scores of the DLI across genders and participants' experiences of parental death.

The DLI was established to be a valid and reliable indicator of death literacy in southern China, and it may provide valuable information for the development of end-of-life care services for dying people and their families. As death literacy of the general public can reflect their knowledge about the availability and accessibility of death-related support or services in the community, the level of death literacy of the public can be utilized as an evaluation to assess the effectiveness of the interventions of hospice services. To investigate the stability, the authors encourage future studies to validate the Chinese DLI in different target groups, such as different age and professional groups, and in different regions across China. Further studies of death literacy across the lifespan are also warranted, since studies suggest death-related perceptions are changeable at different ages, and with the accumulation of life experience (66, 67). As the DLI is beginning to be used in different countries, it can facilitate collaborations across professionals to develop a death system for supporting individuals and their families during end-of-life care and grieving periods.

The current study has a few strengths. First, this study involved five cities in southern China, each representing a different level of economic development and cultural background. Second, the items of the Chinese DLI were culturally adapted and are suitable for populations with southern Chinese culture. Although the sample size in this study is large, the disproportionate proportion of young adults in the sample should be taken into account in the process of generalization and interpretation. Moreover, the sample composition had a large proportion of females and college students. The exploitation of the convenience sampling method may hinder sample representation. It is recommended that future validation studies include a greater number of older people, males, and working individuals, to improve the representativeness of these groups. Additionally, the Chinese DLI has not been compared with other scales, such as the Death Anxiety Scale (68) and the Palliative Care Knowledge Scale (69). Therefore, it is recommended that further analysis be conducted to differentiate the Chinese DLI from other measurement tools, to identify different concepts relating to death in the Chinese population. The content validity of the translated DLI was not reviewed by an expert panel in the field;

it was reviewed only by the translation panel. This gap will be addressed in future studies. Finally, this study only examined the effect of parental death on the DLI. However, other experiences of loss might also affect death literacy. It is suggested that future studies to explore the relationship between experiences of loss of other significant others and death literacy.

5. Conclusion

It is expected that the increased needs for end-of-life care among people in Chinese society will prompt the government to devote more resources into the health and social care system. The current study demonstrated that the Chinese DLI is a valid and reliable tool for death literacy assessment among the southern Chinese population. Therefore, the Chinese DLI can be used to identify public needs for end-of-life care services, and to measure the effectiveness intervention development for people of southern China.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by the Research Management and Development Department of Kiang Wu Nursing College of Macau. The participants provided their written informed consent to participate in this study.

Author contributions

Conceptualization and investigation: SLC, WIN, XL, and MZ. Methodology: SLC, WIN, and XL. Formal analysis, data curation, writing—original draft preparation, and visualization: SLC. Writing—review and editing: WIN, XL, and MZ. Supervision, project administration, and funding acquisition: WIN. All authors have read and approved the submitted version.

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Conflict of interest

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1140475/full#supplementary-material

References

1. Kastenbaum R, Moreman CM. *Death, Society, and Human Experience*. New York: Routledge (2018).

2. Goh CR. Medicalization of dying: are we turning the corner? *J Palliat Med.* (2012) 15:728–9. doi: 10.1089/jpm.2012.9579

3. Kellehear A. Health-promoting palliative care: developing a social model for practice. *Mortality.* (1999) 4:75–82. doi: 10.1080/713685967

4. Gerber K, Lemmon C, Williams S, Watt J, Panayiotou A, Batchelor F, et al. ‘There for me’: a qualitative study of family communication and decision-making in end-of-life care for older people. *Progress Palliative Care*. (2020) 28:354–61. doi: 10.1080/09699260.2020.1767437

5. Mori M, Morita T. End-of-life decision-making in Asia: a need for in-depth cultural consideration. *Palliat Med.* (2020) 0269216319896932. doi: 10.1177/0269216319896932

6. World Health Organization. *Integrating Palliative Care and Symptom Relief Into Primary Health Care: A WHO Guide for Planners, Implementers and Managers*. Geneva: World Health Organization (2018).

7. World Health Organization. *Ageing and Health*. (2022). Available online at: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health#:$\sim$:text=By%202050%2C%20the%20world’s%20population,2050%20to%20reach%20426%20million (accessed January 9, 2023).

8. Foreman KJ, Marquez N, Dolgert A, Fukutaki K, Fullman N, McGaughey M, et al. Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016-40 for 195 countries and territories. *Lancet.* (2018) 392:2052–90. doi: 10.1016/S0140-6736(18)31694-5

9. Sleeman KE, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, et al. The escalating global burden of serious health-related suffering: projections to 2060

by world regions, age groups, and health conditions. *Lancet Glob Health.* (2019) 7:e883–92. doi: 10.1016/S2214-109X(19)30172-X

10. Yan Y, Zhang H, Gao W, Liu D, Endo M, Deshpande GA, et al. Current awareness of palliative care in China. *The Lancet Global Health.* (2020) 8:e333–5. doi: 10.1016/S2214-109X(20)30006-1

11. The Economist Intelligence Unit. *The 2015 Quality of Death Index: Ranking Palliative Care Across the World.* London: The Economist Intelligence Unit (2015).

12. Ning X. Hospice/palliative care research in Mainland China: current situation and future direction. *Palliat Med.* (2019) 33:1129–30. doi: 10.1177/0269216319857495

13. General Office of the National Health and Family Planning Commission. *Notice of the General Office of the National Health and Family Planning Commission on the issuance of Hospice Care Practice Guidelines (Trial).* Beijing: General Office of the National Health and Family Planning Commission (2017).

14. Shi H, Shan B, Zheng J, Peng W, Zhang Y, Zhou X, et al. Knowledge and attitudes toward end-of-life care among community health care providers and its influencing factors in China: a cross-sectional study. *Medicine.* (2019) 98:e17683. doi: 10.1097/MD.0000000000017683

15. Song L, Su C. Studies on the quality of death among the elderly in China: current status and countermeasures. *Soc Sci Beijing.* (2021) 6:119–28. doi: 10.13262/j.bjsshkxy.bjshkx.210611

16. Chan KS. Palliative care: the need of the modern era. *Hong Kong Med J.* (2018) 24:391–9. doi: 10.12809/hkmj187310

17. Wong EL-Y, Kiang N, Chung RY-N, Lau J, Chau PY-K, Wong SY-S, et al. Quality of palliative and end-of-life care in Hong Kong: perspectives of healthcare providers. *Int J Environ Res Public Health.* (2020) 17:5130. doi: 10.3390/ijerph17145130

18. Chung RY, Dong D, Chau NNS, Chau PY, Yeoh EK, Wong EL. Examining the gaps and issues of end-of-life care among older population through the lens of socioecological model-a multi-method qualitative study of Hong Kong. *Int J Environ Res Public Health.* (2020) 17:5072. doi: 10.3390/ijerph17145072

19. Hospital Authority. *Strategic Service Framework for Palliative Care.* Hong Kong: Hospital Authority (2017).

20. Lam W-M. Palliative care in Hong Kong – past, present and future. *J Hong Kong College Family Phys.* (2019) 41:39–46.

21. Kiang Wu Hospital. *The past 20 Years of the Hospice and Palliative Care Center.* (2020). Available online at: http://www.kwh.org.mo/news%20info.php?nid=2331 (accessed January 9, 2023).

22. The Government of the Macau Special Administrative Region. *Visit of the Secretary for Social Affairs and Culture at the Palliative Care Ward in Coloane.* (2019). Available online at: https://www.gov.mo/zh-hant/news/272053/ (accessed January 9, 2023).

23. Statistics and Census Services of Macao SAR Government. *Demographic Statistics 2000.* (2001). Available online at: https://www.dsec.gov.mo/getAttachment/fa3797a8-f438-4019-a0ec-0d0c1e4ddc30/C_DEM_PUB_2000_Y.aspx (accessed January 9, 2023).

24. Statistics and Census Services of Macao SAR Government. *Demographic Statistics 2021.* (2022). Available online at: https://www.dsec.gov.mo/getAttachment/2fd829b0-00ae-43cc-bcb8-8fb51aa96e29/C_DEM_PUB_2021_Y.aspx (accessed January 9, 2023).

25. The Government of the Macao Special Administrative Region. *Mechanism for the Protection of the Elderly and Ten-Year Plan of Action for Services for the Elderly 2016-2025 of the Macao Special Administrative Region.* Macao: The Government of the Macao Special Administrative Region (2016).

26. Tam KI, Che SL, Zhu M, Leong SM. Home or hospital as the place of end-of-life care and death: a survey among Chinese residents of Macao. *Front Public Health.* (2023) 11:1043144. doi: 10.3389/fpubh.2023.1043144

27. Leonard R, Noonan K, Horsfall D, Psychogios H, Kelly M, Rosenberg J, et al. *Death Literacy Index: A Report on its Development and Implementation.* Sydney, NSW (2020).

28. Schillinger D. Social determinants, health literacy, and disparities: intersections and controversies. *Health Literacy Res Pract.* (2021) 5:e234–43. doi: 10.3928/24748307-20210712-01

29. Leonard R, Noonan K, Horsfall D, Kelly M, Rosenberg JP, Grindrod A, et al. Developing a death literacy index. *Death Stud.* (2022) 46:2110–22. doi: 10.1080/07481187.2021.1894268

30. Graham-Wisener L, Toner P, Leonard R, Groarke JM. Psychometric validation of the death literacy index and benchmarking of death literacy level in a representative uk population sample. *BMC Palliat Care.* (2022) 21:145. doi: 10.1186/s12904-022-01032-0

31. Semerci V, Sönmez Sari E, Seven A. Validity and reliability of the Turkish version of the death literacy index. *Omega.* (2022) 2022:302228221144672. doi: 10.1177/00302228221144672

32. Johansson T. *A 'New Public Health' Perspective on Building Competence for End-of-Life Care and Communication : How Death Literacy Can Be Developed and Measured.* Sweden: Karolinska Institutet (2022).

33. World Health Organization. *Process of Translation and Adaptation of Instruments.* Available online at: http://www.who.int/substance_abuse/research_tools/translation/en/ (accessed June 28, 2023).

34. Boateng GO, Neilands TB, Frongillo EA, Melgar-Quiñonez HR, Young SL. Best practices for developing and validating scales for health, social, and behavioral research: a primer. *Front Public Health.* (2018) 6:149. doi: 10.3389/fpubh.2018.00149

35. Boeije H, Willis G. The cognitive interviewing reporting framework (CIRF). *Methodology.* (2013) 9:87–95. doi: 10.1027/1614-2241/a000075

36. Johanson GA, Brooks GP. initial scale development: sample size for pilot studies. *Educ Psychol Meas.* (2010) 70:394–400. doi: 10.1177/0013164409355692

37. Pett MA, Lackey NR, Sullivan JJ. *Making Sense of Factor Analysis: The Use of Factor Analysis for Instrument development in Health Care Research.* New York, NY: Sage Publications (2003).

38. Gulledge CM, Lizzio VA, Smith DG, Guo E, Makhni EC. What are the floor and ceiling effects of patient-reported outcomes measurement information system computer adaptive test domains in orthopaedic patients? A systematic review. *Arthroscopy.* (2020) 36:901–12.e7. doi: 10.1016/j.arthro.2019.09.022

39. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol.* (2007) 60:34–42. doi: 10.1016/j.jclinepi.2006.03.012

40. Howard MC. A review of exploratory factor analysis decisions and overview of current practices: what we are doing and how can we improve? *Int. J. Hum Comput Interac.* (2016) 32:51–62. doi: 10.1080/10447318.2015.1087664

41. Fornell C, Larcker DF. Evaluating structural equation models with unobservable variables and measurement error. *J Mark Res.* (1981) 18:39–50. doi: 10.1177/002224378101800313

42. Hu Lt, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Eq Model Multidiscip J.* (1999) 6:1–55. doi: 10.1080/10705519909540118

43. Adelirad F, Sabahiazar K, Asghari-Jafarabadi M, Namjoo S, Chattu VK, Allahverdipour H. Gender difference about death anxiety among older adults: structural equation model. *Psychogeriatrics.* (2021) 21:296–303. doi: 10.1111/psyg.12663

44. Wallace CL, Cohen HL, Jenkins DA. Transforming students' attitudes and anxieties toward death and loss: the role of prior death experiences. *Omega.* (2019) 79:52–71. doi: 10.1177/0030222817710140

45. Cheung GW, Rensvold RB. Evaluating goodness-of-fit indexes for testing measurement invariance. *Struct Eq Model Multidiscip J.* (2002) 9:233–55. doi: 10.1207/S15328007SEM0902_5

46. Brennan RL. A generalized upper-lower item discrimination index. *Educ Psychol Meas.* (1972) 32:289–303. doi: 10.1177/001316447203200206

47. Lim S, Jahng S. Determining the number of factors using parallel analysis and its recent variants. *Psychol Methods.* (2019) 24:452–67. doi: 10.1037/met0000230

48. Ren JW. *A Study on the Funeral Social Work in Psychological Adjustment of Undertakers.* Anhui: Anhui University. (2017).

49. Burrell A, Selman LE. How do funeral practices impact bereaved relatives' mental health, grief and bereavement? A mixed methods review with implications for COVID-19. *OMEGA J Death Dying.* (2022) 85:345–83. doi: 10.1177/0030222820941296

50. Tse CY, Chong A, Fok SY. Breaking bad news: a Chinese perspective. *Palliat Med.* (2003) 17:339–43. doi: 10.1191/0269216303pm751oa

51. Ling DL, Yu HJ, Guo HL. Truth-telling, decision-making, and ethics among cancer patients in nursing practice in China. *Nurs Ethics.* (2019) 26:1000–8. doi: 10.1177/0969733017739783

52. Zhang J, Yang D, Deng Y, Wang Y, Deng L, Luo X, et al. The willingness and actual situation of Chinese cancer patients and their family members participating in medical decision-making. *Psychooncology.* (2015) 24:1663–9. doi: 10.1002/pon.3835

53. Hong M, Hong S, Adamek ME, Kim MH. Death attitudes among middle-aged Koreans: role of end-of-life care planning and death experiences. *Int J Aging Hum Dev.* (2017) 86:51–68. doi: 10.1177/0091415016689473

54. Russac RJ, Gatliff C, Reece M, Spottswood D. Death anxiety across the adult years: an examination of age and gender effects. *Death Stud.* (2007) 31:549–61. doi: 10.1080/07481180701356936

55. Pyszczynski T, Lockett M, Greenberg J, Solomon S. Terror management theory and the COVID-19 pandemic. *J Hum Psychol.* (2021) 61:173–89. doi: 10.1177/0022167820959488

56. Spitzenstätter D, Schnell T. The existential dimension of the pandemic: death attitudes, personal worldview, and coronavirus anxiety. *Death Stud.* (2022) 46:1031–41. doi: 10.1080/07481187.2020.1848944

57. Cong Z, Silverstein M. End-of-life co-residence of older parents and their sons in rural China. *Can J Aging.* (2015) 34:331–41. doi: 10.1017/S0714980815000227

58. Ng WI, Che SL, Li X, Zhu MX. What makes Chinese adult children behave differently during parents' end of life: a discriminant analysis of Macao Chinese. *Int J Environ Res Public Health.* (2021) 18:10737. doi: 10.3390/ijerph182010737

59. Zheng X, Li H. How Chinese children's filial piety beliefs affect their parents' life satisfaction and loneliness. *Psych J.* (2022) 11:863–72. doi: 10.1002/pchj.558

60. Chen G-M. Differences in self-disclosure patterns among Americans versus chinese: a comparative study. *J Cross Cult Psychol.* (1995) 26:84–91. doi: 10.1177/0022022195261006

61. Zhao C, Hinds P, Gao G. How and to whom people share: the role of culture in self-disclosure in online communities. In: *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work* (2012).

62. Fan Y, Ma N, Ma L, Xu W, Steven Lamberti J, Caine ED. A community-based peer support service for persons with severe mental illness in China. *BMC Psychiatry.* (2018) 18:170. doi: 10.1186/s12888-018-1763-2

63. Zhou N, Sun Y, She Z, Xu X, Peng Y, Liu X, et al. Grief and growth among Chinese parents who lost their only child: the role of positive and negative experiences of social support from different sources. *Eur J Psychotraumatol.* (2022) 13:2079874. doi: 10.1080/20008198.2022.2079874

64. Yu S, Kowitt SD, Fisher EB, Li G. Mental health in China: stigma, family obligations, and the potential of peer support. *Community Ment Health J.* (2018) 54:757–64. doi: 10.1007/s10597-017-0182-z

65. Hsu C-Y, O'Connor M, Lee S. Understandings of death and dying for people of Chinese origin. *Death Stud.* (2009) 33:153–74. doi: 10.1080/07481180802440431

66. Chopik WJ. Death across the lifespan: age differences in death-related thoughts and anxiety. *Death Stud.* (2017) 41:69–77. doi: 10.1080/07481187.2016.1206997

67. Maxfield M, Pyszczynski T, Kluck B, Cox CR, Greenberg J, Solomon S, et al. Age-related differences in responses to thoughts of one's own death: mortality salience and judgments of moral transgressions. *Psychol Aging.* (2007) 22:341. doi: 10.1037/0882-7974.22.2.341

68. Templer DI. The construction and validation of a death anxiety scale. *J Gen Psychol.* (1970) 82:165–77. doi: 10.1080/00221309.1970.9920634

69. Kozlov E, Carpenter BD, Rodebaugh TL. Development and validation of the palliative care knowledge scale (PaCKS). *Palliat Support Care.* (2017) 15:524–34. doi: 10.1017/S1478951516000997

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Nurses' practices and their influencing factors in palliative care

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Background: In 2017, the Chinese government launched a pilot project in palliative care, in which Shanghai was a pioneer. Nurses play a key role in palliative care services as they are the main providers improving the quality of services for patients and their families. However, little is known about practices and influencing factors in the field of palliative care from a nursing perspective in China. This is an original empirical study that has meticulously analyzed the interrelationship and intensity between practices and other factors among nurses in the initial stage of palliative care in primary healthcare institutions in Shanghai, China.

Methods: A descriptive-correlational study design was used to sample 2,829 eligible palliative care nurses by purposive sampling survey in 225 healthcare institutions in Shanghai, China. Descriptive analyses were performed using IBM SPSS 24.0 software. Structural equation modeling was applied to analyze the data by AMOS 20.0. Data were collected using the well-designed Knowledge, Attitudes, and Practices of Hospice Care (KAPHC) scale.

Results: The final model showed a good model fit. Self-efficacy directly influenced practices ($\beta = 0.506$, $P < 0.01$) and indirectly influenced practices ($\beta = 0.028$, $P < 0.01$) through intention. Subjective norm directly influenced practices ($\beta = 0.082$, $P < 0.01$) and indirectly influenced practices ($\beta = 0.030$, $P < 0.01$) through intention. Intention ($\beta = 0.152$, $P < 0.01$) and knowledge ($\beta = 0.068$, $P < 0.01$) directly influenced practices. Perceived susceptibility ($\beta = -0.027$, $P < 0.01$), perceived benefits ($\beta = -0.017$, $P < 0.01$), and perceived barriers ($\beta = -0.014$, $P < 0.01$) indirectly influenced practices through intention.

Conclusion: This study provided evidence of the associations of knowledge, perceived susceptibility, benefits, barriers, subjective norm, self-efficacy, intention, and practices among nurses concerning palliative care and interventions improving their actual work practices. Our findings revealed that self-efficacy, intention, and subjective norms greatly influenced practices. It is imperative to take interventions that focus precisely on self-efficacy, intention, and subjective norms to improve nurses' practices.

KEYWORDS

nurse, practices, structural equation model, influencing factors, palliative care

Introduction

Palliative care is the active holistic care of individuals of all ages with serious health-related suffering due to severe illness and especially those near the end of their life (1). With two batches of national pilots launched in 2017 and 2019, China initially established a palliative care service system (2). In clinical palliative care practices, nurses play an active, and often lead role in managing the whole process of patients' disease diagnosis, treatment, and dying and death, as well as meeting their physical, spiritual, cultural, and religious needs during different periods (3). Previous studies have concluded that nurses should equip themselves with diversified psychological and compassionate care comprehensively, instead of previous simple physical symptom management (4, 5). In addition, previous studies have preceded that compared to physicians, nurses had more positive attitudes toward palliative care (6). Furthermore, in the initial stage of palliative care pilot work, there is a shortage of composition and proportion of a specialized team (7). The roles of social workers and psychological counselors in interdisciplinary groups were not fully involved (8, 9); therefore, nurses undertake multi-functional roles and diversified nursing such as communication. The behavioral practices of palliative care nurses directly affect the quality of palliative care services.

However, previous studies were mostly limited to small sample surveys of specialist nurses in one institution in China (10–12). There are scarce in-depth systematic studies focusing on the interrelationship between nurses' practices and large sample surveys on influencing factors. Therefore, based on the above current situation, it is important to comprehensively measure the behavioral profile of palliative care nurses and explore the facilitators of practice in China.

Methods

Study design and participants

This is a cross-sectional study based on purposive sampling. We investigated all health institutions registered with palliative care from November to December 2019, including hospitals, community health centers, and nursing homes covering the whole area of Shanghai. Moreover, 15 registered nurses were recruited from each institution ideally. If the number is <15, all registered nurses were investigated. The participants' inclusion criteria were as follows: nurses (1) who were nurse practitioners and (2) who voluntarily agreed to participate in the anonymous survey.

Based on a strict logical structure, the questionnaire in Chinese was scientifically designed and electronic, and all key information is required to ensure that all returned questionnaires are valid. The anonymous questionnaire survey was conducted through SO JUMP, a professional online questionnaire survey platform used by a large number of companies and individuals. The QR link and code of the questionnaire were sent to the head nurses, who distributed the questionnaires to the nurses who met the inclusion criteria in their departments. They can fill in the questionnaire using mobile phones or computers. Finally, 2,829 nurses from 225 health institutions were investigated.

Measures

This study employed a descriptive-correlational study by well-designed Knowledge, Attitudes, and Practices of Hospice Care (KAPHC) questionnaire demonstrating good validity and reliability (https://onlinelibrary.wiley.com/doi/10.1002/hpm.3074) (13, 14). The questionnaire contained five sections: demographic and relevant objective work-experience characteristics, knowledge (15 items), attitudes (24 items with four sub-concepts), confidence (11 items), and self-reported practices (11 items). Demographic and relevant objective work-experience characteristics included age (years), gender (male = 0, female = 1), educational level (junior middle school or less = 0, high school or vocational college = 1, and bachelor or above = 2), marital status (unmarried = 0, married = 1, and divorced or widowed = 2), nationality (minorities = 0, Han = 1), religious belief (none = 0, other = 1), professional title (none = 0, junior = 1, intermediate = 2, and senior = 3), the experience of death witness (no = 0, yes = 1), the willingness of providing palliative care (no = 0, yes = 1), and institution type (nurse home = 0, community health centers = 1, and hospital = 2). The Cronbach's α coefficient of knowledge, attitude, confidence, and

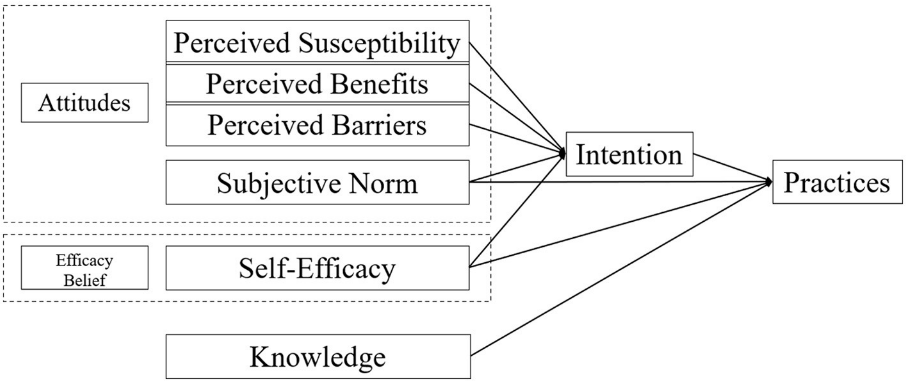

FIGURE 1
Hypothetical model for practices and their influencing factors among nurses concerning palliative care.

TABLE 1 Demographic characteristics of the respondents ($N = 2{,}829$).

	N	%
Gender		
Female	2,754	97.35
Male	75	2.65
Age		
≤30	1,244	43.97
31–50	1,487	52.56
≥51	98	3.46
Educational degree		
Bachelor or above	1,444	51.04
High school or vocational college	1,186	41.92
Junior middle school or less	199	7.03
Marriage status		
Unmarried	672	23.75
Married	2,082	73.59
Divorced or widowed	75	2.65
Nationality		
Han	2,744	97.00
Minorities	85	3.00
Religious Belief		
None	2,389	84.45
Other	440	15.55
Professional title		
Senior	48	1.70
Intermediate	963	34.04
Junior	1,570	55.50
None	248	8.77
Experience of death witness		
Yes	2,413	85.30
No	416	14.70
Willingness of providing hospice and palliative care		
Yes	1,752	61.93
No	1,077	38.07
If yes, your main consideration is		
It's a task from the superior.	269	15.35
It's my duty.	1,283	73.23
My religious belief.	43	2.45
It's charitable.	157	8.96
If no, your main consideration is		
It's stressful.	823	76.42
Low salary.	140	13.00
Unvalued.	32	2.97
Meaningless.	23	2.14
Blind-alley job.	59	5.48
Institution type		
Hospital	363	12.83
Community health centers	1,958	69.21
Nursing home	508	17.96

practices scale was 0.686, 0.868, 0.960, and 0.971, respectively (13). Scores for each subcategory were calculated separately. Regarding the knowledge scale, a score of 1 was given for a correct answer and 0 for an incorrect or unknown answer. The overall score ranges from 0 to 15, with higher scores indicating better palliative care knowledge. Meanwhile, each item in the attitudes section was scored by a 5-point Likert scale (1 = totally disagree to 5 = totally agree) and higher scores indicate better attitudes. Self-efficacy was assessed by a confidence scale (1 = no confidence to 5 = extreme confidence). The overall score ranges from 11 to 55, with higher scores indicating greater self-efficacy. Practices were scored by a 5-point Likert scale (1 = never do to 5 = always do). The overall score ranges from 14 to 70, with higher scores indicating greater work practices.

Model construction

The theoretical framework in this study originates from three classical and widespread health and behavior theories: the Health Belief Model (HBM) (15), the Theory of Reasoned Action (TRA) (16), and the Integrated Behavior Theory (IBT) (17). According to the HBM theory, which is a model of health education that changes people's behavior by intervening in their psychological activities such as perceptions, attitudes and beliefs, perceived susceptibility, perceived benefits, perceived barriers, and self-efficacy influence behavior change. Based on the TRA, whether a person engages in behavior directly depends on their intention to act. In addition, subjective norm affects behavioral intention. IBT theory suggests that behavior is influenced by knowledge. Based on the theoretical components and dimensions mentioned in the above three theories and existing domestic and international research, knowledge, attitudes, self-efficacy, intention, and practices were incorporated into the hypothesis model (Figure 1) for confirmatory analysis. Behavioral intention is a fundamental intermediary factor, determined by self-efficacy and attitudes of individuals. Consequently, nurses' practices in palliative care may be affected by knowledge, attitudes, self-efficacy, and intention in our hypothetical model.

Therefore, in the current study, we verified the associations among knowledge, self-efficacy, subjective norm, perceived susceptibility, benefits, barriers, intention, and practices using the structural equation model. Based on the theoretical framework and literature review, we developed a model to identify the following hypotheses: (1) Intention directly influences practices. (2) Subjective norms and self-efficacy have direct and indirect effects on practices through intention.

TABLE 2 Respondents' knowledge of palliative care ($N = 2,829$).

Items	Correct number (%)	Mean ± SD
1. The provision of hospice care requires emotional detachment.	482 (17.04)	0.17 ± 0.376
2. Psychological, social, and spiritual problems are paramount to the hospice care team who give appropriate consultation and management.	2,468 (87.23)	0.87 ± 0.344
3. Three steps make up the WHO analgesic ladder.	2,404 (84.98)	0.85 ± 0.357
4. The hospice care team provides bereavement support for the family after the patient's death.	2,072 (73.24)	0.73 ± 0.443
5. Home hospice care is in line with China's folk customs.	1,678 (59.31)	0.59 ± 0.491
6. For children's bereavement care, children can attend funerals and even participate in preparations.	964 (34.08)	0.34 ± 0.475
7. During the terminal stages of an illness, respiratory depression medicine is appropriate for certain treatments of severe dyspnea.	812 (28.70)	0.29 ± 0.452
8. Use of Mirabilite in Shenque acupoint application can relieve ascites.	1,481 (52.35)	0.52 ± 0.499
9. Pain threshold is lowered by fatigue or anxiety.	969 (34.25)	0.34 ± 0.475
10. Men generally reconcile their grief more quickly than women.	910 (32.17)	0.32 ± 0.467
11. Individuals who are taking opioids should also follow a bowel regime.	1,468 (51.89)	0.52 ± 0.500
12. To strengthen the construction of hospice care institutions was written into the "Healthy China 2030" strategic plan.	2,100 (74.23)	0.74 ± 0.437
13. Morphine point injections can be used to relieve cancer pain in the terminal period.	1,954 (69.07)	0.69 ± 0.462
14. The most authoritative guidelines on health care planning recommend that hospice care should be provided by (1) a multi-professional hospice care team that includes the family's general physicians, (2) general physicians, (3) a multi-professional hospital team led by a pain therapist, (4) specialized nursing staff in collaboration with an anesthetist, and (5) specialized nursing staff	2,557 (90.39)	0.90 ± 0.295
15. The purposes of melodic therapy are not (1) to relieve physical pain, (2) entertainment, (3) to express emotions, (4) to evoke memories, or (5) to relieve grief	1408 (49.77)	0.50 ± 0.500
Total	23727 (55.91)	8.39 ± 2.780

(3) Knowledge directly influences practices. (4) Perceived susceptibility, benefits, and barriers have indirect effects on practices through intention.

Statistical methods

Descriptive data were generated for all variables. Statistical analyses were performed using commercial software IBM SPSS Statistics 24.0 and AMOS version 20.0 (IBM Corporation, Armonk, NY). The level of significance was set at a $p < 0.05$. Categorical data were described by frequencies and percentages, and continuous data by means of standard deviations (SD). Pearson's (r) correlation was performed to verify the relationship between all variables. $0 \leq |r| < 0.3$ means low correlation; $0.3 \leq |r| < 0.8$ means medium correlation; $0.8 \leq |r| \leq 1.0$ means high correlation. A $P < 0.05$ was considered statistically significant. A structural equation model was used to test the associations between all variables. Path analysis was used to identify both direct and indirect relationships in the model. Standardized regression coefficients (β) and lower and upper bounds for β were reported for direct, indirect, and total effects. The model fit was assessed using the following model-fit indices: relative chi-square (χ^2/df) < 3; goodness of fit index (GFI) > 0.900, adjusted goodness of fit index (AGFI) > 0.900, comparative fit index (CFI) > 0.900, normed fit index (NFI) > 0.900, incremental fit index (IFI) > 0.900, Tucker–Lewis index (TLI) > 0.900, and root mean squared error of approximation (RMSEA) < 0.06 (18).

Results

Participants' characteristics

A total of 2,829 nurses from 225 institutions across Shanghai's districts were enrolled. The demographic characteristics of the respondents are listed in Table 1. The nurses' work units included the following: community health centers (69.21%) were the most common units, followed by nursing homes (17.96%) and hospitals (12.83%). The mean age was 36.83 ± 9.35 years.

Knowledge

The mean score of the knowledge scale was 8.39 ± 2.780; the response accuracy was 55.91%. Table 2 details the questions and scores.

Attitudes

The mean score on the attitudes scale was 84.79 ± 10.561, and the total scoring rate was 70.66%. Table 3 presents the attitudes

TABLE 3 Respondents' attitudes toward palliative care ($N = 2,829$).

Items	Mean ± SD
Perceived susceptibility:	2.88 ± 1.193
1. Uncomfortable taking care of advanced cancer patients.	2.43 ± 1.200
2. Hopeless for the cure.	3.23 ± 1.166
3. Unable to easily face the dying process and distress.	2.80 ± 1.167
4. Makes me feel weak.	2.91 ± 1.231
5. I feel guilty when an amine patient dies.	3.04 ± 1.200
Perceived benefits:	4.15 ± 0.876
6. Able to promote life quality and keep dignity.	4.32 ± 0.901
7. Able to die peacefully and have a good death.	4.33 ± 0.849
8. Having care and being accompanied by a medical team.	4.39 ± 0.793
9. Emotional support.	4.30 ± 0.820
10. Able to have family support.	4.22 ± 0.851
11. Respect for the patient's religion and burial rites.	4.29 ± 0.871
12. Help to die at home.	3.59 ± 1.004
13. Better communication with advanced patients.	4.14 ± 0.857
14. Help medical staff to take care of patients better.	4.23 ± 0.826
15. Avoid the idea of euthanasia.	3.65 ± 0.987
Perceived barriers:	2.71 ± 1.147
16. Shorten a patient's life, just like euthanasia.	2.32 ± 1.175
17. No active treatment for physical symptoms.	2.67 ± 1.165
18. Make patients feel hopeless.	2.30 ± 1.145
19. Advanced patients have many complex symptoms.	3.45 ± 1.065
20. Keep providing long-term hospice care services will lose enthusiasm.	2.83 ± 1.183
Subjective norms:	3.83 ± 0.960
21. It is meaningful.	4.17 ± 0.877
22. I experienced the death of my family member, which affected me to provide hospice care.	3.50 ± 1.060
23. It is a part of the duty of medical staff.	3.96 ± 0.929
24. With the approval and support of the department leader, colleagues, relatives, and friends, I was encouraged to provide hospice care.	3.70 ± 0.975
Total	84.79 ± 10.561

scale items and their mean scores. The mean scores of perceived susceptibility, perceived benefits, perceived barriers, and subjective norms were 2.88 ± 1.193, 4.15 ± 0.876, 2.71 ± 1.147, and 3.83 ± 0.960, respectively.

Self-efficacy and practices

The mean score of self-efficacy was 40.59±7.691, which was approximately 73.80% of the total score. The mean score of practices was 46.42±11.959, which was approximately 66.31% of the total score. Table 4 presents the mean scores of each item.

Bivariate analysis

Bivariate correlations are shown in Table 5. Knowledge was positively associated with perceived benefits ($r = 0.342$, $P < 0.01$), subjective norm ($r = 0.332$, $P < 0.01$), self-efficacy ($r = 0.318$, $P < 0.01$), and practices ($r = 0.279$, $P < 0.01$). Perceived susceptibility was positively associated with barriers ($r = 0.338$, $P < 0.01$). Benefits were positively associated with the subjective norm ($r = 0.601$, $P < 0.01$), self-efficacy ($r = 0.506$, $P < 0.01$), and practices ($r = 0.346$, $P < 0.01$). Subjective norm was moderately positively associated with self-efficacy ($r = 0.594$, $P < 0.01$) and practices ($r = 0.446$, $P < 0.01$). Self-efficacy was positively associated with practices ($r = 0.622$, $P < 0.01$).

Structural equation modeling

The model was modified by removing the non-significant paths using AMOS until the final model showed a good model fit. The revised model is shown in Figure 2. The final model manifested a satisfactory model fit ($\chi^2/df = 2.624$; GFI = 0.999, AGFI = 0.992, NFI = 0.998, IFI = 0.999, TLI = 0.992, CFI = 0.999; RMSEA = 0.024, 90%CI = 0.006–0.042). The standardized direct, indirect, and total coefficients are summarized in Table 6. Several important results of this study are as follows: (1) Intention directly influenced practices. The standardized path coefficient of the direct effect is 0.152 ($P < 0.01$). (2) Subjective norm and self-efficacy had direct and indirect impacts on practices through intention. The standardized path coefficient of the direct, indirect, and total effect of subjective norm on practices was 0.082 ($P < 0.01$), 0.030 ($P < 0.01$), and 0.112 ($P < 0.01$), respectively. The standardized path coefficient of the direct, indirect, and total effect of self-efficacy on practices was 0.506 ($P < 0.01$), 0.028 ($P < 0.01$), and 0.534 ($P < 0.01$), respectively. (3) Knowledge directly influenced practices. The standardized path coefficient of the direct effect is 0.068 ($P < 0.01$). (4) Perceived susceptibility, perceived benefits, and perceived barriers had indirect effects on practices through intention. The standardized path coefficients of indirect effect are −0.027 ($P < 0.01$), −0.017 ($P < 0.01$), and −0.014 ($P < 0.01$), respectively.

Discussion

Our original study has analyzed the interrelationship and intensity between practices and related factors among palliative care nurses in Shanghai, providing evidence of the associations of knowledge, perceived susceptibility, benefits, barriers, subjective norm, self-efficacy, intention, and practices aiming at palliative care nurses and interventions improving their actual work practices. The structural equation model authenticated the interrelationship and intensity between all dimensions, highlighting that self-efficacy, intention, and subjective norms greatly influenced practices among nurses concerning palliative care. Concretely, self-efficacy and subjective norms had direct and indirect impacts on

TABLE 4 Scores of respondents' self-efficacy and practices in palliative care ($N = 2{,}829$).

Items	Self-efficacy Mean ± SD	Practices Mean ± SD
1. Alleviate the pain and discomfort of dying patients.	3.56 ± 0.946	3.54 ± 1.009
2. Make pain assessments of patients.	3.82 ± 0.873	3.54 ± 1.072
3. Reduce unnecessary treatment costs.	3.53 ± 0.917	3.26 ± 1.062
4. Satisfy the physical and mental needs of dying patients.	3.67 ± 0.940	3.55 ± 1.015
5. Explain the expected dying process to the patient's family.	3.60 ± 0.950	3.20 ± 1.086
6. Tell family specific things they can do to provide meaningful service to patients.	3.85 ± 0.836	3.43 ± 1.026
7. Understand the wishes and pain of the family to help them.	3.83 ± 0.855	3.46 ± 1.012
8. Create a good relationship between the medical staff and family members.	3.86 ± 0.871	3.65 ± 0.997
9. Coordinate the media resources for medical, social, psychological, and spiritual care.	3.64 ± 0.941	3.27 ± 1.113
10. Help risk grieving families to get through better.	3.59 ± 0.976	3.31 ± 1.053
11. Guide the management of afterward and funeral preparation for families.	3.67 ± 0.951	3.17 ± 1.129
12. Proactively talk to patients and families about death-related topics*	NA	2.99 ± 0.968
13. Proactively recommend medical institutions for end-of-life care to terminal patients and their families*	NA	2.84 ± 1.067
14. Talk to the patient's family proactively about "respecting the patient's wishes"*	NA	3.23 ± 1.044
Total	40.59 ± 7.691	46.42 ± 11.959
Average	3.69 ± 0.914	3.32 ± 1.047

*This entry is a question closely related to behavior and is not included in the original KAPHC scale.
NA, not available.

TABLE 5 Descriptive statistics and correlation coefficients among variables ($N = 2{,}829$).

	Intention	Knowledge	Perceived susceptibility	Perceived benefits	Perceived barriers	Subjective norm	Self-efficacy
Knowledge	0.147**						
Perceived susceptibility	−0.274**	−0.100**					
Perceived Benefits	0.110**	0.342**	−0.004				
Perceived Barriers	−0.196**	−0.092**	0.338**	−0.074**			
Subjective norm	0.272**	0.332**	−0.127**	0.601**	−0.086**		
Self-efficacy	0.298**	0.318**	−0.212**	0.506**	−0.174**	0.594**	
Practices	0.335**	0.279**	−0.197**	0.346**	−0.133**	0.446**	0.622**

**$P < 0.01$.

practices. Intention and knowledge directly influenced practices. Perceived susceptibility, perceived benefits, and perceived barriers had indirect effects on practices through intention. The above hypotheses are verified by the model.

Our study found that the average score rating of nurses' practices (66.3%) was lower than that of all health providers in Shanghai (74.5%) (19) and that of oncology nurses in Shandong Province (82.2%) (20). This result may be in part because the majority of the participants in our study worked in primary healthcare institutions, including community health centers and nursing homes. In the initial stage of palliative care pilot work in Shanghai, there is a shortage of multidisciplinary team composition, and nurses undertake multi-functional roles and diversified nursing in primary healthcare institutions. Strategies to improve nurses' practices should be addressed when developing interventions.

In the model, self-efficacy, which was defined as the degree of confidence of nurses in the provision of palliative care services in this study, had profound the most important direct impacts on practices, indicating that nurses with better confidence have a stronger disposition to practices. A cross-sectional study showed that exploring the traditional Chinese philosophy of life was essential for the improvement of hospice care self-efficacy (21). Another study showed a positive and statistically significant correlation between communication skills and self-efficacy (22). Therefore, it is crucial to strengthen communication skills and enhance confidence through comprehensive and systematic training in respect of Chinese traditional concepts of life and death in order to further promote practical palliative care practice. Meanwhile, this result was in line with the previous study in which a significantly positive association between self-efficacy and practices has been observed (23), indicating that it is also a critical predictor

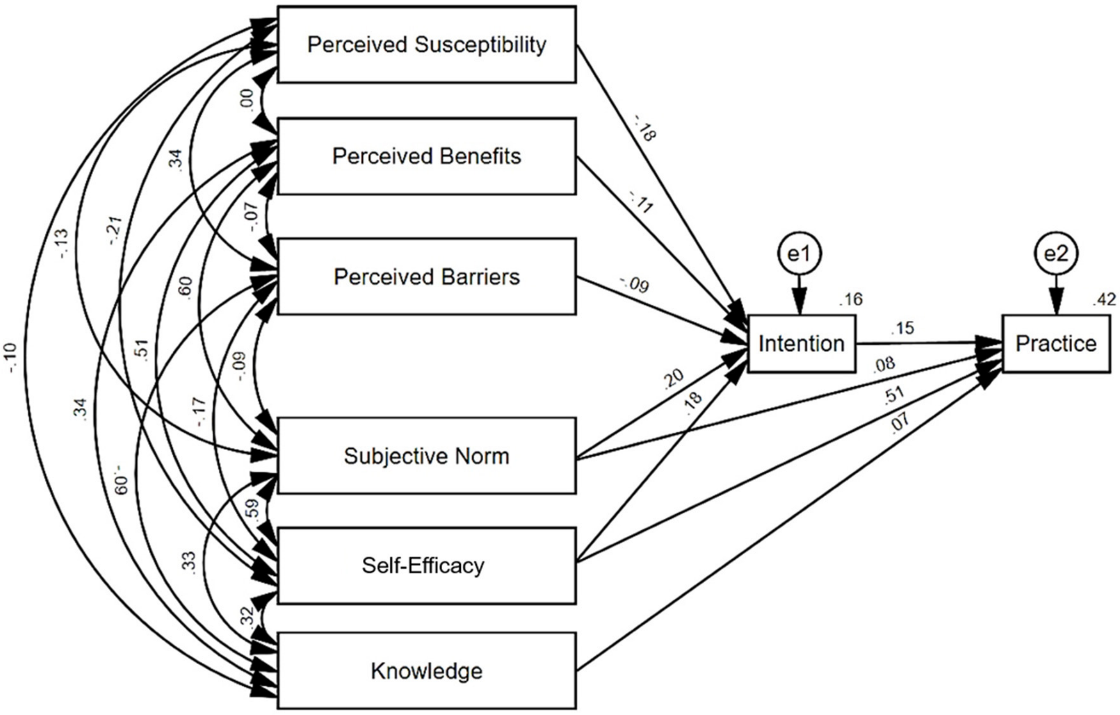

FIGURE 2
Structural equation model of nurses' practices in palliative care (standardized estimates).

and appropriate index measuring the self-efficacy of nurses to evaluate the level of practices.

Intention, which was defined as a willingness to practice, directly influenced and had a significantly positive association with practices. As shown in the model, the intention was positively affected by subjective norms and self-efficacy and negatively affected by perceived susceptibility to the condition of terminal patients' deterioration and perceived barriers to palliative care service provision. An analysis showed that whether nurses had clinical hospice care experience affected their willingness to practice (23). However, the demographic characteristics of the respondents showed that a part of the participants had no experience with death witnesses and was unwilling to provide palliative care services, which reduced practice frequency. Therefore, nurses should be emboldened to improve their behavioral intention by participating in the real case of end-of-life, improving clinical practices and training on death, and establishing an objective view of life and death.

Subjective norms also had direct and indirect impacts on practices, indicating that social values, expectations of leaders, and encouragement of colleagues had a great impact on the provision of palliative care services. There is a significantly positive correlation between subjective norms and practices, which was in line with another study (24), manifesting that the potential usefulness of subject consciousness and motivation in respect of palliative care services were self-evident. Strategies enhancing norm belief and compliance motivation and interventions, such as implicit messages and intentional teaching, should be considered (25).

The model also revealed the direct effects of knowledge on practices, reflecting the effectiveness of continuing education to improve nurses' competence in providing qualified palliative care services. Empirical research proved that targeted training in palliative care can address the knowledge and skills gaps in time. Moreover, a significantly positive correlation between knowledge and practices was obtained, which resembled another study (10). Despite the frequent phenomenon of knowing without doing, the great majority of researchers hold the view that the effect of knowledge on practices is worth affirming fully and permanently among other factors (26). Previous study showed that the lack of adequate end-of-life and legal literacy training for nurses was a key reason why the overall knowledge of health service providers in Shanghai was generally moderate (21) and a lack of adequate training on end-of-life will and legal knowledge for nurses is a key reason (27). Consequently, it is highly necessary for nurses, the major primary health service providers in diversified nursing, to systematically learn theoretical knowledge in palliative care, strengthen education on life and death, and improve the understanding of the concept and significance of palliative care services.

Perceived susceptibility, benefits, and barriers had negative indirect effects on practices through intention. First, perceived susceptibility had the most dramatic effect among three dimensions, indicating that nurses always felt upset, anxious, weak, hopeless, guilty, suffocated, and grieved and were unable to easily face the dying process of coping with patient death, which was unanimous with another study (28). Second, perceived barriers had indirect effects on practices, showing that nurses

TABLE 6 Direct, indirect, and total effects of variables in the final model (*N* = 2,829).

Endogenous variables	Predicting variables	Standardized direct effect			Standardized indirect effect			Standardized total effect		
		β	Lower bounds	Upper bounds	β	Lower bounds	Upper bounds	β	Lower bounds	Upper bounds
Intention	Perceived susceptibility	−0.179**	−0.216	−0.144				−0.179**	−0.216	−0.144
	Perceived benefits	−0.109**	−0.152	−0.067				−0.109**	−0.152	−0.067
	Perceived barriers	−0.094**	−0.131	−0.059				−0.094**	−0.131	0.059
	Subjective norm	0.199**	0.153	0.244				0.199**	0.153	0.244
	Self-efficacy	0.181**	0.135	0.223				0.181**	0.135	0.223
Practices	Perceived susceptibility				−0.027**	−0.036	−0.020	−0.027**	−0.036	−0.020
	Perceived benefits				−0.017**	−0.025	−0.010	−0.017**	−0.025	−0.010
	Perceived barriers				−0.014**	−0.021	−0.009	−0.014**	−0.021	−0.009
	Subjective norm	0.082**	0.042	0.118	0.030**	0.022	0.041	0.112**	0.071	0.148
	Self-efficacy	0.506**	0.469	0.543	0.028**	0.020	0.037	0.534**	0.498	0.570
	Knowledge	0.068**	0.038	0.099				0.068**	0.038	0.099
	Intention	0.152**	0.122	0.184				0.152**	0.122	0.184

β, standardized regression coefficient.

$^{**}P < 0.01$.

who had more perceived difficulties concerning palliative care had lower behavior, which was consistent with a previous study (29). Finally, perceived benefits had an indirect effect on practices. This phenomenon manifests that although nurses can realize the benefit of patients receiving palliative care is that patients are able to die peacefully and had a good death with omnidirectional care, highlife quality, and dignity (30). The patient's religion and burial rites should be respected (31). However, some participants perceived the provision of palliative care services as a serious burden, concerning occupational prospects, low salaries, and coping with a broad range of stressors in actual work practices. Thus, perceived susceptibility and barriers remain dominant factors, which is showing no difference with another study (32). Hence, it is necessary to provide effective strategies to treat themselves with empathy, kindness, and awareness of common humanity in clinical practices, contributing to their wellbeing.

Knowledge and attitudes are the antecedents and prerequisites. Before producing behavior, people transform external and internal needs into motivation and purpose through self-consciousness and understanding, to guide and regulate behavior and practices. After the change in knowledge and attitudes, behavior ultimately changes. A previous study showed that, in regular and continuous behavior, there is a two-way influence in the relationship between motivation, attitudes, beliefs, and behavior (33). In providing palliative care services, nurses' work practices will, in turn, promote changes in their own knowledge, attitudes, subjective norms, self-efficacy, and intention.

Strengths and limitations

The availability and accessibility of palliative care continue to be major global public health problems and are more challenging in China. However, few studies have investigated the interrelationship and intensity between practices and their influencing factors among nurses in palliative care. To our best knowledge, this is an original large-scale empirical study that has meticulously analyzed the interrelationship and intensity between practices and other factors among nurses in the initial stage concerning palliative care in primary healthcare institutions in Shanghai, China. Our findings have some practical implications and valuable information for nurses concerning palliative care. High-quality palliative care services can be achieved only by scaling up interventions to enhance self-efficacy, intention, subjective norm, and knowledge to motivate nurses to provide patient-centered integrated, and comprehensive behavior.

However, several limitations should be noted. First, most recent health behavior theories used in China originated from western culture. Because behavior is the profound embodiment of culture, the suitability of these theories in China is worth considering. Furthermore, most of the participants worked mainly in primary healthcare institutions. There is an urgent need for future basic and applied research studies on the influencing factors on nurses' practices in secondary and tertiary medical institutions. Finally, although the structural equation model is an advanced and reliable quantitative analysis method, it still contains subjective cognition from researchers. Therefore, other several complex mathematical models and analysis methods should be considered in further study to avoid bias.

Conclusion

This study preliminarily established a theoretical foundation by structural equation model among 2,892 nurses in healthcare institutions in Shanghai. The hypothetical model verified the interrelationship and intensity between nurses' practices of palliative care and several significant factors; Intention and knowledge directly influence practices; Subjective norm and self-efficacy have both direct and indirect impacts on practices through intention; Additionally, perceived susceptibility, perceived benefits, and perceived barriers had indirect effects on practices through intention. Ultimately, it is imperative to scale up targeted interventions focusing on self-efficacy, intention, and subjective norms to improve the practices of nurses, especially for nurses working in primary healthcare institutions. High-quality palliative care services can be achieved by motivated nurses with strong practical nursing abilities.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

LJ secured the funding to conduct this research and was responsible for conceptualizing the manuscript. JH participated in project design and grant article publication. YX and XT collected and analyzed the data. ZS contributed to the design of the scale. YX and SZ drafted the initial manuscript. ML and TC revised and polished the manuscript. JW and YM proofread the logical framework. SL coordinated the investigation. All authors were responsible for critical revisions and approval of the final manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, et al. Redefining palliative care-a new consensus-based definition. *J Pain Symptom Manage.* (2020) 60:754–64. doi: 10.1016/j.jpainsymman.2020.04.027

2. Xu YF, Jing LM, Li XY, Li SJ. Hospice and palliative care services development in Shanghai. *Open Access J Complement Altern Med.* (2021). doi: 10.32474/OAJCAM.2021.03.000165. [Epub ahead of print].

3. Lukovsky J, McGrath E, Sun C, Frankl D, Beauchesne MA, A. Survey of hospice and palliative care nurses' and holistic nurses' perceptions of spirituality and spiritual care. *J Hosp Palliat Nurs.* (2021) 23:28–37. doi: 10.1097/NJH.0000000000000711

4. Gómez-Urquiza JL, Albendín-García L, Velando-Soriano A, Ortega-Campos E, Ramírez-Baena L, Membrive-Jiménez MJ, et al. Burnout in palliative care nurses, prevalence and risk factors: a systematic review with meta-analysis. *Int J Environ Res Public Health.* (2020) 17:7672. doi: 10.3390/ijerph17207672

5. Greene PE. The pivotal role of the nurse in hospice care. *CA Cancer J Clin.* (1984) 34:204–05. doi: 10.3322/canjclin.34.4.204

6. Teng XH, Jing LM, Shu ZQ, Xu YF, Shu ZQ. Survey on attitude and influencing factors of hospice care among health providers in Shanghai. *Chin J Gen Pract.* (2021) 20:556–61. doi: 10.3760/cma.j.cn114798-20200815-00909

7. Ling M, Wang XC, Ma YH, Long Y. A review of the current state of hospice care in China. *Curr Oncol Rep.* (2020) 22:99. doi: 10.1007/s11912-020-00959-y

8. Bitschnau KW, Firth P, Wasner M. Social work in hospice and palliative care in Europe: Findings from an EAPC survey. *Palliat Support Care.* (2020) 18:662–69. doi: 10.1017/S1478951520000279

9. Middleton AA, Head BA, Remke SS. Role of the hospice and palliative care social worker #390. *J Palliat Med.* (2020) 23:573–74. doi: 10.1089/jpm.2019.0698

10. Lin HY, Chen CI, Lu CY, Lin SC, Huang CY. Nurses' knowledge, attitude, and competence regarding palliative and end-of-life care: a path analysis. *PeerJ.* (2021) 9:e11864. doi: 10.7717/peerj.11864

11. Wang HA, Wang DL, Chen YH, Yuan FF, Yang Q, A. qualitative study on nursing experience of hospice care specialist nurse for patients with advanced cancer. *Chin Community Doc.* (2021) 37:134–35. doi: 10.3969/j.issn.1007-614x.2021.32.064

12. Wu X, Zhang X, Zhang J, Cui X. Analysis of knowledge, attitude and behavior of oncology medical staff in palliative care. *Ann Palliat Med.* (2020) 9:985–92. doi: 10.21037/apm-20-851

13. Shu ZQ, Wang YT Li TT, Jing LM, Sun XM. Instrument development of health providers' Knowledge, Attitude and Practice of Hospice Care Scale in China. *Int J Health Plann Manage.* (2021) 36:364–80. doi: 10.1002/hpm.3074

14. Teng XH, Tang MC, Jing LM, Xu YF, Shu ZQ. Healthcare provider knowledge, attitudes, and practices in hospice care and their influencing factors: a cross-sectional study in Shanghai. *Int J Health Policy Manag.* (2022) 11:3090–100. doi: 10.34172/ijhpm.2022.6525

15. Rosenstock IM, Strecher VJ, Becker MH. Social learning theory and the Health Belief Model. *Health Educ Q.* (1988) 15:175–83. doi: 10.1177/109019818801500203

16. He J, Wan L, Luo B. Intentions and influencing factors regarding natural childbirth among urban pregnant women in China, based on the theory of reasoned action and structural equation modeling. *J Int Med Res.* (2019) 47:4482–91. doi: 10.1177/0300060519862089

17. Glanz K, Rimer KB, Viswanath K. Theory of reasoned action, theory of planned behavior, and the integrated behavioral model. In: *Health behavior: Theory, Research, and Practice,* Glanz K, Rimer BK, Viswanath V. (eds.). Jossey-Bass/Wiley. p. 95–124.

18. Hu, LT, Bentler, PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Equ Modeling.* (1999) 6:1–55. doi: 10.1080/10705519909540118

19. Xu YF, Jing LM, Teng XH, Shu ZQ Li SJ. Survey on practice of hospice care and influencing factors among health providers in Shanghai. *Chin J Gen Pract.* (2021) 20:562–67. doi: 10.3760/cma.j.cn114798-20200815-00910

20. Zhu C, Miao ZL, Wei XA. Investigation on knowledge, belief and practice of hospice care among cancer nurses and its related factors. *Int J Nursing.* (2021) 40:3677–81. doi: 10.3760/cma.j.cn221370-20191230-01037

21. Teng XH, Shu ZQ, Jing LM, Xu YF. Survey on knowledge and influencing factors of hospice care among health providers in Shanghai. *Chin J Gen Pract.* (2021) 20:452–57. doi: 10.3760/cma.j.cn114798-20200815-00908

22. Leal-Costa C, Tirado GS, Ramos-Morcillo AJ, et al. Communication skills and professional practice: does it increase self-efficacy in nurses? *Front Psychol.* (2020) 11:1169. doi: 10.3389/fpsyg.2020.01169

23. Chen L, Li XH, Pan X, Pan QN, Huang HQ, Tao PY, et al. Nurses' knowledge, attitudes, and willingness to practice hospice care: an analysis of influencing factors. *PLoS One.* (2022) 17:e259647. doi: 10.1371/journal.pone.0259647

24. Sheeran P, Maki A, Montanaro E, Avishai-Yitshak A, Bryan A, Klein WM, et al. The impact of changing attitudes, norms, and self-efficacy on health-related intentions and behavior: A meta-analysis. *Health Psychol.* (2016) 35:1178–88. doi: 10.1037/hea0000387

25. Billings ME, Engelberg R, Curtis JR, Block S, Sullivan AM. Determinants of medical students' perceived preparation to perform end-of-life care, quality of end-of-life care education, and attitudes toward end-of-life care. *J PALLIAT MED.* (2010) 13:319–26. doi: 10.1089/jpm.2009.0293

26. Lü ZZ. *Health Education and Health Promotion.* Beijing: Peking University Medical Press. (2002).

27. Xu YF, Wang YT, Teng XH, Jing LM, Shu ZQ Li SJ, et al. Training needs and influencing factors of hospice care for health providers in Shanghai. *Chin J Gen Pract.* (2021) 20:470–74. doi: 10.3760/cma.j.cn114798-20200815-00911

28. Zheng R, Lee SF, Bloomer MJ. How nurses cope with patient death: A systematic review and qualitative meta-synthesis. *J Clin Nurs.* (2018) 27:e39–49. doi: 10.1111/jocn.13975

29. Wu XY, Zhou ZH, Zhang YH, Lin XY, Zhang M, Pu FL, et al. Factors associated with behaviors toward end-of-life care among chinese oncology nurses: a cross-sectional study. *Asian Nurs Res (Korean Soc Nurs Sci).* (2021) 15:310–16. doi: 10.1016/j.anr.2021.10.003

30. Aghdam AM, Aghaei MH, Hassankhani H, Rahmani A. Awareness and attitude of nurses in regard to providing hospice care. *Asian Pac J Cancer Prev.* (2015) 16:6941–45. doi: 10.7314/apjcp.2015.16.16.6941

31. Holland DE, Vanderboom CE, Dose AM, Moore D, Robinson KV, Wild E, et al. Death and grieving for family caregivers of loved ones with life-limiting illnesses in the era of COVID-19: considerations for case managers. *Prof Case Manag.* (2021) 26:53–61. doi: 10.1097/NCM.0000000000000485

32. Bar-Sela G, Schultz MJ, Elshamy K, Rassouli M, Ben-Arye E, Doumit M, et al. Training for awareness of one's own spirituality: a key factor in overcoming barriers to the provision of spiritual care to advanced cancer patients by doctors and nurses. *Palliat support care.* (2019) 17:345–52. doi: 10.1017/S147895151800055X

33. Weinstein ND, Rothman AJ. Commentary: revitalizing research on health behavior theories. *Health Educ Res.* (2005) 20:294–97. doi: 10.1093/her/cyg125

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Seasonal patterns in the epidemiology of Bell's palsy in Hungary

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Introduction: Epidemiological data on Bell's palsy are vital for elucidating disease prevalence and enhancing therapeutic options. Our objective was to explore the prevalence and possible risk factors associated with Bell's palsy recurrence in the Clinical Center of the University of Debrecen service area. Secondary data analysis was performed using hospital discharge data, including patient information and comorbidities.

Methods: Data was obtained from the Clinical Center of the University of Debrecen, on Bell's palsy patients who were treated at the hospital between January 1, 2015 and December 31, 2021. Multiple logistic regression analysis was used to examine the factors associated with Bell's palsy recurrence.

Results: Of the 613 patients analyzed, 5.87% had recurrent paralysis, and the median time interval between episodes was 315 days. Hypertension was significantly associated with Bell's palsy recurrence. Moreover, seasonal distribution analysis revealed that the number of Bell's palsy episodes was higher in colder seasons, with spring and winter having a significantly higher number of episodes than summer and autumn.

Discussion: This study provides insights into the prevalence and associated risk factors of Bell's palsy recurrence, which could aid in its management and help reduce the long-term consequences of the disease. Further research is necessary to determine the precise mechanisms underlying these findings.

KEYWORDS

facial nerve paralysis, Bell's palsy, recurrence, seasonality, epidemiology

1. Introduction

Despite the fact that Bell's palsy is a widespread condition, the epidemiological data on the disease are scarce (1). Bell's palsy can be described as an idiopathic, rapid-onset facial nerve paralysis. It is the most prevalent cause of facial paralysis, and it is defined by the sudden development of lower motor neuron weakening in the facial nerve with no apparent explanation (2).

Infectious, immunological and ischemic processes are all implicated in the pathogenesis of Bell's palsy (3). The most likely explanation is still the viral one, which suggests that the neurotropic herpes simplex (HSV-1, HSV-2) and Varicella zoster viruses reactivated in the geniculate ganglion (4, 5). In addition, other viral infections and autoimmune disease has also been suggested as potential pathomechanisms (6).

In different groups, the yearly incidence of Bell's palsy has been found to range from 11 to 40/100,000 people (7), with a one-in-sixty chance of developing the disease in one's lifetime. In around 71% of untreated instances, the disease resolves completely (8, 9).

About 30% of patients are expected to experience long-term consequence, including incomplete eye closure, crocodile tears, oral incompetence during eating and drinking, articulation problems, muscular contracture, synkinesis, and facial discomfort. Facial palsy can negatively affect psychological wellbeing, quality of life and cause functional and aesthetic deficits (10). Patients with face paresis could experience lower social functioning, since verbal communication and the expression of emotions are impaired by loss of facial function (11). The prevalence of anxiety and depression are higher among them (12), and psychosocial dysfunctions related to facial palsy are more common in women (13).

The variables linked to the occurrence of Bell's palsy, such as age, gender, season, pregnancy, and diabetes mellitus, have been subjected to much debate (9, 10, 14).

The aim of this research was to explore the possible influencing factors and to estimate the prevalence of the reoccurrence of Bell's palsy in the service area of the Clinical Center of University of Debrecen. Moreover, we also aimed to describe the seasonality of the disease.

2. Materials and methods

Based on the information from the Clinical Center of University of Debrecen, secondary data analysis was carried out using hospital discharge data (including all outpatient and inpatient medical records). Bell's palsy cases were identified by ICD-10 codes (G51.0). The data contained detailed information (age, gender, risk factors, date of admission and discharge, comorbidities, side of the paralysis) on Bell's palsy patients treated at the institution between January 1, 2015, and December 31, 2021. To identify reoccurrence of cases, we defined a minimum 90 days interval between the last and the next admission of patients (15).

The occurrence of all patients was investigated according to the months of the admission. To investigate seasonal variations in the occurrence of BP, months was classified as follows: March to May as spring, June to August as summer, September to November as autumn, and December to February as winter.

The total sample consisted of 650 patients. Patients with missing information on the side of paralysis ($n = 37$) were excluded, thus the final sample consisted of 613 patients with BP.

Text mining tools were also used to assure the diagnoses of International Classification of Diseases (ICD) codes based on free text analysis. Proportions with 95% confidence intervals were calculated for episodes in seasons. Multiple logistic regression model was used to explore the factors associated with the occurrence of Bell's palsy. Odds ratio (OR) with the corresponding 95% confidence intervals were calculated to determine the strength of association. Stata v17 (StataCorp. 2021. Stata Statistical Software: Release 17. College Station, TX: StataCorp LLC.) was used for statistical analysis; $p < 0.05$ indicated statistical significance.

The study was approved by the Regional Ethical Committee of University of Debrecen [5678-2021].

3. Results

Of the 613 patients 51.71% were male ($n = 317$) and 48.29% were female ($n = 296$). The age of the studied patients varied between 1 and 96 years, the mean age (±SD) was 43.02 ± 22.96 years.

We analyzed seasonal distribution of Bell's palsy based on episodes of care for the 613 people within the investigated period (another episode was considered separate if it occurred more than 90 days after the previous one) (15). Figure 1 shows the number of episodes in relation to seasonality. The highest number of episodes occurred in the colder seasons. The number of episodes were significantly higher in spring and winter compared to the warmer seasons. Although, there was no significant difference between seasons regarding recurrence, the highest peak was observed in autumn (Figure 2).

Thirty-six patients (5.87%) had recurrent paralysis 90 days after last admission. The median time interval between the last and next episode was 315 days.

Table 1 shows the baseline characteristics and most prevalent comorbidities occurred among patients with recurrent paresis and seasons at occurrence. Out of all the non-recurrent cases, 8.15% had non-insulin-dependent diabetes mellitus (NIDDM), 5.20% had hypertension, 1.04% had hyperlipidemia, and 0.87% had headache. On the other hand, among the recurrent cases, 11.11% had NIDDM, 16.67% had hypertension, 5.56% had hyperlipidemia, and 2.78% had headache.

Table 2 shows the associated factors with recurrence in a multiple logistic regression model. The results showed that the age group was not significantly associated with Bell's palsy recurrence ($OR = 0.99$, $p = 0.095$, 95% CI: 0.078–1.01). Gender was also not significant ($OR = 1.45$, $p = 0.334$, 95% CI: 0.68–3.11). However, hypertension was found to be a significant predictor of Bell's palsy recurrence ($OR = 4.16$, $p = 0.007$, 95% CI: 1.47–11.79). The analysis also revealed that the season was a significant predictor of Bell's palsy recurrence, where autumn compared with spring ($OR = 3.16$, $p = 0.031$, 95% CI: 1.11–8.97) and dyslipidemia ($OR = 7.95$, $p = 0.024$, 95% CI: 1.31–48.17) were significantly associated with higher odds of recurrence.

4. Discussion

In summary, age and gender were not found to be a significant factor in the model. In the present research, the mean age (±SD) was 43.02 ± 22.96 years, and 51.71% of the patients were male, which showed similar pattern to the existing literature regarding demographic composition of patients with Bell's palsy (16). According to research, the incidence of Bell's palsy is higher in adults aged 20 to 50 (9, 17–19), whereas others indicated that those aged 60 and older are more affected (20–24).

In this study, recurrent Bell's palsy was observed in 36 cases (5.87%), which was occurred mostly within 1 year after the last admission. The recurrent Bell's palsy, which can develop on either the ipsilateral or contralateral side of the first episode, is more likely to occur in the first 2 years from the onset (25). Findings of different studies are consistent with our findings, as they suggest a recurrence rate between 2.6 and 15.2% of individuals, who have

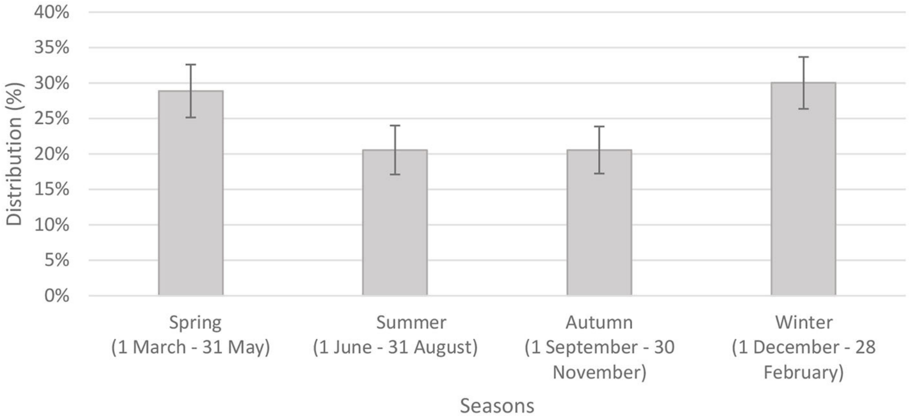

FIGURE 1
Seasonal distribution of episodes of care with 95% confidence intervals ($n = 613$).

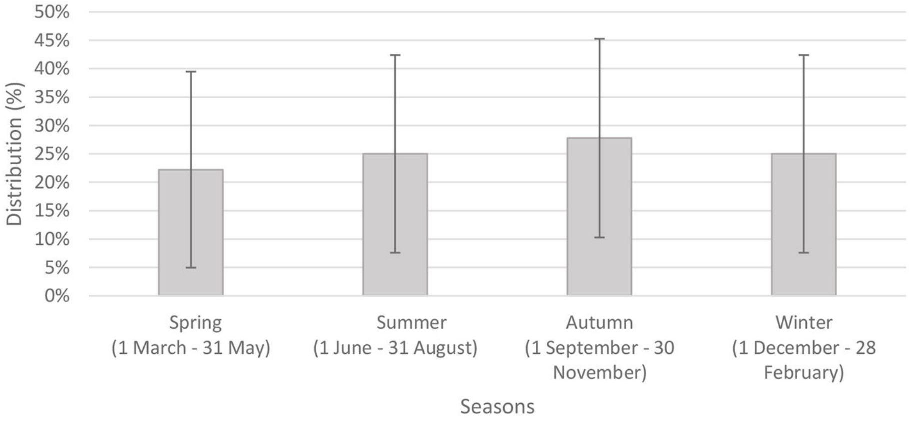

FIGURE 2
Seasonal distribution of recurrent episodes of care with 95% confidence intervals ($n = 36$).

already experienced an initial episode, are affected by recurrent facial palsy (26).

Our results showed that some factors were found to be associated with the recurrence such as hyperlipidemia, hypertension and seasonal factors (specifically autumn), while age, gender and NIDDM were not significant predictors.

In our study, only hypertension showed significant association with recurrence. Patients with Bell's palsy had a higher rate of arterial hypertension (27). The delicate balance of pressure systems inside the facial canal is disrupted by blood pressure variations, particularly diastolic hypertension, resulting in impaired intrafunicular circulation and, as a result, nerve injury (27).

According to the literature, diabetes mellitus, as well as hypertension, dyslipidemia, and the combination of all three comorbidities (diabetes mellitus, hypertension, and dyslipidemia) in a single patient, may affect the initial severity of blood pressure (3).

The influence of diabetes mellitus, hypertension, and dyslipidemia on the result of the facial nerve in Bell's palsy is still the subject of an ongoing debate. Some authors have established in more recent research that there is no link between diabetes mellitus, hypertension, dyslipidemia, and eventual recovery from Bell's palsy (1).

According to our results, Bell's palsy has been observed to occur more likely in spring and winter, while reoccurrence showed highest peak in autumn. Others also found that a higher incidence occurs during the cold seasons (28, 29). The association between seasons and the disease can be explained by several reasons. Kim and Park (30) presented that although low temperature and humidity are related to the onset of Bell's palsy, a marked drop in temperature (autumn) has a greater impact on the occurrence of BP than the actual low temperature (winter). Several studies have also shown associations between temperature differences and increased probability of Bell's palsy occurrence (2). Low temperature, extreme wind chill factors, and unexpected shift in atmospheric pressure have all been associated with an increased risk of Bell's palsy (30, 31). As noted earlier, the consequences of seasons and meteorological circumstances differ by climate and by techniques of data gathering and statistics, underlining the need for further well-designed studies from diverse climatic zones (30).

TABLE 1 Baseline characteristics and prevalence of most common comorbidities and seasons for recurrence of Bell's palsy.

Influencing factors	Baseline sample ($n = 613$)	Reccurent ($n = 36$)	Non-recurrent ($n = 577$)	p-value
Demographic data				
Age (65-X)	140 (22.84%)	7 (19.44%)	133 (23.05%)	0.617
Gender (male)	317 (51.71%)	20 (55.56%)	276 (47.83%)	0.368
Comorbidities				
NIDDM	51 (8.32%)	4 (11.11%)	47 (8.15%)	0.532
Hyperlipidaemia	**8 (1.31%)**	**2 (5.56%)**	**6 (1.04%)**	**0.021**
Hypertension	**36 (5.87%)**	**6 (16.67%)**	**30 (5.20%)**	**0.005**
Headache	6 (0.98%)	1 (2.78%)	5 (0.87%)	0.258
Side of paralysis				
Right side	215 (47.99%)	15 (46.88%)	200 (48.08%)	0.837
Left side	225 (50.22%)	16 (50.00%)	209 (50.24%)	0.837
Both sides	8 (1.79%)	1 (3.13%)	7 (1.68%)	0.837
Season				
Spring	177 (28.87%)	8 (22.22%)	169 (29.29%)	0.523
Summer	126 (20.55%)	9 (25.00%)	117 (20.28%)	0.524
Autumn	126 (20.55%)	10 (27.78%)	116 (20.10%)	0.525
Winter	184 (30.02%)	9 (25.00%)	175 (30.33%)	0.526

NIDDM, non-insulin-dependent diabetes mellitus.
Bold indicates significant results ($p < 0.05$).

TABLE 2 Multiple logistic regression model of possible influencing factors on Bell's palsy recurrence.

New episode	OR*	p-value	95% CI	
Age group (65-X/1–64)	0.99	0.095	0.078	1.01
Gender (female/male)	1.45	0.334	0.68	3.11
Hypertension (presence/absence)	**4.16**	**0.007**	**1.47**	**11.79**
Season (summer/spring)	1.98	0.222	0.66	5.90
Season (autumn/spring)	**3.16**	**0.031**	**1.11**	**8.97**
Season (winter/spring)	0.87	0.801	0.29	2.63
Dyslipidemia (presence/absence)	7.95	0.024	1.31	48.17

*The model was adjusted for each variable included in the table and for side of Bell's palsy, T2DM, headache.
OR, odds ratio; CI, confidence interval.
Bold indicates significant results ($p < 0.05$).

The specific etiology of Bell's palsy needs to be determined in order to develop targeted treatment strategies (2). Immediate treatment and referral to specialist is essential to increase the chance of full recovery (14). However, patient's self-perception of facial appearance is also necessary to evaluate the success of surgical and non-surgical interventions (32). Facial palsy has substantial impact on a individuals' life, thus measuring impairment and disability is particularly important. Several instruments have been developed to measure the impact of facial dysfunction on quality of life in facial palsy patients. The most widely used patient-reported measures are Facial Clinimetric Evaluation (FaCE) (33) scale and the Facial Disability Index (FDI) (34), which measure both physical and psychosocial function associated with facial palsy (13). Since the disease has significant psychosocial consequences, psychological and social aspects of facial palsy should be also considered during the treatment of patients in order to achieve a better quality of life.

4.1.Strength and limitation

The strength of this study is that the database is representative to the Eastern Hungarian population, and we were able to investigate a time period. The study has some limitations. First, although the studied population is large, extrapolation of results should be made with caution, because our study is not representative for the whole Hungarian population. We used administrative database containing hospital discharge data, in which several lifestyle and socioeconomic factors could be underestimated; therefore, these factors were not involved in this secondary data analyses.

5. Conclusion

Our findings highlight the importance of considering factors (gender, hypertension, season) when managing patients with Bell's palsy. Bell's palsy was more frequently observed throughout the winter and spring seasons, while the peak of reoccurrence was in autumn.

There has been a lot of debate over whether underlying comorbidities like diabetes and hypertension have a role in the recurrence of Bell's palsy.

Further research is needed to better understand the underlying mechanisms and etiology of disease to prevent recurrent Bell's palsy and improve the patients' quality of life.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Author contributions

Study design, manuscript drafting, data collection, and analysis and interpretation: EV and AN. Critical revision of the manuscript: UB, IS, LH, and NK. All authors approval of the final version for publication.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Lee JS, Kim YH. Epidemiological trends of Bell's palsy treated with steroids in Korea between 2008 and 2018. *Muscle Nerve.* (2021) 63:845–51. doi: 10.1002/mus.27213

2. Zhang W, Xu L, Luo T, Wu F, Zhao B, Li X. The etiology of Bell's palsy: a review. *J Neurol.* (2020) 267:1896–905. doi: 10.1007/s00415-019-09282-4

3. Psillas G, Dimas GG, Sarafidou A, Didangelos T, Perifanis V, Kaiafa G, et al. Evaluation of effects of diabetes mellitus, hypercholesterolemia and hypertension on Bell's palsy. *J Clin Med.* (2021) 10:2357. doi: 10.3390/jcm10112357

4. Murakami S, Mizobuchi M, Nakashiro Y, Doi T, Hato N, Yanagihara N. Bell palsy and herpes simplex virus: identification of viral DNA in endoneurial fluid and muscle. *Ann Intern Med.* (1996) 124:27–30. doi: 10.7326/0003-4819-124-1_Part_1-199601010-00005

5. Steiner I. Human herpes viruses latent infection in the nervous system. *Immunol Rev.* (1996) 152:157–73. doi: 10.1111/j.1600-065X.1996.tb00915.x

6. Greco A, Gallo A, Fusconi M, Marinelli C, Macri GF, de Vincentiis M. Bell's palsy and autoimmunity. *Autoimmun Rev.* (2012) 12:323–8. doi: 10.1016/j.autrev.2012.05.008

7. De Diego-Sastre JI, Prim-Espada MP, Fernández-García F. [The epidemiology of Bell's palsy]. *Rev Neurol.* (2005) 41:287–90. doi: 10.33588/rn.4105.2004593

8. Somasundara D, Sullivan F. Management of Bell's palsy. *Aust Prescr.* (2016) 40:94–6. doi: 10.18773/austprescr.2017.030

9. Peitersen E. Bell's palsy: the spontaneous course of 2,500 peripheral facial nerve palsies of different etiologies. *Acta Otolaryngol Suppl.* (2002) 122:4–30. doi: 10.1080/000164802320401694

10. Eviston TJ, Croxson GR, Kennedy PGE, Hadlock T, Krishnan AV. Bell's palsy: aetiology, clinical features and multidisciplinary care. *J Neurol Neurosurg Psychiatry.* (2015) 86:1356–61. doi: 10.1136/jnnp-2014-309563

11. Coulson SE. O'dwyer NJ, Adams RD, Croxson GR. Expression of emotion and quality of life after facial nerve paralysis. *Otol Neurotol.* (2004) 25:1014–9. doi: 10.1097/00129492-200411000-00026

12. Hotton M, Huggons E, Hamlet C, Shore D, Johnson D, Norris JH, et al. The psychosocial impact of facial palsy: a systematic review. *Br J Health Psychol.* (2020) 25:695–727. doi: 10.1111/bjhp.12440

13. Bylund N, Hultcrantz M, Jonsson L, Marsk E. Quality of life in Bell's palsy: correlation with sunnybrook and house-brackmann over time. *Laryngoscope.* (2021) 131:E612–8. doi: 10.1002/lary.28751

14. Holland NJ, Weiner GM. Recent developments in Bell's palsy. *BMJ.* (2004) 329:553–7. doi: 10.1136/bmj.329.7465.553

15. Steinhäuser J, Volk GF, Thielker J, Geitner M, Kuttenreich AM, Klingner CM, et al. Multidisciplinary care of patients with facial palsy: treatment of 1220 patients in a german facial nerve center. *JCM.* (2022) 11:427. doi: 10.3390/jcm11020427

16. Zhao H, Zhang X, Tang Y, Zhu J, Wang XH, Li ST. Bell's palsy: clinical analysis of 372 cases and review of related literature. *Eur Neurol.* (2017) 77:168–72. doi: 10.1159/000455073

17. Campbell KE. Effects of climate, latitude, and season on the incidence of Bell's palsy in the US Armed Forces, October 1997 to September 1999. *Am J Epidemiol.* (2002) 156:32–9. doi: 10.1093/aje/kwf009

18. El Tallawy HNA, Farghaly WMA, Rageh TA, Shehata GA, Metwaly NA, Abo Elftoh N, et al. Epidemiology of major neurological disorders project in Al Kharga district, New Valley, Egypt. *Neuroepidemiology.* (2010) 35:291–7.

19. Khedr EM, Fawi G, Abbas MAA, El-Fetoh NA, Zaki AF, Gamea A. Prevalence of Bell's palsy in Qena Governorate, Egypt. *Neurol Res.* (2016) 38:663–8. doi: 10.1080/01616412.2016.1190121

20. Savettieri G, Salemi G, Rocca WA, Meneghini F, Santangelo R, Morgante L, et al. Incidence and lifetime prevalence of Bell's palsy in two Sicilian municipalities. *Acta Neurol Scand.* (1996) 94:71–5. doi: 10.1111/j.1600-0404.1996.tb00043.x

21. Chang YS, Choi JE, Kim SW, Baek SY, Cho YS. Prevalence and associated factors of facial palsy and lifestyle characteristics: data from the Korean National Health and Nutrition Examination Survey 2010–2012. *BMJ Open.* (2016) 6:e012628. doi: 10.1136/bmjopen-2016-012628

22. Brandenburg NA, Annegers JF. Incidence and risk factors for Bell's Palsy in Laredo, Texas: 1974–1982. *Neuroepidemiology.* (1993) 12:313–25. doi: 10.1159/000110333

23. Nicoletti A, Sofia V, Bartoloni A, Bartalesi F, Marletta C, Lo Bartolo ML, et al. Lifetime prevalence of Bell's palsy in rural bolivia: a door-to-door survey. *Neuroepidemiology.* (2002) 21:100–4. doi: 10.1159/000048624

24. Rowlands S, Hooper R, Hughes R, Burney P. The epidemiology and treatment of Bell's palsy in the UK. *Eur J Neurol.* (2002) 9:63–7. doi: 10.1046/j.1468-1331.2002.00343.x

25. Cirpaciu D, Goanta C, Cirpaciu M. Recurrences of Bell's palsy. *J Med Life.* (2014) 7(Spec Iss 3):68–77.

26. Mancini P, Bottaro V, Capitani F, De Soccio G, Prosperini L, Restaino P, et al. Recurrent Bell's palsy: outcomes and correlation with clinical comorbidities. *Acta Otorhinolaryngol Ital.* (2019) 39:316–21. doi: 10.14639/0392-100X-2415

27. Paolino E, Granieri E, Tola MR, Panarelli MA, Carreras M. Predisposing factors in Bell's palsy: a case-control study. *J Neurol.* (1985) 232:363–5. doi: 10.1007/BF00313837

28. Spengos K, Sameli S, Stouraitis G, Kolias A, Koulouri O, Kokkinos Z, et al. Seasonal variation of Bell's palsy in Athens, Greece - a hospital-based retrospective evaluation over fifteen years. *Eur Neurol.* (2006) 55:84–8. doi: 10.1159/000092779

29. Hsieh RL, Wang LY, Lee WC. Correlation between the incidence and severity of Bell's palsy and seasonal variations in Taiwan. *Int J Neurosci.* (2013) 123:459–64. doi: 10.3109/00207454.2013.763804

30. Kim MH, Park SY. Population-based study and a scoping review for the epidemiology and seasonality in and effect of weather on Bell's palsy. *Sci Rep.* (2021) 11:16941. doi: 10.1038/s41598-021-96422-4

31. Kokotis P, Katsavos S. Effects of wind chill factor, temperature and other meteorological parameters on the incidence of Bell's palsy: results based on a retrospective, 7-year long, greek population study. *Neuroepidemiology.* (2015) 45:44–9. doi: 10.1159/000433542

32. Ho AL, Scott AM, Klassen AF, Cano SJ, Pusic AL, Van Laeken N. Measuring quality of life and patient satisfaction in facial paralysis patients: a systematic review of patient-reported outcome measures. *Plast Reconstr Surg.* (2012) 130:91–9. doi: 10.1097/PRS.0b013e318254b08d

33. Kahn JB, Gliklich RE, Boyev KP, Stewart MG, Metson RB, McKenna MJ. Validation of a patient-graded instrument for facial nerve paralysis: the FaCE scale. *Laryngoscope.* (2001) 111:387–98. doi: 10.1097/00005537-200103000-00005

34. VanSwearingen JM, Brach JS. The Facial Disability Index: reliability and validity of a disability assessment instrument for disorders of the facial neuromuscular system. *Phys Ther.* (1996) 76:1288–98. discussion 1298–300. doi: 10.1093/ptj/76.12.1288

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Global estimates of rehabilitation needs and disease burden in tracheal, bronchus, and lung cancer from 1990 to 2019 and projections to 2045 based on the global burden of disease study 2019

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Background: The global cancer burden is substantial and spiraling. Although rehabilitation specialists could offer assistance, oncologic rehabilitation is still underutilized and not a routine part of clinical oncology guidelines worldwide. Global investigations of disease prevalence and years lived with disability (YLDs) for tracheal, bronchus, and lung (TBL) cancer are valuable for facilitating clinical practice improvement and health resource management. The objective of this study is to report the global estimates of rehabilitation needs and disease burden of TBL cancers from 1990 to 2019 and provide predictions for 2045.

Methods: To estimate the need for rehabilitation, the data used from the Global Burden of Disease Study 2019 to calculate the prevalence, YLDs, and the attributable risk factors of TBL cancer. The Bayesian age-period-cohort model and Auto-Regressive Integrated Moving Average model were established to forecast the future health burden. All analyses were done at the global level and then some in the aggregation with the seven World Bank regions. All the data were analyzed by R software (x64 version 4.2.1) and Microsoft Excel (version 2019).

Results: Globally in 2019, 3,212,307 cases of TBL cancer (95% UI 2,937,037-3,488,346) could have benefitted from rehabilitation, contributing to 544,215 (95% UI 396,134-700,099) YLDs. Over the past 30 years, the age-standardized rate (ASR) of prevalence (EAPC = 0.51) and YLDs (EAPC = 0.03) increased. Throughout this period, the global prevalence and YLDs counts were greater in males than females. The ASR of prevalence and YLDs are projected to show a slight downward trend by 2045 on the global scale, the overall prevalence and YLDs due to TBL cancer are likely to increase further, but all indicators show a growing trend in females.

Conclusion: TBL cancer remains one of the major public health issues globally. According to the forecasted results, the burden of YLDs due to TBL cancer will continue to rise, and the increment is higher in females than males. A rising number of patients worldwide will benefit from rehabilitation services in the future to achieve precise control and management throughout the TBL cancer patient lifecycle.

KEYWORDS

years lived with disability, prevalence, rehabilitation need, projection, TBL cancer

1 Introduction

Tracheal, bronchial, and lung (TBL) cancer has the highest mortality rate globally and is the second largest group of new cancer cases (1). In 2019, it was reported that the percentage of disability-adjusted life-years (DALYs) among all diseases for TBL cancer was ranked 17th in all ages and was ranked 5th in 50-74 years (2). It imposes a huge global health threat. In recent years, advances in cancer treatment options and technology have increased life expectancy and reduced the mortality rate of lung cancer. The improved prognosis for lung cancer patients draws the time course of the disease closer to that of chronic diseases (3). However, the malignant disease itself, the burden of cancer-related symptoms, and the side effects of cancer treatment can all impair the quality of life and functional status of lung cancer patients and survivors, even leading to permanent disability (4, 5). According to recent studies, tracheal, bronchial, and lung cancers will cost the global economy $3.9 trillion between 2020 and 2050, placing a heavy financial burden on patients, families, and society (6).

The current global health challenges include the dramatic increase in the incidence of non-communicable chronic diseases and the increasing number of people lived in with restricted function (2, 7), which are particularly pronounced among people with TBL cancer. As disability accounts for a large component of the disease burden, it also accounts for a huge share of health expenditure. Conditions with higher disability weight contributed more to years lived with disability (YLDs) than others, corresponding to more rehabilitation needs. The disability (8) weights for the diagnosis and primary therapy phase, the metastatic phase, and the terminal phase of TBL cancer are 0.28, 0.451, and 0.54, which are greater than the disability weight for severe lower back pain. As a result, there is a growing interest in health policies and interventions that can extend TBL cancer patient's life and promote health. Strengthening the capacity of health systems to provide rehabilitation services (9, 10) could help reduce the impact of disability and optimize remaining functions. Growing evidence shows that pulmonary rehabilitation is beneficial to patients with lung cancer and cost-effective (11–14). Therefore, pulmonary rehabilitation is gradually incorporated into the multidisciplinary management of lung cancer (15).

Despite the known benefits of rehabilitation for TBL cancer patients which translate to substantial economic benefits across the world, there remains a high prevalence of unmet rehabilitation needs in cancer patients. Cancer patients and survivors face many adverse symptoms related to the disease itself or its treatments. Although there are many types of symptoms, many are physical impairments, such as cachexia, lymphoedema, breathlessness, and limited range of motion in joints (16). The overall improved survival rate in the face of prolonged physical dysfunction creates an immense need for both acute and long-term rehabilitation services (17). However, rehabilitation has not been a priority in cancer care in all countries and remains under-resourced. This is not surprising, given the primary concern of oncologists and patients is to prevent tumor progression or reoccurrence through cancer treatment. There also has been a lack of public awareness about cancer rehabilitation and limited access to cancer rehabilitation specialists (18, 19).

The Global Burden of Disease (GBD) Study 2019 provides annual estimates of health losses from 369 diseases and injuries and associated risk factors for 204 countries and territories from 1990 to 2019 (2). All data are available and accessible to researchers through the GBD online system, facilitating the use of these data to analyze changing trends in different diseases. The traditional measures of disease burden mainly include incidence, prevalence, mortality, etc., which only consider the survival quantity, not the quality of life. Hence, in this study, we use data from the Global Burden of Disease Study 2019 to assess the need for rehabilitation by presenting prevalence and YLDs for TBL cancers (20), thus challenging the current dilemma of cancer rehabilitation.

The purpose of this study is to provide up-to-date insights into the rehabilitation needs and the burden of TBL cancer from 1990 to 2019 and attributable risk factors by gender and age. We also attempt to make projections to 2045, which will help guide the allocation of rehabilitation resources and the formation of a multidisciplinary model of cancer care, as well as precise control and full life-cycle management of TBL cancer. Specifically, we try to answer the following questions:① How large are the rehabilitation needs and disease burden of TBL cancer in 2019 (e.g., in nominal numbers, age-standardized rates), and how have those values evolved since 1990? ②What risk factors contribute to the increase of YLDs in TBL cancer? Which of them is modifiable? ③After 2019, what are the trends of rehabilitation needs and disease burden for the next 26 years?

2 Methods

2.1 Overview

TBL cancer was identified using the International Classification of Diseases(ICD) codes, Tenth Revision and Ninth Revision (ICD-10 and ICD-9, respectively), which was defined as the ICD-10 code C33, C34–C34.92, Z12.2, Z80.1–Z80.2, Z85.1–Z85.20 and the ICD-9 code 162–162.9, 209.21, V10.1–V10.20, V16.1–V16.2, V16.4–V16.40 (2, 21). The GBD study evaluated 369 diseases and injuries and associated 87 risk factors for 204 countries, 21 regions, and 7 super-regions (2). In the GBD project, uncertainty estimation was performed by generating 1000 draws for each estimate. The custom aggregation for this study was done at the draw level, taking 2.5th and 97.5th percentile to generate 95% uncertainty intervals (UI), standardized by GBD standard population and reported per 100,000 populations. In addition to the absolute number and rate per 100,000 persons, we also applied the age-standardized rate (ASR) per 100,000 persons, including the age-standardized prevalence rate (ASPR) and age-standardized YLDs rate (ASYR), given the heterogeneity in the age structure of the population.

2.2 Measures

Previous studies estimated the rehabilitation needs through YLDs (20, 22–24), which is the measure in the GBD study that focuses exclusively on non-fatal health losses. The YLDs refer to years lived with any short-term or long-term health loss weighted for severity by the disability weights. Sequelae were each mapped to a health state with an associated disability weight (8), valuing the severity of the sequela. The four common sequelae for TBL cancers in GBD and their corresponding disability weights were considered for cancer (Supplementary 1 Table S1) (2). Disability weight is used to calculate years lived with disability (YLD) for these outcomes in a given population, which represented the magnitude of health loss associated with specific health outcomes. The weights are measured on a scale from 0 to 1, where 0 equals a state of full health and 1 equals death. The prevalence is a measure of disease burden, which is defined as the proportion of people in a population who are a case of a disease, injury, or sequela.

2.3 Data sources

Previous studies have described the detailed methodology of processes for estimating the burden and rehabilitation needs of cancers, and risk factor quantification in the GBD 2019 Study (2, 20, 25). We extracted data on the global prevalence and YLDs of TBL cancer (1990 to 2019) from the official website of the GBD 2019 Study (2, 26), which is available from the Institute for Health Metrics and Evaluation (IHME) for free.

We chose "Global" and seven "World Bank Regions" ("East Asia & Pacific –WB", "Europe & Central Asia –WB", "Latin America & Caribbean –WB", "Middle East & North Africa –WB", "North America", "South Asia –WB", "Sub-Saharan Africa -WB") (See detailed regional division for Supplementary 2) from the database as the location, "Tracheal, bronchus, and lung cancer" for the cause, "Prevalence" and "YLDs (Years Lived with Disability)" for measures. In this study, we present the prevalence and YLDs for TBL cancer globally by sex and age. The study also presents the percentage change of these indicators from 1990 to 2019 to reflect the trends in cancer burden. And to identify risk factors of YLDs for TBL cancer, we chose "Risk factor" from the database at the GBD Estimate, "percent" for the metric, and "YLDs (Years Lived with Disability)" measures. These risk factors were smoking, ambient particulate matter, high fasting plasma glucose levels, low fruit and vegetable consumption, and exposure to pollutants, such as occupational secondhand smoke, asbestos, radon, household air pollution, occupation silica, occupational nickel, occupational arsenic, occupational diesel, and occupational polycyclic aromatic hydrocarbons, which defined in detail and their relative risk for TBL cancer could be found in a previous article (25).

Additional information including data sources used results, and analytical code can be found at http://ghdx.healthdata.org/gbd-results-tool and https://vizhub.healthdata.org/gbd-compare/. The estimated population of Global was taken from the United Nations World Population Prospects 2019 Revision, by year (up to 2100), age, and sex (https://population.un.org/wpp/Download/Standard/Population/).

2.4 Data management and analysis

All data analyses and image presentations are conducted by Microsoft Excel (version 2019) and the open-source software R (version 4.2.1). Packages included ggplot2 and RColorBrewer.

2.4.1 Description of the past and the present

We showed the secular trend in TBL cancer burden along with its attributable risk factors by sex, year, region, and age. Data on the prevalence and YLDs of TBL cancer were analyzed descriptively. Cases were divided into 5-year age groups to describe the number of prevalence and YLDs in 1990 and 2019.

2.4.2 Analysis of long-term trend

To reflect trends in cancer burden, we also calculated the global change in the number of people with TBL cancer by Microsoft Excel and the estimated annual percentage change (EAPC) by software R in age-standardized prevalence and age-standardized YLDs rates from 1990 to 2019. The EAPC was introduced to measure the temporal trends in age-standardized rates (ASRs). Calculations were based on a regression model fitted to the natural logarithm of the rate, i.e. $y = \alpha + \beta x + \varepsilon$, was fitted to the natural logarithm of the rates, where y was referred to ln(ASR), and x the calendar year (27). EAPC was calculated as $100 \times (\exp^{[\beta]} - 1)$ and its 95% confidence intervals (*CI*s) were obtained from the linear model (27). If the EAPC and the corresponding 95% CI are positive, the detection rate increases; if the EAPC and the corresponding 95% CI are negative, the detection rate decreases; otherwise, it is stable.

2.4.3 Risk factors for TBL cancer burden and rehabilitation

To describe the trends in each risk-outcome pair, we obtained the attributable TBL cancer YLDs globally and in the World Bank Region by sex, year, and age. Then we reported the percent of YLDs owing to TBL cancer which was attributable to smoking, ambient particulate matter, high fasting plasma glucose levels, low fruit and vegetable consumption, and exposure to pollutants.

2.4.4 The future projections of rehabilitation needs and disease burden

The Bayesian age-period-cohort (BAPC) model turned out to be the most appropriate statistical method of projecting the cancer burden compared with a generalized additive model, Nordpred model, Joinpoint model, smooth spline model, and Poisson regression, especially for short-term projections (28–30). In accordance with the characteristics of the BAPC model, and to ensure the accuracy of the prediction, and considering that the cancer burden will continue to change with the rapid development of medical treatment and the continuous updating of cancer treatment methods, our study predicts the demand for rehabilitation and the disease burden by 2045. We performed BAPC model analyses by sex using the BAPC package in R integrated with the nested Laplace approximation (INLA) to predict the prevalence and YLDs in age-standardized rates (ASRs) due to TBL cancer from 2019 to 2045, taking into account rates of change and demographic changes, which have been well documented and accepted in previous studies (31–35).

Auto-Regressive Integrated Moving Average (ARIMA) model was widely used in epidemiological studies to predict future trends (36–38). The ARIMA model was built-in R to predict the number of people with the prevalence and YLDs due to TBL cancer from 2019 to 2045, refer to this study (38) for specific sources of R codes. Based on the predicted results, the model was box-tested and $p > 0.05$ indicates that the model has a good fit effect.

Detailed information about the BAPC model and the ARIMA model, also includes the prediction R codes are given respectively in Supplementary Materials 3, 4. (The prediction plots of our study can be recapitulated from the data information and R codes in these Supplementary Materials.)

3 Results

3.1 The temporal trend in TBL cancer burden and rehabilitation needs in global

On a global scale in 2019, 3,212,307 cases of TBL cancer (95% UI 2,937,037-3,488,346) patients had symptoms that would benefit from rehabilitation services at some point during disease, contributing to 544,215(95% UI 396,134-700,099) YLDs. Over the past 30 years, the prevalence and YLDs of TBL cancer had increased by the 1.32-fold and 1.07-fold increase from 1990, respectively, while the ASPR (EAPC = 0.51) and ASYR (EAPC = 0.03) increased slightly from 1990 to 2019. Throughout this time, the global prevalence and YLDs were greater in males than in females. ASPR (EAPC = -0.18) and ASYR (EAPC =-0.33) in males showed modest declines since 1990, while in females there was an upward trend by ASPR (EAPC =0.45) and ASYR (EAPC =0.8). (Table1)

In 2019, among World Bank (WB) regions, the East Asia & Pacific-WB had the highest need for rehabilitation services with the highest absolute number (prevalence=1,658,888; YLDs=279,857) of TBL cancer, followed by the Europe & Central Asia-WB (prevalence=720,942; YLDs=122,125), while the lowest absolute number (prevalence= 46,144; YLDs=9,848) in Middle East & North Africa-WB. Furthermore, the number of TBL cancer patients increased in all WB regions, with the highest increase in East Asia & Pacific-WB (2.63-fold), while the ASPR and ASYR decreased respectively in Latin America & Caribbean-WB (EAPC =-0.5; -0.68) and North America (EAPC = -0.69; -1.09) from 1990 to 2019. The trends of the ASPR (EAPC =0.2) and ASYR (EAPC = -0.36) are opposite in Europe & Central Asia-WB (Table 1).

Regardless of time and age groups, the males had a higher prevalence and YLDs than females. Globally, both prevalence and YLDs were highest for people aged 45–80 years old and lowest in people aged less than 25 or 95 and older. The female YLDs in the age group 35-90 years old was increasing, gradually narrowing the gap between females and males, especially the significant change between 50-85 years old. In addition, TBL cancer patients between 50-85 years have shown a greater need for rehabilitation (Figure 1).

3.2 Projections of TBL cancer burden and rehabilitation need *via* prevalence and YLDs from 2020 to 2045

The projections of TBL cancer prevalence, YLDs, and corresponding ASRs for 2020–2045 to reflect changes in cancer burden and rehabilitation needs were presented in Figures 2, 3. From 2020 to 2045, ASPR and ASYR of both genders and male TBL cancer patients would decrease, and males showed a more noticeable decline than all gender (Figures 2A, B, 3A, B). However, as for female TBL cancer, there would be a slight upward trend in ASPR and ASYR (Figures 2C, 3C). The projected number of TBL cancer prevalent cases and YLDs would increase steadily (Figures 2D–F, 3D–F), and the absolute number would be much larger in males than that in females, but women had a higher increment than men (Supplementary Material 5). By the year 2045, there would be 3,647,906 male TBL cancer cases and 598,340 YLDs in males, 2,237,459 female prevalent cases, and 350,986 YLDs in females (Figures 3E, F).

TABLE 1 The number of prevalence and YLDs of tracheal, bronchial and lung cancer in global and regions in 1990 and 2019, the change in counts and the estimated annual percentage changes from 1990 to 2019.

Characteristics	Prevalence				YLDs			
	1990 Numbers (95% UI)	2019 Numbers (95% UI)	1990–2019 Change in Counts	1990–2019 EAPC in ASR (95% CI)	1990 Numbers (95% UI)	2019 Numbers (95% UI)	1990–2019 Change in Counts	1990–2019 EAPC in ASR (95% CI)
Global	1385579 (1334784-1443423)	3212307 (2937037-3488346)	1.32	0.51 (-0.98-2.02)	262763 (190730-331420)	544215 (396134-700099)	1.07	0.03 (-3.62-3.83)
Sex								
Female	375419 (358092-392604)	1102899 (989626-1214657)	1.94	0.45 (-1.13-2.05)	69319 (49994-87919)	178776 (128528-231634)	1.58	0.8 (-4.14-5.99)
Male	1010159 (965158-1062112)	2109409 (1895836-2337805)	1.09	-0.19 (-2.5-2.17)	193445 (140046-244602)	365439 (266230-468546)	0.83	-0.33 (-3.29-2.73)
World Bank Regions								
East Asia & Pacific-WB	457428 (414828-500717)	1658888 (1449615-1868682)	2.63	1.84 (1.7-1.98)	91001 (65141-117611)	279857 (201246-364959)	2.08	1.14 (1.02-1.26)
Europe & Central Asia-WB	486659 (476662-495194)	720942 (650006-797695)	0.48	0.2 (0.1-0.29)	93632 (67661-118339)	122125 (87247-157531)	0.30	-0.36 (-0.44–0.29)
Latin America & Caribbean-WB	51560 (50313-52586)	111264 (98714-124508)	1.16	-0.5 (-0.53–0.46)	11241 (8016-14274)	23310 (16444-30696)	1.07	-0.68 (-0.71–0.65)
Middle East & North Africa-WB	15370 (13513-17261)	46144 (40204-52944)	2.00	0.56 (0.5-0.62)	3421 (2417-4448)	9848 (6965-13127)	1.88	0.4 (0.35-0.45)
North America	306727 (298508-313496)	499549 (437947-571551)	0.63	-0.69 (-0.89–0.49)	47990 (35383-59946)	69595 (50234-90028)	0.45	-1.09 (-1.25–0.92)
South Asia-WB	45125 (38920-51747)	125826 (108230-143575)	1.79	0.37 (0.3-0.44)	10283 (7039-13845)	28276 (19633-37629)	1.75	0.25 (0.18-0.31)
Sub-Saharan Africa-WB	21483 (18020-25341)	46870 (40601-54173)	1.18	0.05 (-0.01-0.11)	4946 (3402-6744)	10663 (7463-14275)	1.16	0.04 (-0.02-0.09)

Generated from data available from http://ghdx.healthdata.org/gbd-results-tool.
UI, uncertainty interval; ASR, age standardized rate; EAPC, estimated annual percentage change; CI, confidence interval; YLDs, years lived with disability; WB, World Bank.

3.3 Proportion of YLDs Attributable to risk factors in 2019

At the global level, a substantial proportion of YLDs was attributable to the six risk factors for which GBD estimates were available, including 64.2% (95% UI 62.1–66.4) attributable to smoking, 18.2% (13.9–22.7) to particulate matter pollution, 14.2% (11.0–17.5) to occupational carcinogens, 8.5% (2.0–18.3) to high fasting plasma glucose, 5.6% (3.4–8.3) to second-hand smoke, and 3.8% (1.1–5.6) to diet low in fruits (Figure 4A). Smoking was the highest risk factor in all regions and the impact of the rest of these risk factors varied by region. For example, the impact of occupational carcinogens was highest in Europe & Central Asia-WB (21.4% of YLDs were attributable to occupational carcinogens) and North America (18.7%), where occupational carcinogens are still prevalent, and lowest in the Middle East & North Africa-WB (7.8%). Likewise, the impact of particulate matter pollution was the highest in South Asia-WB (31.5% of YLDs attributable to particulate matter pollution) and Sub-Saharan Africa-WB (30.2%), and lowest in North America (3.9%). The proportion of YLDs attributable to a diet low in fruit was generally low (only 4.9%).

Due to differences in lifestyles and occupational exposure, the risk factors to which the genders and the various age groups were exposed varied substantially. Smoking is the most significant risk factor for TBL cancer disability in both sexes, followed by particulate matter pollution. In addition, the common risk factors for males were occupational carcinogens and high fasting plasma glucose, while females were second-hand smoke and high fasting plasma glucose. Smoking is a significant risk factor for men over 40

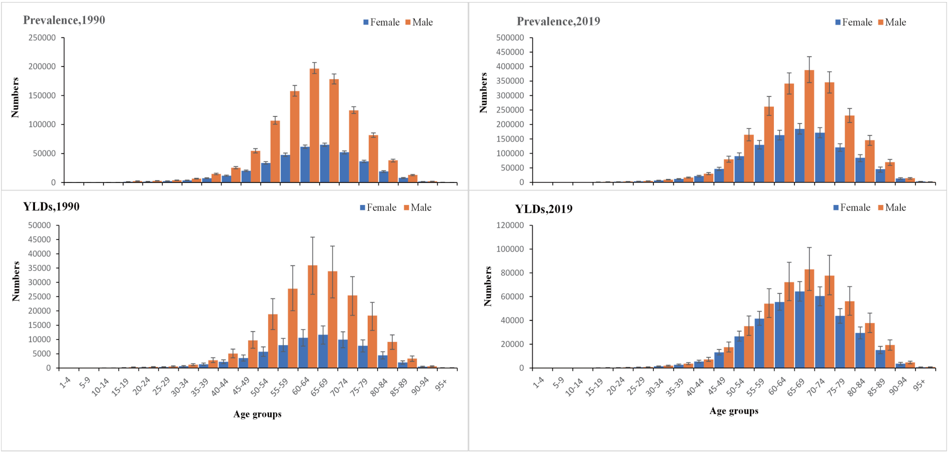

FIGURE 1
The global number of prevalent cases with conditions that would benefit from rehabilitation and the corresponding years of life lived with disability by age and sex with 95% uncertainty intervals, 1990 and 2019. YLDs, years lived with disability.

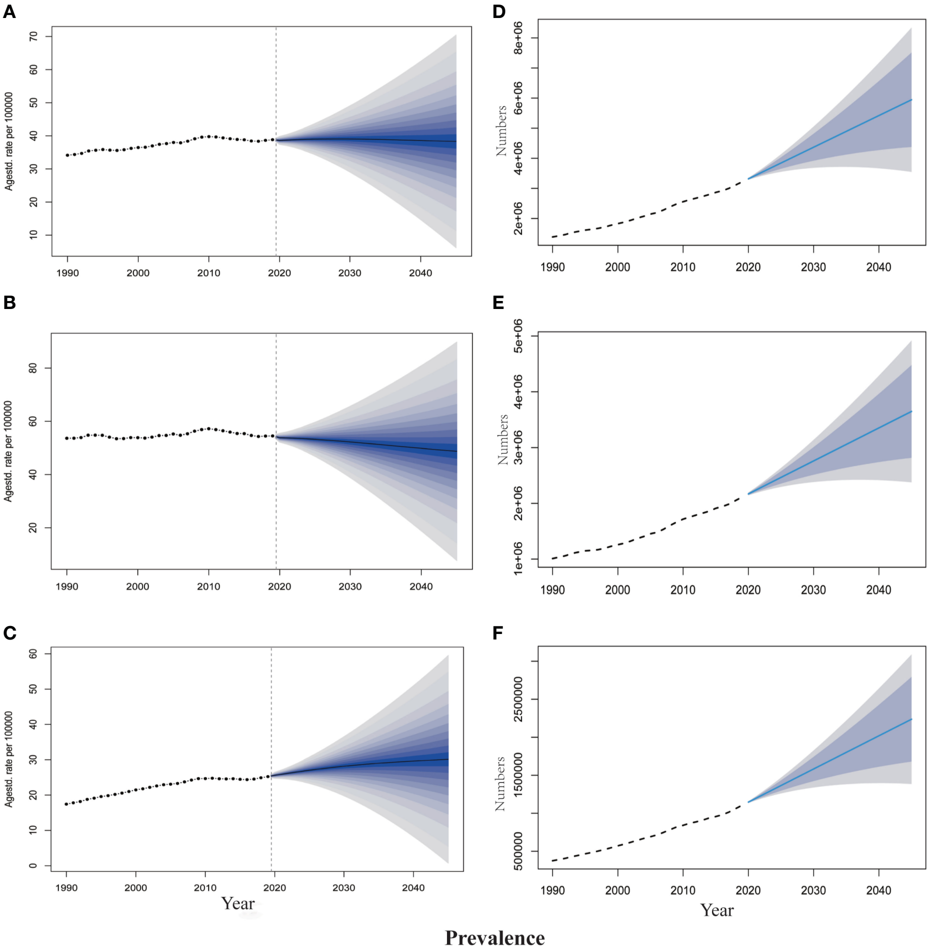

FIGURE 2
The projection of TBL cancer prevalence from 2020 to 2045 worldwide. **(A)** The age-standardized prevalence rate for all gender. **(B)** The age-standardized prevalence rate for males. **(C)** The age-standardized prevalence rate for females. **(D)** The projected numbers of prevalence for all gender. **(E)** The projected numbers of prevalence for males; **(F)** The projected numbers of prevalence for females. The predictive mean is shown as a solid line. The dotted line represents the observational values from the GBD dataset. The vertical dashed line indicates where the prediction starts. The predictive mean value is shown as a solid black line. Agestd., Age standardized.

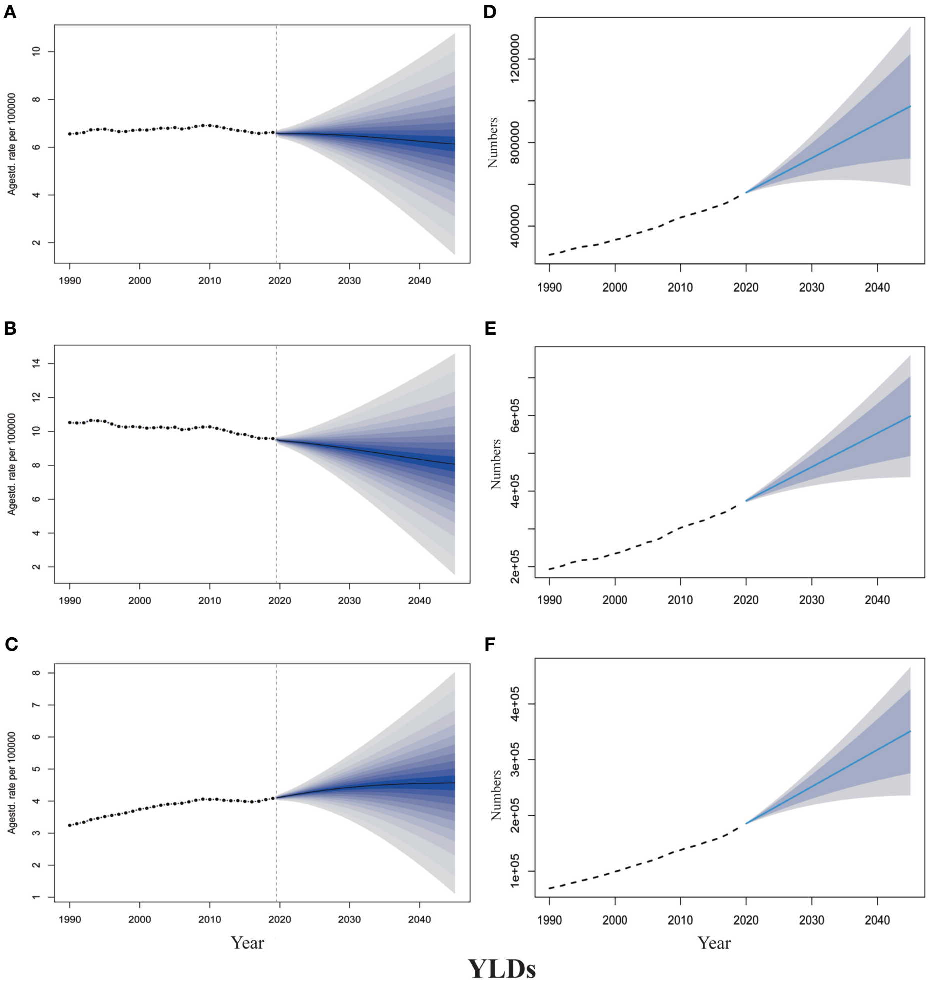

FIGURE 3
The projection of TBL cancer years lived with disability (YLDs) from 2020 to 2045 worldwide. **(A)** The age-standardized YLDs rate for all gender. **(B)** The age-standardized YLDs rate for males. **(C)** The age-standardized YLDs rate for females. **(D)** The projected numbers of YLDs for all gender. **(E)** The projected numbers of YLDs for males; **(F)** The projected numbers of YLDs for females. The predictive mean is shown as a solid line. The dotted line represents the observational values from the GBD dataset. The vertical dashed line indicates where the prediction starts. The predictive mean value is shown as a solid black line. Agestd., Age standardized.

years of age, the proportion of YLDs attributable to smoking is over 50% and up to 79%. While in women it is mainly concentrated in 60-85 years of age, with the highest at 47%. The main risk factors for young and middle-aged women aged 25-50 are high fasting glucose and second-hand smoke. The proportion of risk factors for occupational carcinogens in males is increasing with age due to long-term exposure to carcinogens in the work environment and the development of TBL cancer after a long latency period (Figure 4B).

4 Discussion

4.1 Summary of main findings

The increasing disease burden of TBL cancer is a major concern for healthcare institutions worldwide. Based on the GBD 2019 data, this study provides a multifaceted analysis of the current global TBL cancer burden and rehabilitation needs. Prevalence and YLDs are the two indicators used to analyze the long-term trends of cancer burden and rehabilitation needs from 2020-2045. We estimated the need for rehabilitation services for TBL cancer globally, and our findings suggest that 3,212,307 cases of TBL cancer (95% UI 2,937,037-3,488,346) could benefit from rehabilitation services. According to the sequelae of TBL cancer and corresponding disability weights in the GBD 2019 study, this finding shows that the majority of TBL patients worldwide could benefit from rehabilitation at some point during their disease, and this result contradicts the commonly held view that rehabilitation is a service for only a few.

Our results found that the number of prevalence and YLDs due to TBL cancer increased more than 1-fold globally from 1990 to 2019. According to the age-sex pattern of prevalence and YLDs, more male patients developed lung cancer than female patients. The

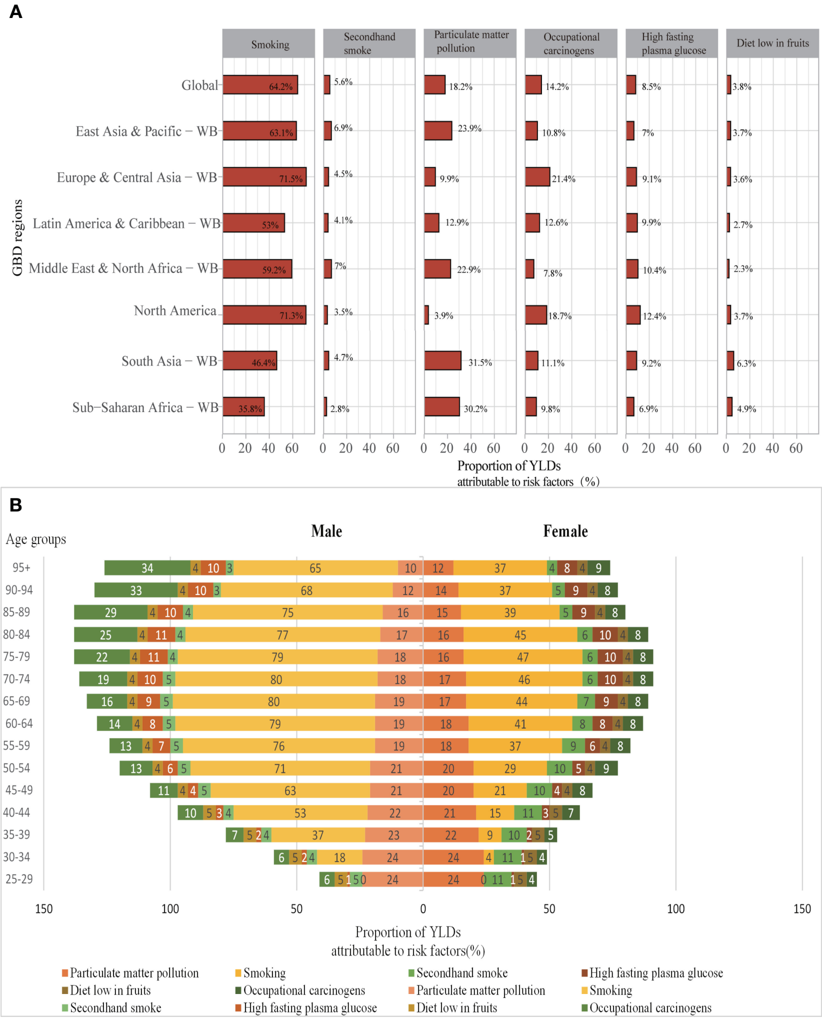

FIGURE 4
(A) Proportions of TBL cancer YLDs attributable to risk factors for global and World Bank regions in 2019; **(B)** Proportions of YLDs attributable to risk factors by age and sex in 2019. YLDs, years lived with disability; WB, world bank; GBD, Global Burden of Diseases.

global ASPR and ASYR did not change significantly overall, but an increasing trend was observed in women, not men. Although the projected ASPR and ASYR show a slight downward trend by 2045 globally, the total number of prevalence and YLDs due to TBL cancer is likely to increase further, which predicted the trend would be consistent with the occupational carcinogenic lung cancer burden (mortality and disability-adjusted life years) in China (34). Predicted results from another study similarly confirm that the burden of lung cancer in China has been increasing (35). However, prevention and control of TBL cancers are complicated by significant differences in the global burden of TBL cancers due to differences in specific pathological patterns, risk factors, regions, sex, and age groups. These temporal trends suggest that TBL cancers remain a major disease burden worldwide, and their total cancer burden and rehabilitation needs are likely to continue to increase. This further indicates that without the implementation of effective rehabilitation interventions for TBL cancers globally in the future, the burden of YLDs due to TBL cancers will further increase in the global population, especially in women, along with population aging.

4.2 The burden of TBL cancer in the female population cannot be ignored

According to the predicted results of this study, the number of prevalence and YLDs, as well as ASPR and ASYR of TBL cancer in females from 1990 to 2045 was rising. In contrast, the ASPR and ASYR show a downward trend for males. Attention should be paid to the burden of TBL cancer in females. The rising rates of lung cancer in women have also been attributed to genetic variants, hormonal factors, environmental exposures, and oncogenic viruses (39, 40). Genetic and biological differences between males and females could explain the differences in lung cancer incidence and mortality, but many questions remain unanswered, suggesting that women should be screened at lower pack years than men and younger ages (41). Efforts to prevent smoking initiation for adolescent girls and to encourage adult smokers to quit are most likely to reduce the burden of lung cancer in women (42).

4.3 The attributable YLDs risk factor: high fasting plasma glucose

This study identified modifiable risk factors intending to be able to reduce YLDs in TBL cancer through effective intervention strategies in clinical settings. As far as we know, smoking (64.2%), particulate matter pollution (18.2%), and occupational carcinogens (14.2%) are the top three attributions to YLDs of global TBL cancer for both sexes in 2019. This result is different from the proportion of the top three risk factors for DALYs: smoking (62.4%), ambient particulate matter (15.3%), and high fasting plasma glucose (9.9%) (43). Smoking is the most recognized risk factor for developing TBL cancer, increasing the burden of the disease (44). According to the 2019 global, regional, and national cancer burden study, almost 1 in 4 deaths and 1 in 5 DALYs were found to be due to smoking, smoking remains a significant risk factor (45). For TBL cancer prevention, the immediate priority is still to control smoking rates and minimize exposure to second-hand smoke (21). Besides smoking, high fasting plasma glucose is another risk factor worthy of attention. Furthermore, in a recent study, high fasting plasma glucose was also an essential risk factor affecting disability-adjusted life years attributable to cancer (46). The results of a study found in 2019 that high fasting plasma was associated with a greater burden of cancer, especially in older men living in developed countries (47). Hyperglycaemia may be one of the direct biological mechanisms underlying the association between diabetes and cancer. Hyperglycaemia is associated with the level of extracellular glucose to the dynamic regulation of 5hmC through the glucose–AMPK–TET2–5hmC axis (48). The high glucose levels can provide a nutritional base to maximize tumor cell proliferation (49). Patients with diabetes mellitus should accept the recommended age and gender-appropriate cancer screening to promote primary prevention and early detection. In addition, cancer should be screened for in routine diabetes assessments (50).

4.4 Early interventions in cancer rehabilitation for the management throughout TBL cancer life-cycle

The need for rehabilitation has been growing globally as the prevalence of disability has risen. A study (23) found that the number of YLDs worldwide has increased by 66% since 1990, and the world's per capita physical need for rehabilitation has increased by 17%. Usually, people believe only antineoplastic treatment is valued for TBL cancer patients. And rehabilitation services are unnecessary, disadvantageous, and burdensome (51). But our findings challenged this view, as we show that 3,212,307 cases may need rehabilitation in the study. Furthermore, there is growing evidence that many TBL cancer patients will suffer from sequelae of varying severity afterward, increasing the global demand for rehabilitation services. More research and development investment is needed to identify new, more effective intervention strategies. As the prevalence of TBL cancer continues to rise and the population ages, the number of cancer patients who will benefit from rehabilitation close to home will also increase.

Many oncology guidelines include recommendations for rehabilitation referrals and interventions, demonstrating that rehabilitation is a recognized and necessary service in oncology care. Evidence-based guidelines support the use of rehabilitation assessments and interventions to treat individual physical and cognitive impairments in many different cancer types. They also suggested using the guideline recommendations to manage oncology treatment-related symptoms and conditions in the clinical setting. Encouraging participation in rehabilitation care could optimize function and quality of life for cancer patients and survivors (52). Physiotherapists could play a critical role in lung cancer and the management of lung cancer needs to focus on physiotherapy interventions to improve its cancer treatment-related side effects (53). Palliative care aims to break down cancer treatment barriers, enabling patients to cope with cancer in the later stages of the cancer journey. Integrating function-directed treatments and pulmonary rehabilitation into palliative care may serve as one of those options (54). Therapeutic exercises should be an essential intervention for cancer rehabilitation. There is growing evidence for exercise interventions to reduce cancer morbidity in lung cancer. Exercise could prevent deterioration and maximize or restore physical status before, during, and following treatment (53). Rehabilitation services can be provided before (55–57)and after (58, 59) TBL cancer surgery, during cancer treatment in hospital (60, 61), outpatient (62), community, and at home (63, 64) throughout the full life-cycle of cancer management. The current telehealth trend shows that telecare may be a potential choice for lung cancer during the COVID-19 pandemic (65).

4.5 Limitations

Our study presents some limitations. First, it is important to first consider all the limitations presented in the GBD study, which had been emphasized before (2). Indeed, the quality and quantity of estimates available in GBD studies are critical to the accuracy of our estimates. For example, it is not possible to assess the disease burden in countries and regions without an established and organized structure for registering, recording, and reporting diseases. Detection bias may be partly responsible for the observed variation in prevalence and YLDs due to changes in screening programs over time and between countries. In addition, we selected anyone who could benefit from rehabilitation at any time during the disease, which does not imply that all populations with TBL cancer have an urgent need for rehabilitation. Not including all of the potential risk factors for TBL cancer can be another limitation of the GBD study and the current one. Future studies should address these limitations to improve our understanding of the overall disease burden.

5 Conclusion

This study provides a global estimate of the need for rehabilitation services for TBL cancer. Our findings suggest that 3,212,307 cases of TBL cancer could benefit from rehabilitation services, which challenge the common view that only a minority of people need rehabilitation. The corresponding increase in ASPR and ASYR were shown for lung cancer occurred from 1990 to 2019 for all genders globally, but projections from 2020 to 2045 showed a decreasing trend in both ASPR and ASYR. In addition, male patients are significantly more affected and have been on the decline, while females have been on the increasing trend. From 1990 to 2045, the number of patients with both sex and number of YLDs has been an increasing trend, which was greater in males than females. The sex-specific differences in risk factors attributed to YLDs underscore the need for targeted strategies to reduce the burden of lung cancer. Our results could help conduct preventive measures for precise control of symptoms and full life-cycle management of TBL cancer. Furthermore, these data could also contribute to the development of health policies, the allocation of rehabilitation resources, and the establishment of multidisciplinary cancer care models.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material. Further inquiries can be directed to the corresponding author.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent from the participants' legal guardian/next of kin was not required to participate in this study in accordance with the national legislation and the institutional requirements.

Author contributions

Study concept, design, and supervision: XL and YZ. Refining and modifying R Code: CL, MN, XL, and YaY. Data processing, analysis, and charting: XL. YuY, SG, WH, and LC revised the manuscript for important intellectual content. Drafting of the manuscript: XL. Revision of the manuscript: YZ and XL. All authors have edited, reviewed, and approved the final version of the manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fonc.2023.1152209/full#supplementary-material

References

1. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: Cancer J Clin* (2021) 71(3):209–49. doi: 10.3322/caac.21660

2. GBD 2019 Diseases and Injuries Collaborators. Global burden of 369 diseases and injuries in 204 countries and territories, 1990-2019: a systematic analysis for the global burden of disease study 2019. *Lancet (London England)* (2020) 396(10258):1204–22. doi: 10.1016/S0140-6736(20)32226-1

3. Steiner MC. Should pulmonary rehabilitation be a standard of care in lung cancer? *Thorax* (2019) 74(8):725–6. doi: 10.1136/thoraxjnl-2019-213157

4. Wang H, Liu X, Rice SJ, Belani CP. Pulmonary rehabilitation in lung cancer. *Pm R* (2016) 8(10):990–6. doi: 10.1016/j.pmrj.2016.03.010

5. Polanski J, Jankowska-Polanska B, Rosinczuk J, Chabowski M, Szymanska-Chabowska A. Quality of life of patients with lung cancer. *Onco Targets Ther* (2016) 9:1023–8. doi: 10.2147/OTT.S100685

6. Chen S, Cao Z, Prettner K, Kuhn M, Yang J, Jiao L, et al. Estimates and projections of the global economic cost of 29 cancers in 204 countries and territories from 2020 to 2050. *JAMA Oncol* (2023) 465–72. doi: 10.1001/jamaoncol.2022.7826

7. Jakovljevic MB, Milovanovic O. Growing burden of non-communicable diseases in the emerging health markets: the case of BRICS. *Front Public Health* (2015) 3:65. doi: 10.3389/fpubh.2015.00065

8. Salomon JA, Haagsma JA, Davis A, de Noordhout CM, Polinder S, Havelaar AH, et al. Disability weights for the global burden of disease 2013 study. *Lancet Glob Health* (2015) 3(11):e712–23. doi: 10.1016/S2214-109X(15)00069-8

9. Krug E, Cieza A. Strengthening health systems to provide rehabilitation services. *Bull World Health Organ* (2017) 95(3):167. doi: 10.2471/BLT.17.191809

10. Gimigliano F, Negrini S. The world health organization "Rehabilitation 2030: a call for action". *Eur J Phys Rehabil Med* (2017) 53(2):155–68. doi: 10.23736/S1973-9087.17.04746-3

11. Mosher CL, Nanna MG, Jawitz OK, Raman V, Farrow NE, Aleem S, et al. Cost-effectiveness of pulmonary rehabilitation among US adults with chronic obstructive pulmonary disease. *JAMA Netw Open* (2022) 5(6):e2218189. doi: 10.1001/jamanetworkopen.2022.18189

12. Griffiths TL, Phillips CJ, Davies S, Burr ML, Campbell IA. Cost effectiveness of an outpatient multidisciplinary pulmonary rehabilitation programme. *Thorax* (2001) 56(10):779–84. doi: 10.1136/thorax.56.10.779

13. Böckmann D, Szentes BL, Schultz K, Nowak D, Schuler M, Schwarzkopf L, et al. Cost-effectiveness of pulmonary rehabilitation in patients with bronchial asthma: an analysis of the EPRA randomized controlled trial. *Value Health* (2021) 24(9):1254–62. doi: 10.1016/j.jval.2021.01.017

14. Burns DK, Wilson EC, Browne P, Olive S, Clark A, Galey P, et al. The cost effectiveness of maintenance schedules following pulmonary rehabilitation in patients with chronic obstructive pulmonary disease: an economic evaluation alongside a randomised controlled trial. *Appl Health econ Health policy* (2016) 14(1):105–15. doi: 10.1007/s40258-015-0199-9

15. Rivas-Perez H, Nana-Sinkam P. Integrating pulmonary rehabilitation into the multidisciplinary management of lung cancer: a review. *Respir Med* (2015) 109(4):437–42. doi: 10.1016/j.rmed.2015.01.001

16. Stout NL, Baima J, Swisher AK, Winters-Stone KM, Welsh J. A systematic review of exercise systematic reviews in the cancer literature (2005-2017). *PM R* (2017) 9(9S2):S347–S84. doi: 10.1016/j.pmrj.2017.07.074

17. Stuiver MM, Stout NL, Dennett AM, Speksnijder CM, Campbell KL. An international perspective on integrating physiotherapists in oncology care. *J Physiother* (2019) 65(4):186–8. doi: 10.1016/j.jphys.2019.07.004

18. Rosario-Concepción RA, Calderín YB, Aponte CL, López-Acevedo CE, Sepúlveda-Irizarry FL. Oncologists' attitude and knowledge about cancer rehabilitation. *Pm R* (2021) 13(12):1357–61. doi: 10.1002/pmrj.12547

19. Smith SR, Zheng JY. The intersection of oncology prognosis and cancer rehabilitation. *Curr Phys Med Rehabil Rep* (2017) 5(1):46–54. doi: 10.1007/s40141-017-0150-0

20. Cieza A, Causey K, Kamenov K, Hanson SW, Chatterji S, Vos T. Global estimates of the need for rehabilitation based on the global burden of disease study 2019: a systematic analysis for the global burden of disease study 2019. *Lancet (London England)* (2021) 396(10267):2006–17. doi: 10.1016/S0140-6736(20)32340-0

21. GBD 2019 Diseases and Injuries Collaborators. Global, regional, and national burden of respiratory tract cancers and associated risk factors from 1990 to 2019: a systematic analysis for the global burden of disease study 2019. *Lancet Respir Med* (2021) 9(9):1030–49. doi: 10.1016/S2213-2600(21)00164-8

22. Jesus TS, Landry MD, Brooks D, Hoenig H. Physical rehabilitation needs per condition type: results from the global burden of disease study 2017. *Arch Phys Med Rehabil* (2020) 101(6):960–8. doi: 10.1016/j.apmr.2019.12.020

23. Jesus TS, Landry MD, Hoenig H. Global need for physical rehabilitation: systematic analysis from the global burden of disease study 2017. *Int J Environ Res Public Health* (2019) 16(6):980. doi: 10.3390/ijerph16060980

24. Jesus TS, Landry MD, Hoenig H, Zeng Y, Kamalakannan S, Britto RR, et al. Physical rehabilitation needs in the BRICS nations from 1990 to 2017: cross-national analyses using data from the global burden of disease study. *Int J Environ Res Public Health* (2020) 17(11):4139. doi: 10.3390/ijerph17114139

25. GBD 2019 Risk Factors Collaborators. Global burden of 87 risk factors in 204 countries and territories, 1990-2019: a systematic analysis for the global burden of disease study 2019. *Lancet (London England)* (2020) 396(10258):1223–49. doi: 10.1016/S0140-6736(20)30925-9

26. Global Burden of Disease Collaborative Network. *Global burden of disease study 2019(GBD 2019) results* (2020). Available at: http://ghdx.healthdata.org/gbd-results-tool.

27. Hankey BF, Ries LA, Kosary CL, Feuer EJ, Merrill RM, Clegg LX, et al. Partitioning linear trends in age-adjusted rates. *Cancer Causes Control* (2000) 11 (1):31–5. doi: 10.1023/A:1008953201688

28. Jurgens V, Ess S, Cerny T, Vounatsou P. A Bayesian generalized age-period-cohort power model for cancer projections. *Stat Med* (2014) 33(26):4627–36. doi: 10.1002/sim.6248

29. Knoll M, Furkel J, Debus J, Abdollahi A, Karch A, Stock C. An r package for an integrated evaluation of statistical approaches to cancer incidence projection. *BMC Med Res Methodol* (2020) 20(1):257. doi: 10.1186/s12874-020-01133-5

30. Riebler A, Held L. Projecting the future burden of cancer: Bayesian age-period-cohort analysis with integrated nested Laplace approximations. *Biom J* (2017) 59 (3):531–49. doi: 10.1002/bimj.201500263

31. Li J, Chen C, Nie J, Wang L, Zhang Z, Li Y. Changes in the disease burden of breast cancer along with attributable risk factors in China from 1990 to 2019 and its projections: an analysis of the global burden of disease study 2019. *Cancer Med* (2022) 1888–902. doi: 10.1002/cam4.5006

32. Li S, Chen H, Man J, Zhang T, Yin X, He Q, et al. Changing trends in the disease burden of esophageal cancer in China from 1990 to 2017 and its predicted level in 25 years. *Cancer Med* (2021) 10(5):1889–99. doi: 10.1002/cam4.3775

33. Du Z, Chen W, Xia Q, Shi O, Chen Q. Trends and projections of kidney cancer incidence at the global and national levels, 1990-2030: a Bayesian age-period-cohort modeling study. *biomark Res* (2020) 8:16. doi: 10.1186/s40364-020-00195-3

34. Fan Y, Jiang Y, Li X, Li X, Li Y, Wu H, et al. Burden of lung cancer attributable to occupational carcinogens from 1990 to 2019 and projections until 2044 in China. *Cancers (Basel)* (2022) 14(16):3883. doi: 10.3390/cancers14163883

35. Fang Y, Li Z, Chen H, Zhang T, Yin X, Man J, et al. Burden of lung cancer along with attributable risk factors in China from 1990 to 2019, and projections until 2030. *J Cancer Res Clin Oncol* (2022) 1–10. doi: 10.1007/s00432-022-04217-5

36. Foreman KJ, Marquez N, Dolgert A, Fukutaki K, Fullman N, McGaughey M, et al. Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016-40 for 195 countries and territories. *Lancet (London England)* (2018) 392(10159):2052–90. doi: 10.1016/S0140-6736(18)31694-5

37. Song Y, Cheng W, Li H, Liu X. The global, regional, national burden of nasopharyngeal cancer and its attributable risk factors (1990-2019) and predictions to 2035. *Cancer Med* (2022) 4310–20. doi: 10.1002/cam4.4783

38. Zhang T, Xu J, Ye L, Lin X, Xu Y, Pan X, et al. Age, gender and geographic differences in global health burden of cirrhosis and liver cancer due to nonalcoholic steatohepatitis. *J Cancer* (2021) 12(10):2855–65. doi: 10.7150/jca.52282

39. Patel JD, Bach PB, Kris MG. Lung cancer in US women: a contemporary epidemic. *JAMA* (2004) 291(14):1763–8. doi: 10.1001/jama.291.14.1763

40. Bain C, Feskanich D, Speizer FE, Thun M, Hertzmark E, Rosner BA, et al. Lung cancer rates in men and women with comparable histories of smoking. *J Natl Cancer Inst* (2004) 96(11):826–34. doi: 10.1093/jnci/djh143

41. Mederos N, Friedlaender A, Peters S, Addeo A. Gender-specific aspects of epidemiology, molecular genetics and outcome: lung cancer. *ESMO Open* (2020) 5 (Suppl 4):e000796. doi: 10.1136/esmoopen-2020-000796

42. Ernster VL. Female lung cancer. *Annu Rev Public Health* (1996) 17:97–114. doi: 10.1146/annurev.pu.17.050196.000525

43. Safiri S, Sohrabi MR, Carson-Chahhoud K, Bettampadi D, Taghizadieh A, Almasi-Hashiani A, et al. Burden of tracheal, bronchus, and lung cancer and its attributable risk factors in 204 countries and territories, 1990 to 2019. *J Thorac Oncol* (2021) 16(6):945–59. doi: 10.1016/j.jtho.2021.03.030

44. Barta JA, Powell CA, Wisnivesky JP. Global epidemiology of lung cancer. *Ann Glob Health* (2019) 85(1):8. doi: 10.5334/aogh.2419

45. Safiri S, Nejadghaderi SA, Abdollahi M, Carson-Chahhoud K, Kaufman JS, Bragazzi NL, et al. Global, regional, and national burden of cancers attributable to tobacco smoking in 204 countries and territories, 1990-2019. *Cancer Med* (2022) 11 (13):2662–78. doi: 10.1002/cam4.4647

46. Tran KB, Lang JJ, Compton K, et al. The global burden of cancer attributable to risk factors, 2010-19: a systematic analysis for the global burden of disease study 2019. *Lancet (London England)* (2022) 400(10352):563–91. doi: 10.1016/S0140-6736(22)01438-6

47. Safiri S, Nejadghaderi SA, Karamzad N, Kaufman JS, Carson-Chahhoud K, Bragazzi NL, et al. Global, regional and national burden of cancers attributable to high fasting plasma glucose in 204 countries and territories, 1990-2019. *Front endocrinol* (2022) 13:879890. doi: 10.3389/fendo.2022.879890

48. Wu D, Hu D, Chen H, Shi G, Fetahu IS, Wu F, et al. Glucose-regulated phosphorylation of TET2 by AMPK reveals a pathway linking diabetes to cancer. *Nature* (2018) 559(7715):637–41. doi: 10.1038/s41586-018-0350-5

49. Kim J, DeBerardinis RJ. Mechanisms and implications of metabolic heterogeneity in cancer. *Cell Metab* (2019) 30(3):434–46. doi: 10.1016/j.cmet.2019.08.013

50. Suh S, Kim KW. Diabetes and cancer: cancer should be screened in routine diabetes assessment. *Diabetes Metab J* (2019) 43(6):733–43. doi: 10.4093/dmj.2019.0177

51. Cheville AL, Rhudy L, Basford JR, Griffin JM, Flores AM. How receptive are patients with late stage cancer to rehabilitation services and what are the sources of their resistance? *Arch Phys Med Rehabil* (2017) 98(2):203–10. doi: 10.1016/j.apmr.2016.08.459

52. Stout NL, Santa Mina D, Lyons KD, Robb K, Silver JK. A systematic review of rehabilitation and exercise recommendations in oncology guidelines. *CA: Cancer J Clin* (2021) 71(2):149–75. doi: 10.3322/caac.21639

53. Granger CL. Physiotherapy management of lung cancer. *J Physiother* (2016) 62 (2):60–7. doi: 10.1016/j.jphys.2016.02.010

54. Cheville AL, Morrow M, Smith SR, Basford JR. Integrating function-directed treatments into palliative care. *Pm r* (2017) 9(9s2):S335–s46. doi: 10.1016/j.pmrj.2017.07.073

55. Benzo R, Wigle D, Novotny P, Wetzstein M, Nichols F, Shen RK, et al. Preoperative pulmonary rehabilitation before lung cancer resection: results from two randomized studies. *Lung Cancer* (2011) 74(3):441–5. doi: 10.1016/j.lungcan.2011.05.011

56. Goldsmith I, Chesterfield-Thomas G, Toghill H. Pre-treatment optimization with pulmonary rehabilitation in lung cancer: making the inoperable patients operable. *EClinicalMedicine* (2021) 31:100663. doi: 10.1016/j.eclinm.2020.100663

57. Xu X, Cheung DST, Smith R, Lai AYK, Lin CC. The effectiveness of pre- and post-operative rehabilitation for lung cancer: a systematic review and meta-analysis on postoperative pulmonary complications and length of hospital stay. *Clin Rehabil* (2022) 36(2):172–89. doi: 10.1177/02692155211043267

58. Cesario A, Ferri L, Galetta D, Pasqua F, Bonassi S, Clini E, et al. Post-operative respiratory rehabilitation after lung resection for non-small cell lung cancer. *Lung Cancer* (2007) 57(2):175–80. doi: 10.1016/j.lungcan.2007.02.017

59. Edvardsen E, Skjønsberg OH, Holme I, Nordsletten L, Borchsenius F, Anderssen SA. High-intensity training following lung cancer surgery: a randomised controlled trial. *Thorax* (2015) 70(3):244–50. doi: 10.1136/thoraxjnl-2014-205944

60. Riesenberg H, Lübbe AS. In-patient rehabilitation of lung cancer patients–a prospective study. *Support Care Cancer* (2010) 18(7):877–82. doi: 10.1007/s00520-009-0727-y

61. Jastrzębski D, Maksymiak M, Kostorz S, Bezubka B, Osmanska I, Młynczak T, et al. Pulmonary rehabilitation in advanced lung cancer patients during chemotherapy. *Adv Exp Med Biol* (2015) 861:57–64. doi: 10.1007/5584_2015_134

62. Maeda K, Higashimoto Y, Honda N, Shiraishi M, Hirohata T, Minami K, et al. Effect of a postoperative outpatient pulmonary rehabilitation program on physical activity in patients who underwent pulmonary resection for lung cancer. *Geriatr Gerontol Int* (2016) 16(5):550–5. doi: 10.1111/ggi.12505

63. Edbrooke L, Denehy L, Granger CL, Kapp S, Aranda S. Home-based rehabilitation in inoperable non-small cell lung cancer-the patient experience. *Support Care Cancer* (2020) 28(1):99–112. doi: 10.1007/s00520-019-04783-4

64. Chen HM, Tsai CM, Wu YC, Lin KC, Lin CC. Randomised controlled trial on the effectiveness of home-based walking exercise on anxiety, depression and cancer-related symptoms in patients with lung cancer. *Br J Cancer* (2015) 112(3):438–45. doi: 10.1038/bjc.2014.612

65. Komariah M, Maulana S, Platini H, Pahria T. A scoping review of telenursing's potential as a nursing care delivery model in lung cancer during the COVID-19 pandemic. *J Multidiscip Healthc* (2021) 14:3083–92. doi: 10.2147/JMDH.S337732

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Integration of exercise prescription into medical provision as a treatment for non-communicable diseases: A scoping review

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Background: The purpose of this scoping review is to stimulate interest and to raise awareness, among researchers, healthcare practitioners, and policymakers regarding the current scientific literature related to exercise prescription for non-communicable diseases (NCDs). Exercise prescription is a safe and cost-effective method that enables physicians to use exercise as a complementary addition to NCDs management and treatment.

Methods: This scoping review followed the PRISMA Extension Guidelines for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Using this framework, we considered information from qualitative and quantitative studies to identify research gaps. We provide feasible suggestions to guide future research for the implementation of exercise prescription in the healthcare environment. The literature search was conducted using SPIDER and PICO tools for qualitative, quantitative, and mixed-study designs. Inclusion criteria included articles that investigated patients with NCDs and considered exercise interventions. Systematic searches of PubMed, Web of Science, MEDLINE, EMBASE, and ScienceDirect were undertaken on 26 July 2022 and all reference lists were manually searched. Data processing was performed using EndNote 2.0 software and data charts were used for numerical summary and thematic analysis.

Results: There were 10,951 articles retrieved, of which 28 met the inclusion criteria. Based on the evidence, exercise was a feasible, safe, and acceptable method to prevent and manage non-communicable diseases in inpatient and outpatient settings. Six research directions were identified and discussed. In addition, implementation evidence and suggestions for policy-reconfiguration are also provided.

Conclusion: This scoping review summarizes the current evidence for the effectiveness of exercise in the treatment of non-communicable diseases. The review provides key findings supporting exercise prescription for the inpatient and outpatient healthcare service. We suggest that governments and healthcare policymakers globally advocate the inclusion of structured exercise prescription within the NCDs treatment setting.

KEYWORDS

non-communicable diseases, exercise prescription, inpatient, outpatient, healthcare service, health policy

1. Introduction

The Exercise is Medicine (EIM) initiative was launched in 2007 by the American College of Sports Medicine (ASCM). The concept includes a professional physical activity assessment and standardized promotion in clinical care. Exercise is Medicine connects healthcare with valid, evidence-based physical activity and exercise resources for individuals around the world that is inclusive of all health scenarios. The EIM scheme called for key stakeholders and clinicians to provide consensus in support of the development of infrastructures in healthcare provision to provide the inclusion of exercise into routine patient care (1). In spite of this initiative, there has been little change by the medical profession in the prescription of exercise for healthcare provision. Exercise is a validated methodology and applied intervention that helps individuals to develop healthy lifestyles, addresses related illnesses, promotes individuals' self-esteem, and improves health and wellness (2). There is clear and consistent scientific evidence outlining the benefits of regular exercise interventions on the primary and secondary prevention of diabetes, hypertension, cancers, depression, osteoporosis, and dementia (3). Exercise prescription, physician counseling and referrals for physical activity, can be seen as a non-pharmaceutical treatment during primary and secondary preventions for reducing morbidity and mortality rates from NCDs (4). Many systematic reviews and meta-analyses have demonstrated comprehensive benefits obtained from exercise activity. Exercise prescription can often provide similar or even greater benefits than pharmaceutical interventions, without problematic side effects and associated financial burdens. These observations provide strong evidence for the inclusion of exercise into healthcare provision systems (5–10).

Non-communicable diseases, inclusive of heart disease, stroke, cancer, diabetes and chronic lung disease, etc., are responsible for 74% of deaths globally. This percentage is not equally distributed: 86% of patients dying prematurely or before reaching 70 years are inhabitants of low- and middle-income countries (11). NCDs are also known as chronic diseases, and are predisposed to being of long durations. NCDs normally result from a combination of genetic, physiological, environmental, medical care and behavioral factors (11). Adults, the elderly, and children are vulnerable to the factors contributing to NCDs. These include poor diets, lack of physical activity, and the harmful effects of alcohol and tobacco smoke, etc. (11). However, the most important factors contributing to health outcomes are individual lifestyles and behavior (12).

Globally, it has been suggested that between the years 2011 and 2030, the prevalence of NCDs will result in a cumulative global loss in productivity of US$47 trillion if current trends are not rapidly reversed (13). In poor-resource settings, medication and healthcare costs for the treatment of non-communicable diseases quickly exhaust both household and/or public resources. The costs of NCDs, including treatment, is often lengthy and expensive. These costs in combination with income loss, annually force millions of people into poverty while stifling social and economic development (11, 14). Patient suffering, and family economic and psychological pressures associated with NCDs, come with profound negative consequences for families, governments (locally and nationally), and societies generally (15). Therefore, in addition to the advantages of exercise activity for reducing morbidity and mortality, there are significant socio-economic reasons for introducing exercise prescription into patients' treatment programs.

Non-communicable diseases hinder progress toward the agreed 2030 Agenda for Sustainable Development. The agenda includes specified targets for reducing premature deaths from NCDs by one-third by 2030 (11). There is now an urgent need for healthcare systems globally to create the necessary infrastructure and environment to ensure that supervised exercise can be, and is, prescribed as medicine. If the available evidence indicates that exercise is effective as a treatment for NCDs, why has exercise not been recognized globally as a prophylactic, stimulating policy change relating to the healthcare and wellness agenda? For example, the Royal National Orthopedic Hospital (RNOH) NHS Trust in London has provided a working example by becoming one of the first NHS trusts in the United Kingdom to open an "exercise prescription clinic." The clinic provides counseling for patients on the core tenets of health. These include nutrition, sleep, posture, physical activity, and emotional and mental wellbeing (16). Unfortunately, most physicians, who are traditionally medically trained to manage NCDs, have not been comprehensively trained in exercise prescription at associated medical schools or healthcare institutions (4). Meanwhile, most of the intervention studies designed that use physical activity, exercise interventions, and sports physical therapy, are terminated at the efficacy trial stage, without transfer into best practices for healthcare provision and public health policy-making processes.

It has been suggested by researchers that exercise provides an important therapeutic role in preparing patients for treatment and surgery. Exercise is also important in the management of treatment-related side effects, helping patients recover, and in improving treatment tolerability. Emerging evidence also indicates that there is a potential role for exercise to enhance the effectiveness of other treatments (1). Therefore, it seems critical to examine methods to translate these developments into medical practice ensuring that patients receive optimal care. To our knowledge, there are no current scoping reviews that have evaluated exercise interventions for non-communicable disease treatment in inpatient and outpatient treatment settings. This review was designed to address this deficiency in the existing literature. The two objectives of the review were to: (1) to outline current research on applied exercise prescription for NCDs treatment in inpatient and outpatient settings and (2) to identify potential investigative research areas and discuss exercise implementation to guide future research on NCDs.

2. Methodology

2.1. Protocol and registration

This scoping review followed guidelines obtained from the Joanna Briggs Methods Manual for Scoping Reviews (17, 18). The review followed the PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation (19). The protocol was developed and registered on the Open Science Framework at https://osf.io/x25zc/ on 17 August 2022 prior to commencing this review.

2.2. Eligibility criteria

The literature search was conducted using both SPIDER (Sample, Phenomenon of Interest, Evaluation, Research type) and PICO (Population, Intervention, Comparisons, Outcome) tools for qualitative, quantitative, and mix-study designs to comply with our research design (20–22). The inclusion criteria included articles with patients who were diagnosed with non-communicable diseases and investigated exercise interventions; and contained information pertinent to our research question. The main types of NCDs considered were cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes. Cardiovascular diseases are responsible for most NCDs deaths and account for 17.9 million annually, followed by cancers (9.3 million), respiratory diseases (4.1 million), and diabetes (1.5 million) (11). Therefore, this study focused on NCDs that included cardiovascular diseases (coronary heart disease, cerebrovascular disease, rheumatic heart disease, stroke, hypertension) (23); cancers (all types of cancers); respiratory diseases (chronic obstructive pulmonary disease (COPD), asthma, occupational lung diseases and pulmonary hypertension) (24); and diabetes (type-1 diabetes, type-2 diabetes, and gestational diabetes) (25).

In line with the research aims, studies were included if they met the following criteria: (1) participants/patients diagnosed with non-communicable diseases; (2) studies only evaluating traditional body-type (upper and lower body inclusive of aerobic and anaerobic) exercise interventions (except the studies that only evaluated breathing exercises and oral exercise); (3) the exercise interventions had to provide a well-defined structure was located in an inpatient or outpatient setting and was followed specifically by the patients; (4) studies had to measure and discuss outcomes that related to the research aims; (5) studies were published in English and in peer-reviewed journals within the last decade. All of the following types of studies were excluded: (1) non-primary/original research, including secondary analysis, reviews, commentaries, opinion articles, and viewpoint articles were further excluded to avoid duplication of results; (2) studies where authors could not be contacted to retrieve full texts; (3) studies with data that were not reliably extracted, and animal experiments. If more than one article described a single study presenting the same data, we included the most recent. No exclusion criteria related to age and sex of the patients, medical status, or to culture/sub-cultural factors, geographic location, or race were applied.

2.3. Search strategy

An initial limited search of PubMed was performed to identify relevant articles, ensuring the validity of the proposed idea, confirming and prescribing search items, avoiding duplication of previously addressed questions, and assuring that there were enough articles for conducting the analysis. In the preliminary search, no current scoping reviews focusing on exercise interventions with non-communicable diseases in inpatient and outpatient settings were noted. Following the preliminary search, a comprehensive systematic search was conducted independently of five electronic databases on 26 July 2022: PubMed, Web of Science, MEDLINE, EMBASE, and ScienceDirect were explored by MeSH terms in the titles and abstracts to identify and review all relevant literature published within a decade. We used the MeSH terms ('patient*') AND ('exercise prescription' OR 'exercise intervention*' OR 'exercise treatment' OR 'exercise activity' OR 'physical activity' OR 'exercise training' OR 'exercise therapy' OR 'exercise movement') AND ('non-communicable diseases' OR 'NCD*' OR 'cardiovascular diseases' OR 'coronary heart disease' OR 'cerebrovascular disease' OR 'rheumatic heart disease' OR 'heart attack*' OR 'stroke' OR 'cancer' OR 'tumor' OR 'oncology' OR 'respiratory diseases' OR 'chronic obstructive pulmonary disease' OR 'asthma' OR 'occupational lung diseases' OR 'pulmonary hypertension' OR 'type 1 diabetes' OR 'type 2 diabetes' OR 'gestational diabetes') to search the studies published. Additionally, manual screening for the reference lists of the retrieved and related articles was conducted.

2.4. Data charting process

Identified records were exported to EndNote 20 software for de-duplication. The titles and abstracts were screened independently of all retrieved articles, and the potentially relevant full texts of the remaining articles were screened using eligibility criteria. The following data items were extracted from the included studies: the name of the first author, years and region of publication, characteristics of the patients (sample size, sex, age, medical status, etc.), study design, exercise interventions contents, comparison condition, outcome measures, and the implementation findings of each study. Information relating to publication year, gender characteristics sample size, research design, exercise interventions type, non-communicable diseases categories, and implementation of outcomes was numerically summarized. Additionally, a thematic data analysis from the key findings was also performed. The thematic analysis considered: exercise guidelines, recruitment and adherence, acceptability and resources, existing research, study limitation, experimental context, exercise interventions provider, and future research direction. Data extraction was performed using EndNote 2.0 software. Manually created data charts were used for numerical summary and thematic analysis. The first author developed the data extraction form and a second author checked the form. Any disagreements between authors were resolved through discussion and consultation with a third author.

2.5. Critical appraisal of individual sources of evidence

Our study aim was to map the evidence related to our research target; therefore, we included all studies that met the inclusion criteria.

This method was consistent with standard scoping review methodologies (17, 26). However, we still provided the critical appraisal results. The methodological quality of the studies was assessed by The Joanna Briggs Institute Critical Appraisal Checklist. Four types of checklist were used to assess 20 selected studies (eight studies were not suitable using The Joanna Briggs Institute Critical Appraisal Checklist system due to non-specific research designs) (27). The checklist answers included: Yes, No, Unclear, or Not/Applicable-NA. We assessed the methodological quality of 20 studies and studies only with minor methodological flaws. The individual included studies were assessed independently and any different opinions were resolved through discussion with the third co-author. The individual critical appraisal results are outlined in Supplementary Table S1.[1]

3. Results

3.1. Selection of sources

From the literature search using five electronic databases, a total of 10,951 articles were retrieved. After the removal of duplicates, title and abstract screening, full-text reading, and manual searching, 28 articles were included in this scoping review. The process of article selection and reasons for exclusion are outlined in Figure 1.

3.2. Characteristics of studies

A total of 28 studies comprising 1,368 patients were included in this review. Supplementary Table S2[2] and Supplementary Table S3[3] summarize the characteristics of the included studies. Four categories of non-communicable diseases included:

- Studies that focused on cardiovascular diseases (14%): pulmonary arterial hypertension (PAH) (28) and stroke (29–31).
- Cancer-related studies (68%): lung (32–38), colon (39), acute myeloid leukemia and solid tumors (40), breast (37, 41), pediatric cancer (42–46), prostate cancer (PCa) (47), colorectal (48), lower and upper gastrointestinal tract gastrointestinal tract (GI) (37), gynecological (37), multiple myeloma (37), lymphoma (37), leukemia (37, 49), renal (37), other (37), metastatic cancer (50), pancreatic (38), and biliary tract (38).
- Studies for respiratory diseases (11%): chronic obstructive pulmonary disease (COPD) (51–53).
- Diabetes studies (7%): Type 2 diabetes (54, 55).

A total of 21 studies were conducted in the inpatient setting (29–31, 33, 35, 38–42, 44–49, 51–55) and two studies were conducted in an outpatient setting (28, 32). For the remainder of the studies, two were conducted in a mixed-setting (inpatient and outpatient) (34, 43), and three combined hospital-based and home-based exercise interventions (36, 37, 50). Nine of the selected studies were published during 2012–2016 (28, 32–34, 39–41, 51, 54). However, there has been a rapid increase in research studies over recent years, with 19 further studies published during 2016–2022 (29–31, 35–38, 42–50, 52, 53, 55).

A randomized control trial (RCT) research design comprised 54% of the studies (28–33, 35, 36, 39–42, 44, 51, 52); pilot study research designs were used in another 14% (34, 43, 48, 50, 55); the other designs were interviews (10%) (38, 47, 49); experimental designs (10%) (37, 46, 53); a crossover control study (4%) (54); a cohort study (4%) (45); and a feasibility study (4%) (48). In total, 10 types of exercise interventions were used: these included aerobic exercise (28, 32–35, 37–42, 44–47, 49, 50, 52–54); resistance exercise (31, 33–35, 37–42, 44–51, 55); balance exercise (38, 39); core exercise (39); computer-based exercise intervention (43); sling exercise therapy (29); video-guided exercise (30); flexibility exercise (38); respiratory exercise (35); and progressive relaxation exercises (36). The studies all included positive results, except for one. This study obtained negative results demonstrating no significant differences between hospital plus home exercise program and usual care group patients. The findings of the study outlined that all patients had recovered pre-operative exercise tolerance level by 4 weeks after surgery. However, the study also suggested that a post-discharge walking home, following patient evaluation, might provide additional medical benefit for patients (33).

3.3. Exercise guidelines

Only eight studies used existing guidelines or were tailored according to previous guidelines, which included a sling exercise therapy (SET) program (29); video-guided exercise (30); exercise program protocol were modeled from existing published cancer exercise and UK physical activity recommendations (47); active video game (Microsoft® Xbox 360 Kinect) (43); enhanced recovery after surgery protocols (ERAS) (48); rehabilitation program in chronic obstructive pulmonary disease (COPD) (35); progressive relaxation exercises protocol (36); and an exercise protocol tailored according to previous studies (45); rest of studies were set using initial exercise prescriptions. More than half of the studies provided detailed exercise protocols for replication for future implementation (30, 31, 33, 34, 36, 37, 39–42, 44, 45, 47, 48, 52). There were several other guidelines contributing to the experimental process. These included the American Thoracic Society 2002 guidelines (35); European Respiratory Society recommendations (35); and Guidelines of the Japan Diabetes Society (55) (see Supplementary Table S4[4]).

3.4. Detailed information on exercise intervention

In the selected studies, one study evaluated the acute effects of two types of one-hour exercise interventions for type 2 diabetes patients (54). In other studies, the exercise intervention durations ranged from 2 weeks to 27 weeks, respectively. Some studies' exercise intervention durations depended on the length of the patients' hospital stays (39, 49, 51, 52). The length of each individual exercise intervention also

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[1] https://osf.io/mgbst

[2] https://osf.io/b2jkq

[3] https://osf.io/tvp4w

[4] https://osf.io/jwv7y

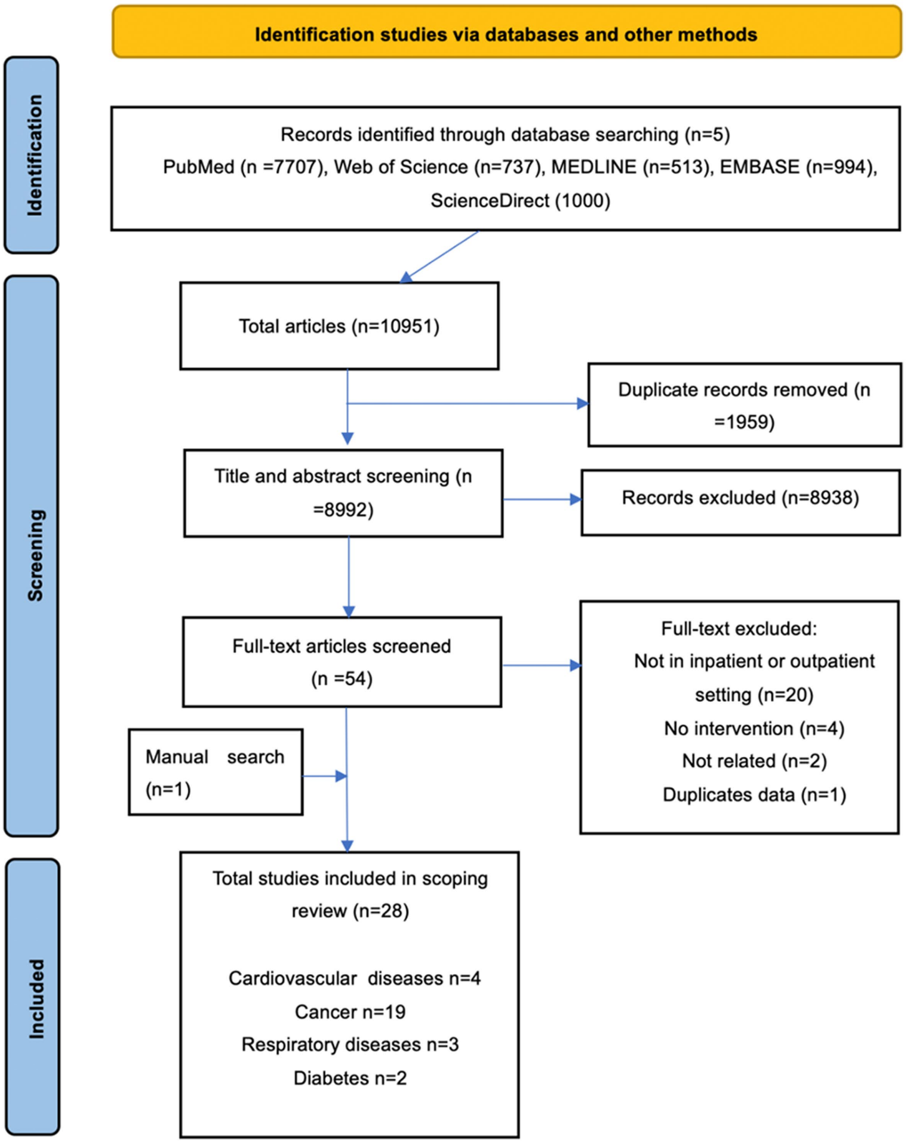

FIGURE 1
Flowchart of screening and selection process.

varied substantially: in one study being more than 2 h (35); in others 60 ~ 70-min (37, 41, 42, 44–47, 54); in some 30 ~ 45-min (28, 29, 32, 33, 36, 39, 40, 43, 48, 50, 53, 55); or along with conventional therapy (40-min) for an additional 15-min (31), or 15 ~ 45-min (49). The intervention frequency ranged from every day (33, 36, 39, 48, 53, 55); to five times a week (29, 31, 34, 35, 40); three times a week (32, 34, 42, 44, 46); twice a week (28, 38, 41, 45, 47, 49, 50); or once per week (37, 47).

For patients with non-communicable diseases, exercise interventions should be supervised and adjusted by the clinician or physical therapist based on the individual's exercise response and the medical condition of patients. The studies were conducted using supervised exercise interventions by physical therapists (29, 30, 32, 37, 39, 41, 47, 50, 51); by fitness instructors (42); sport scientists (34, 43, 46, 49); team kinesiologists (48); medical staff (35, 38, 45, 55); or by study investigators (36). Patients in one study expressed that they felt less motivated when exercising independently and most of the participants seemed to prefer a structured, class exercise model as outlined previously (47). Exercise interventions under supervision and team-based not only provide a professional approach and keep the patients safe; in addition, the social environment provides patients with structured classes, and timetabled appointments provide an antidote to motivational inertia.

Exercise intensities were controlled during the studies using several methods. These included heart rate (28, 33, 41, 44, 45, 47); Borg scale (34); VO_{2peak} (54); low-to-moderate exercise intensity (39, 55); (34, 52); based on the patients' individual health situation (43, 44, 48); based on the baseline measurement results (28, 40, 51); or adjustments by the physical therapist based on individual patients' response (32). Some exercise programs were adjusted by the physical therapist every 1-2 weeks, every 4 weeks, or increased gradually based on the individual's response (32, 41, 44, 45, 52). In a study by Platschek, computer-based exercise provided different types and intensities of games based on the patient's age, individual aerobic capacity, and daily condition (43) (see Supplementary Table S2; see footnote 2).

3.5. Acceptability of exercise intervention

The exercise intervention programs used were easily incorporated into an existing clinical rehabilitation program (28). Even 5-year-old patients could actively participate in the workout sessions (46). An important finding was that the studies did not observe any exercise-related adverse events in the selected studies, and all studies agreed that the exercise modalities were feasible and safe for patients. After 30 days following hospital discharge, only one case of wound infection was reported, and none of the patients had to undergo a second surgery and none were readmitted to the hospital during the follow-up period (39). Through the interactions with study and patient education/consulting, patients in the exercise group learned to cope better with their symptoms (32). Motivational force was attributed to peer support, and the friendly environment in the exercise group that provided benefits for the patients' social development (38, 42, 47). There was an increase in the patients' interest in exercise activity (43). Furthermore, participants had high confidence to continue exercising following cessation of the program, according to a self-efficacy item provided in one survey (37). Participants described physical and psychosocial benefits from the exercise and commented on the highly valued staff (37). Moreover, participants reported they were satisfied with the program and would recommend it to others (37). Some exercise interventions were easier to conduct: for example, resistance training does not require large spaces in wards/hospital (48) (see Supplementary Table S4; see footnote 4).

3.6. Adherence of exercise programs

Patients were recruited from clinics and hospitals in the selected studies. The adherence rate in the four cardiovascular diseases category was 100% in two studies (29, 31); in the other two studies 86% (28) and 79% (30) respectively. With regard to the cancer category (total 19 studies), four studies experienced 100% adherence (42, 43, 45, 46); seven studies were between 80 and 100% (36–41, 48); six studies were between 60 and 80% (32–35, 49, 50); and two studies saw adherence below 60% (44, 47). There were three respiratory disease studies included in this scoping review and the adherence rates were 63% (51), 78% (53), and 100% (52), respectively. Lastly, there were two diabetes studies with adherence rates of 100% (54) (see Supplementary Table S4; see footnote 4).

3.7. Resources of exercise implementation

Measurement questionnaires and guidelines that were used in the exercise program can be used as references for future studies and implementation. These included: the Fatigue Severity Scale (FSS) (28), Human Activity Profile (HAP) (28), Motor Status Scale (MSS) (30), General self-efficacy scale (GSE) (30), Trunk impairment Scale (TIS) (31), Stroke-specific quality of life scale (SS-QOL) (31), Borg Rating of Perceived Exertion (RPE) (32–34, 40, 41, 47, 52), Borg CR10 Breathlessness Scale (BBS) (33), Modified Fatigue Impact Scale (MFIS) (40), Hospital Anxiety and Depression Scale (41), PedsQL™ Multidimensional Fatigue Scale (43), Baseline Borg dyspnea scale (35), Dyspnea Index (BDI) (35), Functional Assessment Cancer Therapy-General (FACT-G) (50), PedsQL-4.0 Generic Core Scales (Italian edition) (46), PedsQL Multidimensional Fatigue Scale (Italian edition) (46), Barthel Index (52), Modified Medical Research Council (MMRC) Dyspnea Scale (53), and Cardio-ankle vascular index (55). Questionnaires used were the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC-QLQ-C30) (40, 50), Short Questionnaire to Assess Health enhancing physical activity (SQUASH) (41), Multidimensional Fatigue Inventory (MFI) (41), Fatigue Quality List (FQL) (41), 30-item European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30 (41), 36-item Short Form Health Survey (SF-36) (41), Modified paper-and-pencil MoodMeter® questionnaire (43), MILES questionnaire (48), Modified Medical Research Council (mMRC) questionnaire (35), Functional Assessment of Chronic Illness Therapy-Fatigue Questionnaire (FACIT-Fatigue)(50), St. George's Respiratory Questionnaire (52), Modified Baecke Physical Activity Questionnaire (52), and the St. George's Respiratory Questionnaire (SGRQ) (53).

The equipment used in the exercise programs included HR monitor (54, 55), Sling suspension equipment (29), Laboratory test equipment (45), Hospital gymnasium (42, 44–46), Cross trainer (47), Metabolic cart (44), Cycle ergometer (34, 40, 47), Resistance bands (48), Weight training machines specifically designed for children (45), Pedometers (33, 38, 53), Dumbbells (47), Portable handheld dynamometer (52), Spirometry (52), Pulse oximeter (52), Treadmill (34, 40, 47, 50), Arm cycling (47), Multigym (47), Active video game (Microsoft® Xbox 360 Kinect) (43), CT (50), In-house software (50), MP3 and earphones (36), Short message service (36), Actiheart; CamNtech—a triaxial accelerometer (54), CGM; Guardian Real-Time with Enlite glucose sensor; Medtronic (54), HBR-2070 (for blood pressure and heart rate measurement) (55), *VS*-1500 (for ankle-brachial index and cardio-ankle vascular index) (55), Mobile tablet (30), and Act iWatch (33) (see Supplementary Table S4; see footnote 4).

3.8. Exercise programs providers

Eight studies included exercise sport science specialist, experienced fitness instructor, or kinesiologist (30, 34, 41, 43, 45, 46, 48, 49). In the rest of the studies, physiotherapist (29, 30, 32, 35, 37, 39, 41, 47, 50–52), researcher/investigator (30–33, 35, 36, 39, 41, 42, 44, 45, 47, 49, 51–53), physician/surgeon (34, 35, 39, 44, 48), nurse (36, 38, 39, 48, 53), and hospital/medical staff (36, 37, 39, 45, 55) were involved in the exercise program. No information about exercise prescription providers qualification and years of experience was provided. During the screening of the studies included in this review, it was noticeable that none included physiologists or clinical physiologists in the intervention process to prescribe exercise which would be desirable (see Supplementary Table S4; see footnote 4).

3.9. Existing research and limitations

We included four categories of studies for NCDs. For cardiovascular diseases, studies focused on investigating the effectiveness of an exercise intervention for pulmonary arterial hypertension (PAH) (28); and to explore the effectiveness of exercise therapy in stroke patients (29–31). Four studies had the limitations of small sample size (28–31); no sample size calculation (30); or single sex participants (28). Some studies experienced patients withdrawing due to changes in medication (28), or low attendance at the exercise sessions (28). Some results were based on self-reports (28), or had potential performance and social desirability biases (30).

Regarding the cancer category, one study focused on determining the effect of progressive relaxation exercise in patients with lung cancer (36); some studies specially focused on non-small cell lung cancer (NSCLC) (32–35). Two studies examined the effects of a postsurgical, inpatient exercise program in colon cancer patients (39), and investigated the feasibility of initiating resistance exercise in colorectal cancer patients (48). Several studies explored perceived exercise benefits and barriers in adults with acute leukemia (49); patients' experience of a structured exercise intervention for men with prostate cancer (PCa) (47); and the effects of an exercise intervention on preventing an increase in fatigue in patients with breast cancer (41). For the pediatric cancer area, studies examined the effects of an in-hospital exercise intervention (42, 44–46) and a computer-based exercise intervention in pediatric cancer patients (43). The rest of the four studies examined the feasibility of embedding a flexible, exercise-based rehabilitation program into cancer treatment (37, 50); the effects of aerobic and strength exercise in hospitalized cancer patients (40); and the experiences of older patients with advanced cancer who participated in an exercise program (38), respectively.

Meanwhile, small sample sizes (32, 34, 37, 39, 40, 43, 44, 46, 49, 50) also existed in the cancer studies. Further limitations were difficulties in recruiting participants (32, 44); adherence problems and low attendance for exercise intervention (32–36, 39, 40, 44, 45, 47, 50); heterogeneity in participants' characteristics (44–46); or non-randomized sampling (37, 45, 46). Considering study design, some exercise studies were unblinded (33, 39, 47), or lacked a control group (34, 43, 47, 48, 50). Measurement limitations included the timing and nature of surgery, meaning that authors were unable to collect preoperative activity data (33); lack of assessment of psychosocial parameters (40); the authors being unable to supervise some processes (33, 37, 50); outcomes being assessed more descriptively instead of being objectively measured and analytical (36, 38, 41, 43, 46, 47, 49); or lack of biochemical marker measurements (35) were also observed weaknesses in some studies. For the outcome results, patients' familiarization with the testing equipment leading to neural adaptation contributing to increases in performance (42). Other limitations included changing hospital policies (making it impossible to meet the recruitment criteria) (39), patients' motivations (32), or changes in some of the testing items for patients 'medical reasons (42).

As for the three respiratory diseases studies, the focus was on measuring the effect of whole-body resistance training in patients hospitalized for exacerbation of chronic obstructive pulmonary disease (COPD) (51); determining the effects of regular walking programs in patients with stage I and II COPD (53); and determining whether an exercise intervention can reduce disability in frail older patients with acute exacerbation of chronic obstructive pulmonary disease (AECOPD) (52). Once again, there were several limitations in the studies reviewed. The test results were influenced by variable patient motivations (51, 52); small sample size (51); adherence problems (51, 53); the patients' early discharge and low attendance rate for exercise interventions (51); the lack of a biopsy to assess muscle condition (52); or self-reported measurements (53).

The two diabetes studies focused on determining whether interval-based exercise improves postprandial glucose tolerance and free-living glycemia more than oxygen consumption- and time duration-matched continuous exercise(54); and investigating the effect of short-term toe resistance training on toe pinch force and toe muscle quality (55), respectively. The limitations were small sample size (54, 55); research design limitation(54); or the lack of a comparison group (55) (see Supplementary Table S5[5]).

4. Discussion

In this scoping review, we selected 28 studies that used exercise interventions with non-communicable diseases patients in inpatient or outpatient settings. There were positive outcomes in 27 studies. These included increasing the patients' physical activity levels (28, 41); improved cardiorespiratory fitness (28, 53); decreased fatigue (28, 40, 41, 43, 46); improved quality of life (29, 31, 34, 46, 50, 53); relief of pain (29); improved body mobility and capacity (31, 32, 34, 35, 38–42, 44, 50–53, 55); alleviating related symptoms (32, 36, 38, 40, 53); reduced hospital stays (39, 45); and better glycemic control (54). Intervening with exercise-based rehabilitation within the treatment unit represents an opportunity for early support, including behavior change strategies during treatment to prevent deterioration in health status (37). Exercise prescription should be individually prescribed and interventions should be based on clinical examination results and the stage of the disease. In this review, exercise interventions conducted at the same time as chemotherapy (35, 36, 40, 42, 44, 45, 49, 50), or after surgery (33, 39, 48), were found to be feasible and acceptable. Additionally, there were positive effects on psychological aspects in patients involved in exercise (38, 43, 46, 49). Data syntheses of results demonstrated that exercise intervention is a safe, effective, and feasible method for non-communicable diseases' patients, with no exercise-related adverse events being reported.

The exercise intervention guidelines summarized in this study, indicating that more than half of the included studies offered very detailed exercise intervention plans. The intervention plans were reliable and provide validated evidence for designing exercise programs that can be replicated in future exercise implementations. Furthermore, there are many sophisticated scales and questionnaires that can be used by physicians in the process of exercise interventions for non-communicable diseases treatment. The exercise equipment used was simple to operate and easily accessible for the implementation process. All the studies were conducted in the hospital (three studies combined hospital and home-based exercise intervention), eight of the 28 studies exercise programs were proscribed by exercise specialist, other involved exercise intervention providers such as physiotherapist, nurse, medical staff, physician, investigator, or researcher who provided exercise supervision and support services during the treatment process. Consequently, the exercise guidelines and resources

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[5] https://osf.io/b3z4f

provide the foundation for exercise interventions in the healthcare system.

Functional clinical testing is recommended before prescribing exercise for patients. As part of the pre-participation health screening process, it is recommended that all moderately to high-risk patients undergo a medical examination and/or stress test, and a formal clinical consultation before commencing on an exercise program (56). In our scoping review, more than 80% of the selected studies provided detailed participant inclusion and exclusion criterion. These are useful references providing information for physicians and practitioners to implement exercise prescription and operate an exercise intervention in the non-communicable diseases' treatment setting. However, adherence rates were a problem in many of the selected studies. The main reasons were due to changes in medication, patients' motivation for exercise, and the patients' early discharge from hospital. In addition, patients' anxiety, aches, and pains cannot be ignored (49). In our review, only two studies mentioned financial issues [Morales's study reported the economic cost of hospitalization, the significantly lower number of hospitalization days in the exercise group, representing a ~ 17% reduction in economic costs compared with the control group (45). In Dennett's study, no additional expenses were incurred for equipment or venue. The primary resource cost was the funding of the staff resource (37)].

In a previous study outlining the benefits of exercise for NCDs, Ezenwankwo discussed embedding exercise service units into clinical oncology settings. The research outlined six studies providing data from 30 exercise programs. Issues relating to funding, lack of a detailed implementation plans, and low organizational buy-in were the major barriers to effective service integration, particularly at the health service level (57). A further study by Kennedy, investigating the implementation of exercise into routine cancer care, was hindered by a web of interrelated challenges across all levels of the healthcare system. These challenges limited the ability of patients to access effective exercise resources during cancer treatment (1).

The studies examined here provide strong and consistent evidence that exercise interventions in the NCDs treatment setting, especially in the inpatient situation, can help enhance conventional treatment methods. Exercise prescription contains both effective and enjoyable activities to match individual patients' preferences, ability, and limitations. Exercise interventions supervised by experienced health practitioners (preferably by the same supervisor throughout the whole duration of the programs) can demonstrate complementary advantages during treatment. Also, optimally coordinated with medical appointments, a holistic, multidisciplinary approach that includes symptom monitoring, provision of advice on symptom management, systematic assessment of patients' health status and information on individual life situations, will increase treatment compatibility. Patients who receive professional guidance from their physician or physiological expertise in the health care team in inpatient and outpatient treatment consultations, will likely develop greater confidence related to the positive effects of exercise and continue exercise routines after discharge.

4.1. Suggestions for implementation

Exercise interventions for NCDs patients are feasible and acceptable for both the medical provider and patient. The evidence indicates that exercise is complementary to conventional therapy, with no adverse events. Detailed information relating to exercise guidelines, and the medical resources in the hospital environment from 28 studies, provide reliable evidence for future practice and implementation.

To bridge the gap from theory to practical implication and the realization of aims, in addition to the scientific policy-making process and suggestions, consideration needs to be given to a general alignment between policy and practice to ensure long-term and effective implementation and delivery. These processes are normally completed by policy actors who are individuals or groups that are directly or indirectly, formally or informally, affiliated with or affected by the policy process at any stage. The roles of the actors in this case include several related groups: the hospital where exercise prescription is especially used; medical school, universities that provide resources for physicians to become qualified to prescribe exercise; medical insurers in some care systems; and even the business organizations that provide the resources for exercise tests and exercise practice equipment. The functions of the actors are to promote patients' healthy behaviors; building and developing capacity such as physician's exercise prescription skills and physiotherapist numbers; improving access to healthcare and other essential goods and health service; changing the hospital and social healthcare institutions attitudes for exercise as a medicine; redistribution of financial or other medical resources, etc. The context for exercise prescription delivery comprises the hospital setting, equipment, medical training system, the physician's skill and ability to provide exercise prescription, and the patients' confidence in the benefits of exercise prescription.

The implementation of exercise prescription will require the coordination by multiple stakeholders including government agencies, politicians, non-government organizations, professional societies, legislatures, healthcare systems, and the healthcare industry (58). Additionally, medical schools, hospital services, and patients exercise education need mobilization for exercise prescription to gain momentum as a formal treatment for non-communicable diseases. The best scenario would include a governmental shift in health provision that includes collaboration with exercise professionals in inpatient and outpatient healthcare provision, along with a re-orientation of the general practice environment toward an exercise health promotion initiative. At the societal level, healthcare support includes developing a practical infrastructure, equipment base, peer networks, and improvements in the confidence of patients for exercise intervention, making them more receptive.

4.2. Future directions

Several suggestions for future research emanating from this scoping review include the following:

- In this study, most of the articles included were retrieved from cancer studies. There are also many original research articles, systematic reviews and meta-analyses conducted investigating cardiovascular diseases (59–62), respiratory diseases (63–65), and diabetes (66–69); however, studies pertaining to exercise prescription in the inpatient and outpatient environment for these three types of non-communicable diseases are limited. Based on this, more RCT studies are needed in the hospital environment to explore the effects of exercise interventions. Further research needs to include larger sample sizes; to explore the optimal duration, intensity, and frequency of exercise training; and further experimentation investigating the design, durability, and generalizability of exercise programs. Additionally, following clinical assessment and to measure the postoperative complications after discharge, wearable device initiatives need to be considered and implemented.

- There is a need for (combined qualitative and quantitative methods) research investigating different ethnic groups, and whether results are consistent across studies. Also, more objective and precise measurements are required in future studies.
- There is also a need to estimate the beneficial effects of exercise interventions in isolation without medication.
- Future work needs further qualitative studies to elucidate both patients' and clinicians' attitudes, motivation and confidence toward exercise as a medicine, and explore the barriers toward participation in exercise programs using a multidisciplinary perspective in order to translate evidence into practice and improve patient outcomes.
- There is a need for further studies that focus on financial issues, such as insurance policy implementation, and the cost of exercise prescription etc.
- More research is required to confirm the benefits of exercise intervention in health service provision, to drive policy-changing and the funding exercise prescription as part of standard care.

4.3. Strengths and limitations

The major strength of this review is that the information provided demonstrates the consistent and substantial benefits of exercise as medicine for patients with non-communicable diseases. A further strength is that the article outlines adequate existing resources for exercise as medicine, and identifies barriers that need to be overcome for success in implementation of the findings in the health-policy-making process. This study has updated the exercise benefits for treatment methods regarding NCDs, outlined the need for future research and indicated where there were discrepancies in the literature. This study has also provided meaningful suggestions for future research directions.

There were some study limitations. Firstly, there were flaws in the experimental design of some of the selected studies. We did not set any restriction for study design and only restricted the exercise interventions conducted in inpatient or outpatient NCDs treatment settings. Therefore, there were problems with small sample sizes; no sample size calculations; self-reported results; single sex participants; lack of control groups; outcomes being assessed more descriptively instead of using objective measurements; outcomes not being analytical; or non-randomized sampling problems. Secondly, we were unable to provide the exercise cost in the inpatient and outpatient setting. Also, the patients' satisfaction level for the exercise interventions of selected studies was not provided. Lastly, there were large data sets for cancer studies, but for the other three NCDs investigated there was less data available for inclusion.

5. Conclusion

Based on the validated evidence, we conclude that the addition of exercise is a powerful complementary treatment method to prevent and manage non-communicable diseases. Exercise prescription as a non-pharmaceutical health intervention can be promoted and implemented in combination with traditional medical science. This medical management treatment approach may be helpful in providing the basis of a new healthcare service model. This review summarizes the evidence and suggests implementing exercise prescription into non-communicable diseases treatment settings in the inpatient and outpatient environment. This would improve the status of the population's health and enhance healthy lifestyles globally, while reducing the social and economic costs associated with NCDs.

Author contributions

DT and AC drafted the study design. RA-S, JB, GA, YDG, FD, and YS provided critical feedback on the protocol. DT and JB did the literature searches. DT and RA-S contributed to the screening process and selection of included studies. DT initially extracted the data and did the qualitative and quantitative data analysis, and it subsequently verified by RA-S. DT completed the data synthesis. All authors had access to the data, critically reviewed and approved the manuscript.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1126244/full#supplementary-material

References

1. Kennedy MA, Bayes S, Newton RU, Zissiadis Y, Spry NA, Taaffe DR, et al. Implementation barriers to integrating exercise as medicine in oncology: an ecological scoping review. *J Cancer Surviv*. (2021) 16:865–81. doi: 10.1007/s11764-021-01080-0

2. O'Regan A, Pollock M, D'Sa S, Niranjan V. ABC of prescribing exercise as medicine: a narrative review of the experiences of general practitioners and patients In: *BMJ open sport and exercise medicine*, vol. *7*. ed. E. Verhagen, United Kingdom: BMJ Publishing Group (2021).

3. Tao D, Supriya R, Gao Y, Li F, Liang W, Jiao J, et al. Dementia and dance: medication or movement? *Phys Act Health*. (2021) 5:250–4. doi: 10.5334/paah.138

4. Trilk JL, Phillips EM. Incorporating 'exercise is medicine' into the university of South Carolina school of medicine Greenville and Greenville health system. *Br J Sports Med*. (2014) 48:165–7. doi: 10.1136/bjsports-2013-093157

5. Scott JM, Zabor EC, Schwitzer E, Koelwyn GJ, Adams SC, Nilsen TS, et al. JOURNAL OF CLINICAL ONCOLOGY efficacy of exercise therapy on cardiorespiratory fitness in patients with cancer: a systematic review and meta-analysis. *J Clin Oncol [Internet]*. (2018) 36:2297–305. doi: 10.1200/JCO.2017.77.5809

6. Bekhet AH, Abdalla AR, Ismail HM, Genena DM, Osman NA, El Khatib A, et al. Benefits of aerobic exercise for breast cancer survivors: a systematic review of randomized controlled trials. *Asian Pac J Cancer Prev*. (2019) 20:3197–209. doi: 10.31557/APJCP.2019.20.11.3197

7. Shawahna R, Batta A, Asaad M, Jomaah M, Abdelhaq I. Exercise as a complementary medicine intervention in type 2 diabetes mellitus: a systematic review with narrative and qualitative synthesis of evidence. *Diabetes Metab Syndr*. (2021) 15:273–86. doi: 10.1016/j.dsx.2021.01.008

8. O'Donoghue G, Blake C, Cunningham C, Lennon O, Perrotta C. What exercise prescription is optimal to improve body composition and cardiorespiratory fitness in adults living with obesity? A network meta-analysis. *Obes Rev*. (2021) 22:e13137. doi: 10.1111/obr.13137

9. Tao D, Gao Y, Cole A, Baker JS, Gu Y, Supriya R, et al. The physiological and psychological benefits of dance and its effects on children and adolescents: a systematic review. *Front Physiol*. (2022) 13:1–13. doi: 10.3389/fphys.2022.925958

10. Sun Y, Gao Y, Yu S, Wang A, Ou X, Tao D, et al. Promoting physical activity among workers: a review of literature and future directions on developing theory-based interventions. *Int J Environ Res Public Health*. (2022) 19:13594. doi: 10.3390/ijerph192013594

11. WHO. Noncommunicable diseases. (2021) Available at: https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases

12. Thompson WR, Sallis R, Joy E, Jaworski CA, Stuhr RM, Trilk JL. Exercise is medicine. *Am J Lifestyle Med*. (2020) 14:511–23. doi: 10.1177/1559827620912192

13. The human and economic toll of NCDs is unacceptable, inequitable, and increasing. (2022). Available at: https://ncdalliance.org/2022-global-week-for-action-on-ncds

14. NCD Countdown Worldwide trends in non-communicable disease mortality and progress towards sustainable development goal target 3.4 NCD countdown 2030 collaborators* [internet]. (2030) Available at: www.thelancet.com/NCD

15. Pedersen BK. The physiology of optimizing health with a focus on exercise as medicine (2018) 81:607–27. doi: 10.1146/annurev-physiol-020518-114339,

16. Chatterjee R, Wolman R. Exercise is medicine: a case study of an exercise prescription clinic in the NHS. *Br J Gen Pract*. (2019) 69:307–8. doi: 10.3399/bjgp19X704033

17. Peters MDJ, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc*. (2015) 13:141–6. doi: 10.1097/XEB.0000000000000050

18. Tricco AC, Cardoso R, Thomas SM, Motiwala S, Sullivan S, Kealey MR, et al. Barriers and facilitators to uptake of systematic reviews by policy makers and health care managers: a scoping review. *Implement Sci*. (2016) 11:4. doi: 10.1186/s13012-016-0370-1

19. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med*. (2018) 169:467–73. doi: 10.7326/M18-0850

20. Jensen KA. Seven steps to the perfect Pico search: evidence-based nursing practice. *EBSCO Health*. (2017):1–9.

21. Cooke A, Smith D, Booth A. Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qual Health Res*. (2012) 22:1435–43. doi: 10.1177/1049732312452938

22. Methley AM, Campbell S, Chew-Graham C, McNally R, Cheraghi-Sohi S. PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. *BMC Health Serv Res*. (2014) 14:579. doi: 10.1186/s12913-014-0579-0

23. WHO. Cardiovascular diseases. (2022) Available at: https://www.who.int/health-topics/cardiovascular-diseases#tab=tab_1

24. WHO. Chronic respiratory diseases. (2022) Available at: https://www.who.int/health-topics/chronic-respiratory-diseases

25. WHO. Diabetes. (2021) Available at: https://www.who.int/news-room/fact-sheets/detail/diabetes

26. Tricco AC, Lillie E, Zarin W, O'Brien K, Colquhoun H, Kastner M, et al. A scoping review on the conduct and reporting of scoping reviews. *BMC Med Res Methodol [Internet]*. (2016) 16:1–10. doi: 10.1186/s12874-016-0116-4

27. The Joanna Briggs Institute. The Joanna Briggs institute critical appraisal tools. Available at: https://jbi.global/critical-appraisal-tools

28. Weinstein AA, Chin LMK, Keyser RE, Kennedy M, Nathan SD, Woolstenhulme JG, et al. Effect of aerobic exercise training on fatigue and physical activity in patients with pulmonary arterial hypertension. *Respir Med*. (2013) 107:778–84. Available from:. doi: 10.1016/j.rmed.2013.02.006

29. Liu J, Feng W, Zhou J, Huang F, Long L, Wang Y, et al. Effects of sling exercise therapy on balance, mobility, activities of daily living, quality of life and shoulder pain in stroke patients: a randomized controlled trial. *Eur J Integr Med*. (2020) 35:101077. doi: 10.1016/j.eujim.2020.101077

30. Kenny M, Gilmartin J, Thompson C. Video-guided exercise after stroke: a feasibility randomised controlled trial. Physiother. *Theory Pract*. (2020) 38:609–20. doi: 10.1080/09593985.2020.1790072

31. Mahmood W, Ahmed Burq HSI, Ehsan S, Sagheer B, Mahmood T. Effect of core stabilization exercises in addition to conventional therapy in improving trunk mobility, function, ambulation and quality of life in stroke patients: a randomized controlled trial. *BMC Sports Sci Med Rehabil*. (2022) 14:1–9. doi: 10.1186/s13102-022-00452-y

32. Hwang CL, Yu CJ, Shih JY, Yang PC, Wu YT. Effects of exercise training on exercise capacity in patients with non-small cell lung cancer receiving targeted therapy. *Support Care Cancer*. (2012) 20:3169–77. doi: 10.1007/s00520-012-1452-5

33. Arbane G, Douiri A, Hart N, Hopkinson NS, Singh S, Speed C, et al. Effect of postoperative physical training on activity after curative surgery for non-small cell lung cancer: a multicentre randomised controlled trial. *Physiotherapy (United Kingdom)*. (2014) 100:100–7. doi: 10.1016/j.physio.2013.12.002

34. Kuehr L, Wiskemann J, Abel U, Ulrich CM, Hummler S, Thomas M. Exercise in patients with non-small cell lung cancer. *Med Sci Sports Exerc*. (2014) 46:656–63. doi: 10.1249/MSS.0000000000000158

35. Rutkowska A, Jastrzebski D, Rutkowski S, Zebrowska A, Stanula A, Szczegielniak J, et al. Exercise training in patients with non-small cell lung cancer during in-hospital chemotherapy treatment: a randomized controlled trial. *J Cardiopulm Rehabil Prev*. (2019) 39:127–33. doi: 10.1097/HCR.0000000000000410

36. Kırca K, Kutlutürkan S. The effect of progressive relaxation exercises on treatment-related symptoms and self-efficacy in patients with lung cancer receiving chemotherapy. *Complement Ther Clin Pract*. (2021) 45:101488. doi: 10.1016/j.ctcp.2021.101488

37. Dennett AM, Zappa B, Wong R, Ting SB, Williams K, Peiris CL. Bridging the gap: a pre-post feasibility study of embedding exercise therapy into a co-located cancer unit. *Supportive Care Cancer*. (2021) 29:6701–11. doi: 10.1007/s00520-021-06261-2

38. Mikkelsen MK, Michelsen H, Nielsen DL, Vinther A, Lund CM, Jarden M. 'Doing what only I can do': experiences from participating in a multimodal exercise-based intervention in older patients with advanced cancer – a qualitative explorative study. *Cancer Nurs*. (2022) 45:E514–23. doi: 10.1097/NCC.0000000000000987

39. Ahn KY, Hur H, Kim DH, Min J, Jeong DH, Chu SH, et al. The effects of inpatient exercise therapy on the length of hospital stay in stages I-III colon cancer patients: randomized controlled trial. *Int J Color Dis*. (2013) 28:643–51. doi: 10.1007/s00384-013-1665-1

40. Oechsle K, Aslan Z, Suesse Y, Jensen W, Bokemeyer C, De Wit M. Multimodal exercise training during myeloablative chemotherapy: a prospective randomized pilot trial. *Support Care Cancer*. (2014) 22:63–9. doi: 10.1007/s00520-013-1927-z

41. Travier N, Velthuis MJ, Steins Bisschop CN, van den Buijs B, Monninkhof EM, Backx F, et al. Effects of an 18-week exercise programme started early during breast cancer treatment: a randomised controlled trial. *BMC Med*. (2015) 13:1–11. Available from:. doi: 10.1186/s12916-015-0362-z

42. Fiuza-Luces C, Padilla JR, Soares-Miranda L, Santana-Sosa E, Quiroga JV, Santos-Lozano A, et al. Exercise intervention in pediatric patients with solid tumors: the physical activity in pediatric cancer trial. *Med Sci Sports Exerc*. (2017) 49:223–30. doi: 10.1249/MSS.0000000000001094

43. Maria PA, Kehe L, Abeln V, Berthold F, Simon T, Str HK. Computer-based exercise program: effects of a 12-week intervention on mood and fatigue in pediatric patients with cancer. *Oncol Nurs Soc*. (2015) 21:280–6. doi: 10.1188/17.CJON.E280-E286

44. Morales JS, Padilla JR, Valenzuela PL, Santana-Sosa E, Rincón-Castanedo C, Santos-Lozano A, et al. Inhospital exercise training in children with cancer: does it work for all? *Front Pediatr*. (2018) 6:1–8. doi: 10.3389/fped.2018.00404

45. Morales JS, Santana-Sosa E, Santos-Lozano A, Baño-Rodrigo A, Valenzuela PL, Rincón-Castanedo C, et al. Inhospital exercise benefits in childhood cancer: a prospective cohort study. *Scand J Med Sci Sports*. (2020) 30:126–34. doi: 10.1111/sms.13545

46. Spreafico F, Barretta F, Murelli M, Chisari M, Gattuso G, Terenziani M, et al. Positive impact of organized physical exercise on quality of life and fatigue in children and adolescents with cancer. *Front Pediatr*. (2021) 9:1–10. doi: 10.3389/fped.2021.627876

47. Fox L, Cahill F, Burgess C, Peat N. SRB research, 2017 undefined. Real world evidence: a quantitative and qualitative glance at participant feedback from a free-response survey investigating experiences of a structured exercise. *HindawiCom*. (2017) 2017:1–10. doi: 10.1155/2017/3507124

48. Schram A, Ferreira V, Minnella EM, Awasthi R, Carli F, Scheede-Bergdahl C. In-hospital resistance training to encourage early mobilization for enhanced recovery programs after colorectal cancer surgery: a feasibility study. *Europ J Surg Oncol*. (2019) 45:1592–7. doi: 10.1016/j.ejso.2019.04.015

49. Bryant AL, Walton AML, Pergolotti M, Phillips B, Bailey C, Mayer DK, et al. Perceived benefits and barriers to exercise for recently treated adults with acute leukemia. *Oncol Nurs Forum*. (2017) 44:413–20. doi: 10.1188/17.ONF.413-420

50. Park JH, Park KD, Kim JH, Kim YS, Kim EY, Ahn HK, et al. Resistance and aerobic exercise intervention during chemotherapy in patients with metastatic cancer: a pilot study in South Korea. *Ann Palliat Med*. (2021) 10:10236–43. doi: 10.21037/apm-21-1432

51. Borges RC, Carvalho CR. Impact of resistance training in chronic obstructive pulmonary disease patients during periods of acute exacerbation. *Arch Phys Med Rehabil*. (2014) 95:1638–45. doi: 10.1016/j.apmr.2014.05.007

52. Torres-Sánchez I, Valenza MC, Cabrera-Martos I, López-Torres I, Benítez-Feliponi Á, Conde-Valero A. Effects of an exercise intervention in frail older patients with chronic obstructive pulmonary disease hospitalized due to an exacerbation: a randomized controlled trial. *COPD: J Chron Obstruct Pulmon Dis*. (2017) 14:37–42. doi: 10.1080/15412555.2016.1209476

53. Yilmaz FT, Aydin HT. The effect of a regular walking program on dyspnoea severity and quality of life in normal weight, overweight, and obese patients with chronic obstructive pulmonary disease. *Int J Nurs Pract*. (2018) 24:1–11. doi: 10.1111/ijn.12636

54. Karstoft K, Christensen CS, Pedersen BK, Solomon TPJ. The acute effects of interval-Vs continuous-walking exercise on glycemic control in subjects with type 2 diabetes: a crossover, controlled study. *J Clin Endocrinol Metab*. (2014) 99:3334–42. doi: 10.1210/jc.2014-1837

55. Kataoka H, Miyatake N, Kitayama N, Murao S, Tanaka S. A pilot study of short-term toe resistance training in patients with type 2 diabetes mellitus. *Diabetol Int*. (2017) 8:392–6. doi: 10.1007/s13340-017-0318-y

56. Thompson PD, Arena R, Riebe D, Pescatello LS. ACSM's new preparticipation health screening recommendations from ACSM's guidelines for exercise testing and prescription, ninth edition. *Curr Sports Med Rep*. (2013) 12:215–7. doi: 10.1249/JSR.0b013e31829a68cf

57. Ezenwankwo EF, Nnate DA, Usoro GD, Onyeso CP, Anieto IB, Ibeneme SC, et al. A scoping review examining the integration of exercise services in clinical oncology settings. *BMC Health Serv Res*. (2022) 22, 236. doi: 10.1186/s12913-022-07598-y

58. Whitsel LP, Bantham A, Jarrin R, Sanders L, Stoutenberg M. Physical activity assessment, prescription and referral in US healthcare: how do we make this a standard of clinical practice? In: *Progress in cardiovascular diseases*, vol. *64*. ed. J. Lavie, United Kingdom: W.B. Saunders (2021). 88–95.

59. Cornelissen VA, Verheyden B, Aubert AE, Fagard RH. Effects of aerobic training intensity on resting, exercise and post-exercise blood pressure, heart rate and heart-rate variability. *J Hum Hypertens*. (2010) 24:175–82. doi: 10.1038/jhh.2009.51

60. Yu T, Zhang Z, Zhou D, Li C. Systematic review and meta-analysis on the rehabilitation effect of different intensity exercise on the patients with cardiovascular diseases. *Comput Math Methods Med*. (2022) 2022:1364985. doi: 10.1155/2022/1364985

61. Choquette S, Riesco É, Cormier É, Dion T, Aubertin-Leheudre M, Dionne IJ. Effects of soya isoflavones and exercise on body composition and clinical risk factors of cardiovascular diseases in overweight postmenopausal women: a 6-month double-blind controlled trial. *Br J Nutr*. (2011) 105:1199–209. doi: 10.1017/S0007114510004897

62. Wang XQ, Pi YL, Chen PJ, Liu Y, Wang R, Li X, et al. Traditional chinese exercise for cardiovascular diseases: systematic review and meta-analysis of randomized controlled trials. *J Am Heart Assoc*. (2015) 5:1–17. doi: 10.1161/JAHA.115.002562

63. Alexiou C, Ward L, Hume E, Armstrong M, Wilkinson M, Vogiatzis I. Effect of interval compared to continuous exercise training on physiological responses in patients with chronic respiratory diseases: a systematic review and meta-analysis. *Chron Respir Dis*. (2021) 18:147997312110415–5. doi: 10.1177/14799731211041506

64. Wada JT, Borges-Santos E, Porras DC, Paisani DM, Cukier A, Lunardi AC, et al. Effects of aerobic training combined with respiratory muscle stretching on the functional exercise capacity and thoracoabdominal kinematics in patients with COPD: a randomized and controlled trial. *Int J COPD*. (2016) 11:2691–700. doi: 10.2147/COPD.S114548

65. Ko FWS, Tam W, Siu EHS, Chan KP, Ngai JCL, Ng SS, et al. Effect of short-course exercise training on the frequency of exacerbations and physical activity in patients with COPD: a randomized controlled trial. *Respirology*. (2021) 26:72–9. doi: 10.1111/resp.13872

66. Reddy R, Wittenberg A, Castle JR, El Youssef J, Winters-Stone K, Gillingham M, et al. Effect of aerobic and resistance exercise on glycemic control in adults with type 1 diabetes. *Physiol Behav*. (2017) 176:139–48. doi: 10.1016/j.jcjd.2018.08.193

67. Hwang C-L, Lim J, Yoo J-K, Kim H-K, Hwang M-H, Handberg EM, et al. Effect of all-extremity high-intensity interval training vs. moderate-intensity continuous training on aerobic fitness in middle-aged and older adults with type 2 diabetes: a randomized controlled trial. *Physiol Behav*. (2017) 176:139–48. doi: 10.1016/j.exger.2018.12.013

68. Pan B, Ge L, Qin XY, Jing CY, Yun GC, Han X, et al. Exercise training modalities in patients with type 2 diabetes mellitus: a systematic review and network meta-analysis. *Int J Behav Nutr Phys Act*. (2018) 15:1–14. doi: 10.1186/s12966-018-0703-3

69. Nieman DC. Physical activity advice only or structured exercise training and association with HbA1c levels in type 2 diabetes: a systematic review and meta-analysis. *Yearbook Sports Med*. (2012) 2012:214–5. doi: 10.1016/j.yspm.2011.12.006

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The end-of-life needs of Aboriginal and immigrant communities: a challenge to conventional medical models

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Introduction: Concerns have been raised internationally about the palliative care needs of migrants and First Nations people. This article presents insights from research investigating the end-of-life needs of Aboriginal and culturally and linguistically diverse people living in Western Sydney, Australia. This region has a large rapidly growing, and highly diverse population and on average low socioeconomic status. The research was guided by an advisory panel made up of representatives of supportive and palliative medicine, bereavement support, Aboriginal health, and multicultural health facilities. It aimed to generate findings to support the delivery of culturally sensitive services in the public health system.

Method: The multi-method design and the conduct of the research were informed by the literature on researching with marginalized groups which highlights the ethical considerations needed to avoid replicating past injustices. Qualitative data was generated from key informants and community focus groups.

Results: The analysis revealed seven themes and some suggested solutions which were relevant across several themes. The seven themes were: the Need for trusted relationships; Talking about death and dying; Knowledge of key services; Decision-making and obtaining consent from the patient; Appropriate physical spaces; Cultural practices around EOL; and Language barriers.

Discussion: Within each theme a variety of cultural beliefs and practices were revealed that conflicted with mainstream medical systems, indicating the need for changes in such systems. 'Compassionate Communities' was identified as a model to support the necessary changes.

KEYWORDS

end-of-life care, culturally and linguistically diverse people, Aboriginal people, palliative care, health promoting palliative care, medical system

1. Introduction

Access to palliative and supportive care has been recognized by the World Health Organization as a global ethical responsibility (1). Palliative care is for individuals who have a life-limiting illness and their families. It is care that focuses on improving the patient's quality of life by meeting their holistic needs (physical, emotional, psychosocial, and spiritual) in a manner that aligns with the patient's care preferences. Sometimes, this care will be known as "Supportive Care" when it is early in the disease trajectory or treats complications of the disease such as infection or metabolic issues that cause symptoms. Much of supportive and palliative care will be directed at living well in the last months or even years of life. Palliative care also involves helping the person and family prepare for the person's last weeks and days of life (the "End-of-Life" phase) and their death. It aims to ensure a death of comfort and dignity supported by high-quality care that aligns with their goals and values (2).

Concerns have been raised internationally about the palliative care needs of migrants and First Nations people. Key considerations for medical staff involve how best to communicate about the disease and prognosis, the treatment choices made, and the care goals and preferences during the EOL phase, including the death rituals and observances (3, 4). For migrant communities, there is particular concern about the marginalization of those with limited English. Some examples are Barwise et al. (5) and Abedini et al. (6) in the U.S.; Elkan et al. (7) in the U.K.; Six et al. (8) in Belgium; Nowara et al. (9) in Germany; and Sacchi et al. (10) in Italy. First Nations peoples in developed countries have reduced life expectancies, particularly from chronic diseases, and the lack of access to and take up of palliative care services is an ongoing concern [Shahid et al. (11), cross-national; Gebauer et al. (12), U.S.; Canadian Virtual Hospice (13); Gott et al. (14), N.Z.]. Australia has a dedicated *National Palliative Care Strategy (2018)* which declares that high-quality evidence-based palliative care should be accessible to all citizens. It was rated fourth out of 81 countries for its EOL care (15). However, there is a lack of detailed nationally consistent data (16), especially for urban Aboriginal communities (17), which would guide the delivery of services in local state-based health districts. The data that *do* exist show that Aboriginal and culturally and linguistically diverse (CaLD) Australians are currently under-served (18).

Theoretical analyses of modern Western health systems support concerns about the unmet palliative care needs of First Nations and culturally and linguistically diverse (CaLD) peoples. The principles of palliative care, with its holistic focus on care rather than cure for the patient and their family, stand in contrast to at least three overriding attributes of most medical systems. First, the fragmentation of care (19) contrasts with a holistic focus. Second, the dominance of mechanistic physiology (20) neglects the phenomenological experiences of the patient with its attention to cure over care (19). Third, health's implicit economic function (19) sees the institution of medicine existing to ensure citizens remain healthy enough to contribute as workers and consumers (21). Thus, people at end-of-life (EOL) especially those who are culturally or economically marginalized will not be a priority of neo-liberal health systems (21).

However, there are alternative models. Health-promoting palliative care (22) emphasizes trusting relationships and networks of care across health services and communities. This public health approach to EOL care is encapsulated in the "compassionate communities" movement (22). Here, dying, caring, and death are not constructed as solely medical events, but as social events (23–25). Moving from systems focused on mechanistic physiology and economics to compassionate communities needs, according to Rosenberg et al. (26), to be guided by three principles: re-evaluation of organizational values; recognition of the primacy of caring networks; and realignment of the inherent paternalism in healthcare provision. These are not necessarily easy changes. They are changes that need to be informed by an appreciation of, and sensitivity to, the cultural diversity of people living and dying within our communities. To that end, this article reports on research designed to amplify the cultural voices often marginalized within the context of EOL care to learn about their EOL and bereavement needs. The research was conducted in Australia and has implications for other national health systems servicing First Nations peoples and significant migrant communities.

More specifically, the research was undertaken within Western Sydney Local Health District (WSLHD). This is a large health jurisdiction with a rapidly growing and highly diverse population, many of whom live with entrenched disadvantages and significant chronic health problems. Public transport and other infrastructure have not kept pace with population growth (27, 28). The current census data (29) show that over one million people (1,1080,820) live in WSLHD. Almost 58.3% of people are non-English speakers at home. The three largest CaLD groups in the LHD are people from Mandarin (6.5%), Hindi (3.5%), and Arabic (5.3%) speaking backgrounds, which are also large language groups across the world (30). Australia's First Nations peoples comprise many culturally and linguistically diverse groups, many historically displaced from their communities in the Country, and many acculturated to urban life (31). Compared with most LHDs in Australia, Western Sydney has a relatively high number of Aboriginal people (16,614), making up 1.5% of the population. Concerningly, relatively few reach old age. Nationally, only 1.7% are over 75 years, whereas the proportion for the general population is 7.5% (32).

Researchers from Western Sydney University's Caring at End-of-Life Research Program worked with WSLHD partners to hear from the community about their culturally specific EOL and bereavement needs. The Caring at End-of-Life Research Program at Western Sydney University addresses the role of informal caring networks and their relationship with formal service providers (33), compassionate communities (34), and community death literacy (35). The WSLHD Advisory Panel consisted of representatives of Supportive and Palliative Medicine, Bereavement support, Aboriginal Health, and Multicultural Health. Together, the researchers and Advisory Panel collaborated to set clear research goals and to develop relevant research questions to achieve them. The specific aim of the research was to conduct a bereavement and palliative care needs analysis to understand (1) the end-of-life needs of Aboriginal and CaLD communities and (2) how services need to adapt to deliver culturally appropriate EOL care. The research questions were:

(1) How do CALD and Aboriginal communities experience death, dying, and caring?
(2) What do these communities already have that works?
(3) What supports and services have they found useful, or believe could be useful, and how is this different from what is already available?
(4) What other support or services do they need and who is best suited to provide this support and/or services?
(5) In what ways do existing services and supports need to change to be culturally appropriate?

2. Materials and methods

2.1. Design

The research was conducted using a mixed methods design that comprised key informant interviews; culture-based community focus groups; an online Death Literacy Index survey; and in-depth personal reflection using the Photovoice method [(36, 37); See Table 1]. This multi-modal, multi-lingual, multi-disciplinary project was developed with the research partners. Aboriginal Health requested the nomenclature Aboriginal rather than Indigenous or First Nations. The research was also informed by input from 17 cultural advisors who represented the four cultural groups participating in the research (Aboriginal, Arabic, Hindi, and Mandarin). The methods followed consolidated criteria for REporting Qualitative research (38) guidelines for the conduct of qualitative research. The design and conduct of the research were also informed by the literature on researching vulnerable and marginalized groups (39–41) which highlights the ethical considerations needed to avoid replicating past injustices. Indigenous Australians and migrant communities have often been subjected to disrespectful and exploitative practices in research including a lack of significant benefit for those being researched (42, 43).

From the outset, the purpose of the research was to amplify marginalized cultural voices to better understand their needs in the palliative and bereavement context. In turn, these valuable perspectives can inform policy and system change recommendations to enable culturally safe and appropriate services for people from different cultural backgrounds and those who care for them at EOL. However, in acknowledging people are the "experts" on their own experience, affording them epistemic privilege meant more than hearing their voices as expert research "subjects" (39). We sought to foster a relationship of equality and genuine participation as co-researchers and co-designers. The exchange of knowledge among the research team members and between researchers and participants ensured that the research goals would be achieved in ways that were simultaneously culturally sensitive.

We approached the research from a position of cultural humility (44) and respectful practices which focused on listening and supporting people to participate. We were inspired also by the Indigenous concept of "Dadirri" which involves reciprocity, sharing stories, "deep listening," self-reflection, and patience [see West et al. (45)]. Normally applied in indigenist research, the principles of Dadirri are equally relevant to all marginalized people since it positions participants as equal to researchers, giving those who are normally powerless an equal voice in the research process. We ensured our collection of data was informed by Multicultural Education Officers for each cultural group and representatives of Aboriginal Health. The voice of participants was at the center of our research project, and in this article, we focus specifically on the qualitative data derived from the community focus groups and key informant interviews held with all four cultural groups. It was this data that most strongly revealed the challenges to current medical models.

2.2. Community focus groups

Culture/language-based focus groups with community members [see Kruger and Casey (46)] were an effective way to understand cultural differences at EOL. They also provided a space to identify possible strategies and barriers or opportunities to developing culturally sensitive EOL and bereavement services. The data were collected in 2021 and till June 2022. The onset of COVID in the initial phase of the research impacted the timing and locations of the focus groups. After the easing of community "lockdowns," recruitment was understandably slow. People were grieving and coming to terms with the significant losses in their communities both in Australia and overseas during the pandemic. There were also ongoing concerns about health vulnerabilities which meant the integration of COVID protocols into the focus group procedures so that participants and researchers felt safe.

2.2.1. Participants

Participants were adult community members from an Aboriginal, Arabic, Mandarin, or Hindi cultural/linguistic background with EOL caring experience and living in the Western Sydney Local Health District (WSLHD) catchment area. Participants were required to have cared for someone at the EOL but with a limitation of more than 6 months before the research to protect their emotional safety. English speaking was not a requirement for participants in the focus groups as interpreters were present and Multicultural Education co-facilitators were of the same language groups. The number of participants in each group ranged from 10 to 13 (see Table 1).

2.2.2. Recruitment

Recruitment flyers (digital and printed) were offered in four languages (English, Mandarin, Arabic, and Hindi). Digital flyers were made available for community leaders/representatives to distribute using their email lists. Interested individuals were screened and those meeting the inclusion criteria were sent a Participant Information Sheet and provided with details of the focus group (including date, time, and location). WSLHD Aboriginal Health Unit and Multicultural Health education teams provided participants with an in-depth explanation of the project (in their preferred language) and assurance that their participation would be voluntary and anonymous. Participants in the three CaLD focus groups consisted of community members who attended the WSLHD-led health education groups. Participants in the Aboriginal focus group consisted of active members of the Aboriginal community and Aboriginal healthcare workers.

2.2.3. Process

Separate 2 h focus groups were conducted face-to-face at a convenient community center with each of the four cultural/linguistic groups. The focus groups were facilitated by a researcher alongside co-facilitators from Aboriginal Health or Multicultural Health who shared the cultural background of the participants. The research assistant managed the consent forms, recording, and note-taking. After an in-depth explanation of the project aims and what participation would involve, participant information sheets in the preferred language were distributed. Following initial verbal consent, written consent was obtained and again clarified before the commencement of the focus groups,

TABLE 1 Distribution of participants by gender across all methods and cultural groups.

Participants	Aboriginal	Arabic	Hindi	Mandarin	Other	Total
Community focus groups	**10**	**13**	**10**	**10**		**43**
(Gender)	(3M 7F)	(4M 9F)	(6M 4F)	(5M 5F)		(18M 25F)
End-of-life key informants	**2**	**5**	**7**	**4**	**27**	**45**
(Gender)	(1M 1F)	(3M 2F)	(1M 6F)	(2M 2F)	(2M 25F)	(9M 36F)
Photo-based personal stories	**4**	**4**	**3**	**4**		**15**
(Gender)	(4F)	(4F)	(1M 2F)	(1M 3F)		(2M 13F)
Death Literacy Survey	**24**	**36**	**60**	**83**		**203**
(Gender)	(3M 21F)	(13M 22F 1NA)	(27M 32F 1NA)	(21M 62F)		(64M 137F 2NA)
Total	**40**	**58**	**80**	**101**	**27**	**306**
(Gender)	(7M 33F)	(20M 37F)	(35M 44F)	(29M 72F)	(2M 25F)	93M 211F 2NA

allowing regular opportunities to review consent using the Process Consent Method [see for example Dewing (47)].

The Arabic and Mandarin focus groups were both conducted in Arabic or Mandarin languages and led by a bilingual Multicultural Education Officer. A state-accredited translator was also present to help translate the discussion for the researcher. The Hindi focus group was conducted in English, as the majority of participants spoke and/or understood English. The Multicultural Education co-facilitator translated for a small group of participants who were not able to express their contributions in English. The groups began with personal introductions for all participants and facilitators including, if they wished, their EOL experience and interest in coming to the group. All focus groups were audio-recorded and transcribed verbatim. The Arabic and Mandarin focus group recordings were sent to a translator to transcribe into English and then sent to the bilingual co-facilitators to check content and accuracy. Feedback was obtained from all co-facilitators. At the end of the research analysis, all participants were invited to any of three public forums to discuss the results.

2.2.4. Material

Sensitive to the fact that speaking about personal EOL experiences is a delicate matter for most of the target communities, focus groups were designed to address the subject of death indirectly. We presented a written hypothetical vignette about a person not known to the participants and they were invited to build upon that story through a series of prompting questions relating to the scenario. The vignette and prompt questions were designed to address the research aims and were prepared in collaboration with the Advisory Panel. The CaLD advisors agreed that vignettes would be an effective tool for their communities to approach the discussion. Professional translations of the vignettes were checked by the Multicultural Education co-facilitators to ensure the integrity of meaning. The Aboriginal advisors chose to use the prompt questions without vignettes to elicit discussion of participants' past experiences. Along with providing a gentle way to lead into the discussion, the vignette and prompt questions proved useful to keep the conversation topic centered on EOL and the aims of the project.

2.3. Key informant interviews

2.3.1. Participants

Participants comprised healthcare workers within supportive, generalist, or palliative EOL care who worked within the Western Sydney Local Health District (WSLHD) catchment area; as well as other adult people working in EOL-related services. The professions of the key informants included hospital palliative care staff and managers, occupational therapists, general practice doctors and their information provider network, Aboriginal health workers, integrated community health, health educators for the multicultural community and transcultural educators for health workers, health interpreters, in-home palliative care workers, and social workers, funeral directors, death doulas, grief and bereavement counselors. Forty-nine key informants were interviewed in 43 individual interviews and 4 repeat interviews (3 interviews had more than one participant). Eighteen interviewees were from an Aboriginal, Arabic, Mandarin, or Hindi cultural/linguistic background (see Table 1).

2.3.2. Recruitment

Key informants were recruited for their expertise through, or on recommendation from, the WSLHD Research Advisory Panel, Multicultural Education officers, and suggestions from other interviewees. After reviewing the initial interviews, specific informants were sought to fill the identified gaps (e.g., general practitioners).

2.3.3. Process

The formally consented interviews were conducted online using Zoom. The interviewer gave a personal introduction about their role and interest in the topic. Participants were first asked to describe their roles and experiences working with the target communities. Prompt questions were used to elicit insights into the traditions and beliefs of the communities and whether death, dying, and caring were experienced differently by the majority population. Participants were invited to describe and comment on the existing services and support available and to offer suggestions for improvements, along with any recommendations for new services or supports. The interviews (of up to 2 h) were conducted in English, recorded on Zoom, and fully transcribed. The visual material was not used. At the end of the research analysis, all participants were invited to any of three public forums to discuss the results.

2.4. Qualitative data analysis

The de-identified key informant interviews were analyzed as one data set, and the four focus groups were analyzed separately. Each de-identified transcript was analyzed independently by at least two members of the research team. Analyzing the transcripts was an interpretative, qualitative, and data-driven inductive process that focused on emergent themes as well as specific research questions. Data were first analyzed for content according to the specific topics of the research questions. Second, the transcripts were analyzed thematically (48–50) by the research team to identify common and recurring themes, similarities, and points of difference among the cultural groups. Quotes were identified that well-illustrated the themes. Any differences between researchers were explored to better understand the data. The themes were interpreted in consultation with the WSLHD Advisory Panel to identify the thematic priorities from a cultural perspective. The Results section of this article presents the emergent themes. It was from these themes rather than from the content analysis that the challenge to conventional medical models emerged.

3. Results

Seven themes were identified relating to the needs of Aboriginal and CaLD people at EOL, along with some suggested solutions which were relevant across several themes. The seven themes cover needs relating to: trusted relationships; talking about death; knowledge of key services; decision-making and obtaining consent from the patient; appropriate physical spaces; cultural practices around EOL; and language barriers. Within each of these thematic areas, a variety of cultural beliefs and practices were revealed that conflicted with mainstream medical practice.

3.1. Theme 1: need for trusted relationships

The most consistent theme to emerge from the interviews and focus groups was the importance of relationships of respect and trust. However, there are people within the health system that insist that different cultures need to adapt to the medical culture. A key informant reported that it was not uncommon to find people who resisted adapting to different cultural needs, for example:

> *If we're going to respect [them]well they have to show Health respect. You can't have it both ways… because we're in a medical institution … they need to follow the rules. And Anglos can follow the rules so why can't they?* (Volunteer coordinator)

In social contexts where there is little trust in government services and the fairness of the law, it makes sense for people to rely on trusted relationships or a chain of trusted relationships. Trust needs to be proactively developed over time:

> *To develop trust, health workers need to walk with them for a while not just provide information. Health workers need to check in with their clients not just go in with a set spiel so they need to research how to approach that conversation and what they can do with the person and what they might offer or not offer that isn't going to offend them and disconnect them.* (Social worker)

Aboriginal people have experienced systematic abuse for over two centuries and still experience discrimination. They cannot ask for help and assume that they will be treated respectfully and given appropriate assistance. It is not surprising, therefore, that they want to deal with Aboriginal staff in hospitals and home care. If there are no Aboriginal staff in the relevant positions, then they would like an Aboriginal person with some authority to accompany them until the new relationship can be established:

> *That first visit where I will go in and make the connection—sit down and have a chat and talk about where they're from and you know, it's quite a non-threatening visit. And then never to do an assessment at that first visit unless it's vitally important. And that's what they said, 'If you do an assessment in that first visit, you'll lose them'.* (Aboriginal Community Nurse)

People in CaLD communities, even if they are not refugees, often come from places where there has been recent social upheaval, corruption, or few affordable services. As a result, they do not have confidence in health services here. Furthermore, although many Australians are welcoming of migrants, there is enough racism around for CaLD people to be cautious:

> *in [named] Hospital, you see the doctor …she was wondering whether it is discrimination, because you can check on their face. … they just said, it's in your head, it's your mind. They couldn't find the problem.* (Mandarin focus group)

Of course, language is another concern for many. Even if they have adequate English for everyday purposes, they can be excluded by the language of the health system. So, they want to work through people from their cultural and language backgrounds and favor trusted relationships.

This focus on relationships is at odds with the health system, which focuses on efficiency and does not allocate time for relationship development. Furthermore, EOL often involves multiple visits to a hospital with a variety of symptoms over several weeks or months. People are allocated to different departments depending on the part of the body affected. Patients are unlikely to see the same doctors and nurses when they return to the hospital unless they are in a specialist unit such as Cancer Care or a Palliative Care Unit (PCU).

Although in some general practices in the community people see a different doctor each time, there are general practitioners (GPs) who have a long-term relationship with their patients. This line of communication often does not connect with the hospital as they are organized as separate systems:

> *Even when there is a GP with shared culture and language, patients and families can feel abandoned when the patient goes into palliative care if the GP does not continue to follow up with them.* (Multicultural Health worker)

However, the community nurses and Palliative Care Unit staff are gradually building connections from the hospital to the GPs when the patient is at home:

> *You're the medico that is looking after this patient. We're not taking over care. You're still looking after the patient and we're helping you to do that, and this is how we'll help you.* (Clinical Nurse Consultant)

Community services are also fragmented, and community workers associated with the PCU are distressed when they need to hand over their patients to an entirely different service:

> *We support them through their chemo, their radiation—the whole thing. And then right at the point where they're literally dying, we have to say goodbye … And then we need to choose another service and I say, 'Oh look (Palliative homecare service) will take you over. As of tomorrow, we're not allowed to come in' … They will get an after-hours service and doctor home visiting and that's through* (Palliative homecare service*) so there's some benefits, but the hardest thing is saying goodbye to people before they actually die.* (Aboriginal Community Nurse)

Being treated with empathy, respect, and dignity was important:

> *In Syria, in our city, there's an association called "Al-Afia" they are responsible for funding major expensive surgeries such as heart surgeries. Merchants make contributions to fund this association. … They treat people with dignity… (*In Australia*) I would like for the government to take care of this in order to protect people's dignity.* (Arabic focus group)
>
> *This paramedic was standing and telling her "Be prepared". The mother was shocked. How can she be prepared? Is her son dying? Did he die? The paramedic said in a very rough way, without any affection, or any emotion "I didn't say this." This is a concern regarding healthcare people. Before you treat the body, you should treat the soul. … I agree with her. This is the humane side that we miss a lot in all aspects of life in Australia. … You find that everything is so materialistic, as if they are dealing with a block and not with human beings.* (Arabic focus group)

Some respondents recognized the fundamental changes that would need to take place for health facilities to be safe respectful places for all patients:

> *If you're really going to be a really respectful kind of organization, you can't just pay it lip service and have all your staff do diversity training but then the rest of the machine works exactly the same.* (Volunteer coordinator)

3.2. Theme 2: talking about death and dying

> *"Sometimes there's this fear of talking about death and talking about grief and bereavement … and to do that well in a culturally sensitive manner is everyone's business."* (Social Worker and Bereavement Counselor)

A range of research participants let us know that culturally, it could be challenging for people to talk about death and dying. Different cultures may have highly coded ways of undertaking these conversations, such as the term 'Sorry Business' being widely used by Aboriginal people. For some cultures, there is a concern that talking about death could invite it in. It could feel like a betrayal of the patient because everyone was giving up on them. Or the belief that seemingly miraculous recoveries were possible meant the patient needed to hold onto hope. It caused distress when patients and carers were required to talk about their situation repeatedly with strangers in each department or service:

> *When I ring an interpreter and tell them this is a palliative call, it runs in direct contrast to a lot of Muslim beliefs of 'We don't talk about dying', we need to keep up hope for as long as possible … it does get tricky cause you're managing a culture, an ingrained cultural [belief]. (*Clinical Nurse Consultant Palliative Homecare Service*)*
>
> *Chinese people don't do their will because they think that is a curse… But they rely on the law to do whatever after they're gone … The new generation are much, much more open.* (Health Educator Mandarin)
>
> *My brother-in-law is a doctor. He would tell him "Your report is very good, Uncle, you don't have anything" up until the last phase when he was kept alive by the oxygen machine.* (Arabic focus group)

In contrast, one PCU manager is a strong believer in speaking clearly about death and dying:

> *I don't like to fluff about because people tend to understand the word "dying." Passing … is not something that I'm a fan of because it's not a true reflection of what is actually happening.* (PCU Manager)

A reluctance to discuss death can make it difficult to formally plan for EOL. The health care system actively promotes Advance Care Plans whereby patients identify how they would like to be treated when they are not able to make decisions. This requires a detailed discussion of bodily decline and the likely success of possible treatments. To be effective, the plans need family support lest families become distressed and seek more intrusive treatment than the patient wanted.

There are added difficulties when people rely on government income support or public housing. Such supports have specific requirements which might be attached to the dying person so there is a risk that other family members will suffer financially, or children will be taken into foster care away from their culture and community:

> *it's important to have these financial conversations as hard as they are, to put in place those measures so those kids don't get taken away, the house doesn't get taken away on top of the family's grief.* (Aboriginal focus group)

3.3. Theme 3: knowledge of key services

Providing opportunities to develop a community understanding of palliative care was a reported need for all groups. Similarly, formal counseling and formal volunteering services are new concepts for many migrants.

3.3.1. Palliative care

Some people had never heard of palliative care because it was not a service available in their country of origin. For others, palliative care was thought to be only for the last days of life, so the mention of palliative was distressing. Some Aboriginal respondents preferred the term "end-of-life" care to palliative care but those in the Hindi group all expressed that it was emotional and scary:

> *end-of-life sounds more appropriate than the word palliative. I didn't know what the word meant . . . That's actually where the Sorry Business starts.* (Aboriginal focus group)

The idea that palliative care meant doctors were giving up was also confronting. The belief that Western medicine is infallible caused shock and anger when it failed their loved ones:

> *It's a mystery how pain that started in his ears within 3 months became a problem with his kidneys. And the doctors didn't know what the issue was? Impossible!* (Arabic focus group)

One participant reported receiving no support in the home or advice from any services. She was horrified when her husband died in the Emergency Department on the floor. Other people in the group also expressed their horror at this story:

> *On the floor. They didn't even give him a bed. How can a hospital do this to a human being? . . . What she said is no different to what happens in our country for the people who have no money. . . . We are here in Australia, okay? Human rights.* (Arabic focus group participants)

Some participants reported that there was an expectation that doctors should keep trying until the last breath. When this did not happen, doctors were thought to be prejudiced because the patient was not from an Anglo background. On the other hand, gratitude for the Australian health system can mean they are unwilling to ask for the things they need:

> *a lot of those cultures will be—I don't know if it's grateful—like obviously the doctors looking after them so 'thank you'. So, they're not going to ask for more because they're getting all this wonderful medical care.* (Volunteer coordinator)

As a result, patients and families were unaware of the assistance that could be given at an early stage when there is time for relationships of trust to develop and patients and families can be supported through the last months:

> *a lot of people want all forms of treatment and it's when everything is exhausted, that then, you get to the point of "well refer to palliative care now" and it's almost like this person now has to accept that perhaps where they had hope, there is no hope—'I am going to die and the best I can hope is for a comfortable death'. Some people don't really accept it and some families don't really accept it, but that's the turning point and that may be really late. That's sometimes the reason we get them so late . . . the ones with slower progression are the ones we get referred early and these have more time to ease into this understanding of what's going on with them and they have more time to get to know our teams.* (Clinical Nurse Consultant Palliative Homecare Service)

3.3.2. Counseling support

From the time it becomes clear that a person is coming to their end of life, the patient, family, and friends will start to experience grief and loss and might need support. However, some cultures do not seek out counseling support. This may be due to counseling being an unfamiliar practice or because of concerns about discussing death and dying with a stranger. Specific cultural aspects were also identified. For example, there was a belief expressed that people, particularly Hindi-speaking wives, should be suffering from their loss which made them reluctant to obtain bereavement support. The Mandarin group valued not bothering other people:

> *The culture and idea for thousands of years pass on, the Chinese is privacy don't bother other people, it's my own suffering.* (Mandarin focus group)

Rules about when you need to stop grieving and move on with life meant that messages about bereavement support can be ignored after 40 days for people from Muslim traditions and 49 days for Mandarin background:

> *. . . about the 49 days, we'd tell ourselves on that day that it's over. . . . it's just a token to comfort oneself. It's a legacy practice or a relic, it's meant to symbolize one's sorrow and missing of their loved one. . . . It's more that you spend 49 days to memorize someone, to remember someone. . . After the 49 days, the person departs to be on their way to Heaven.* (Mandarin focus group)

The issue of how and when to offer help with grieving at EOL is difficult in all cases. It is hard to know when people will be open to reading letters or brochures or receiving phone calls. It is aggravated by the siloing of services whereby most EOL services cease promptly at the death of the patient. Once again relationships were important and contact from someone in the health system with whom they have an existing relationship was welcomed.

3.3.3. Formal volunteer services

There were numerous examples of the great work done by volunteers and ideas for the potential role of volunteers in bridging services (or siloed services). The inequity of relying on volunteers was also highlighted. Overall, volunteers were seen as a major asset especially when they come from diverse backgrounds with diverse and rare languages. Often in collectivist cultures, the idea of volunteering does not exist as there is a cultural expectation that everyone contributes to the community:

> *[some] communities don't… know what a volunteer is 'cos they don't have that word to translate. But they might help each other and be really supportive, but they don't use that [word]. So, trying to explain what we do… doesn't… translate.* (Volunteer coordinator)

Furthermore, if the concept of formal volunteers as being organized, committed, and trained is not familiar, such volunteers can be mistrusted by those from other cultures.

3.4. Theme 4: decision-making and obtaining consent from the patient

Obtaining informed consent from a patient for an operation or procedure is an essential ethical requirement and it is usually a routine and rapid process. Unless the patient is a child or has impaired reasoning, the medical system assumes that individual patients are best placed to make decisions about accepting treatment. However, cultural beliefs and practices add a layer of complexity to the process. In more collectivist cultures, rules about who should make decisions in the family can make it difficult to obtain consent directly from the patient:

> *It's collective from the whole family (*his wife, children, and brothers*). It takes into account mainly the person's faith that they lived by, as well as their inherited norms and practices in their surrounding social environment.* (Arabic focus group)

The patient might not feel able to make that decision and there needs to be a consultation with the head of the family or more broadly with other family members. Sometimes, there can be a debate within the family about who makes the decisions:

> *In the Hindi families, … I do see quite a lot of argy bargy within a family unit sometimes where say the wife might want to be the primary carer for the husband but the more educated or the more well to do person in the family might want to take over.* (Clinical Nurse Consultant Palliative Homecare Service)

Such delays can be annoying and disruptive to the hospital system which assumes patients will follow their timetable. More concerning is the possibility that the patient is not giving willing informed consent. Mandarin-speaking elders were reported as deferring to their sons who often were more fluent in English but did not confer with their parents. It was also reported that Hindi-speaking widows can believe themselves to be of such low worth that they would not be deciding based on their own best interests (Hindi community leader).

Differences were evident when focus groups were asked about the importance of maintaining life through strong medical interventions and life support systems. The Arabic group expressed such interventions were an important sign of respect and affection. The Mandarin group stated that their community had shifted toward focusing on a peaceful death:

> *We say that Allah the almighty, might grant him life again. So they wait, patience, for the end of a human being's life is better. They shouldn't rush the decision.* (Arabic Focus Group)
>
> *In the past people thought we needed to let the person hang on to their last breath, that it was filial on the part of the children to see to that. Now, our thinking is changing, people now would like the person to go peacefully, to have peace in their final leg of the journey.* (Mandarin Focus Group)

The Hindi focus group reported that a decision about turning off life support would be made jointly between the family and doctors. There is no particular cultural pressure to keep the patient alive as long as possible. A decision for the patient to die at home should be up to the patient and respected by the family, and services can come to their home to keep the patient comfortable. Several participants had not known about palliative care at home and were pleasantly surprised to find this was available.

3.5. Theme 5: appropriate physical spaces

The design of health facilities can be alienating. They lack appropriate symbols, food preparation spaces, and prayer rooms which would signal a welcome to diverse cultures. They often lack outside space, which was reported as a preference for Aboriginal people. Major providers of bereavement services have no strategies or staffing to assist Aboriginal or CaLD clients:

> *When somebody's in the (Palliative Care) Unit and they're dying, there'll be lots and lots and lots of visitors. Like really, there could be 30 people and the expectation of the families are the fact that they will be there. They won't do anything; they won't get in anybody's way—they're really good—but the expectation by their culture and their community is that they will attend and just be there.* (Aboriginal community nurse)

Key informants reported on the needs of Aboriginal and CaLD people within the hospital setting. These needs included space for large numbers of visitors who need to come and pay their respects; a kitchen for preparing appropriate food; allowance for music, chanting, and prayers at the bedside; a prayer room with suitable furnishing and prayer mats; and appropriate art and artifacts which make people feel welcome.

Key informants who were familiar with local health facilities identified important differences between the PCU and the acute hospitals in terms of their flexibility to adapt to the cultural needs of patients and families. At the PCU, there could be larger gatherings of people, appropriate food, and appropriate rituals and artifacts. In the focus groups, the PCU was reported very positively by community members:

> *We came whenever we wanted, regardless of anyone's thinking. We were there 24/7 so it didn't matter. We had people coming from the bush … And it was always overcrowded—it was like it was* ***our*** *kitchen anyway. And outside we did what we wanted to do anyway. We didn't ask.* (Aboriginal focus group)
>
> *When the patient is still able to eat, they may wish to have something that they crave, rather than something that the hospital provides. So, this is where the family would prepare food for the patient, food that they like.* (Mandarin focus group)

3.6. Theme 6: cultural practices around end-of-life

3.6.1. Being present at the time of death

All four cultural groups talked about the importance of visiting the dying person. In Aboriginal culture, extended family will gather, often traveling long distances. In Arabic and Hindi cultures, it is important that the dying person is never left alone while alive nor in the period immediately after death. Family and friends do not need to be specifically invited. When a traveler from India was dying, the community visited him. If they could not be beside the patient, they sat outside:

> *Someone is in hospital, but family, friends, always sit outside. Always. Sister, brother, anybody.* (Hindi focus group)

For Hindi-speaking people, prayers and hymns at the bedside are important so a private room is desirable but if not, they will just draw the curtains:

> *A feeling that the positive vibe goes to the patient so it's not that difficult to get out from the physical body—so their spirit comes out with no difficulties. That's our cultural perspective. All the family members recite the hymns actually and with all the prayers and the positive vibes the soul passes away.* (Hindi focus group)

The Mandarin group also reported that the patient should not be left alone and that being present at the time of death was important. It was also stated that dying at home was not desirable because of the belief that bad luck could pass on to those who used the home and visitors. However, hospitals are often not equipped to deal with a large influx of visitors:

> *We all stay at the hospital to die, but at the very last minutes, the family should be around them. … Going by the current rules of the hospital, this probably cannot happen. Could the system be that if the doctor determines that the patient is now in their final moments, then could the family be quickly notified.* (Mandarin Focus Group)

There was significant additional cultural distress around this issue during our research which was conducted at the time of the COVID pandemic when hospital visits were severely limited.

3.6.2. Customs around food

Food is symbolic as well as nutritious and pleasurable. Hindi background visitors always bring food:

> *The well-wishers and the family members and relatives—if the patient is in a position to eat anything they definitely don't come empty handed actually. So, they come with food.* (Hindi focus group)

People from Mandarin background were known for coaxing the dying person to eat so they will not be hungry in the afterlife even when their digestive system is failing:

> *Culturally food is what brings us together and so sometimes the family still want to feed the person who's dying. So that's very difficult. We struggle around that a little bit in just saying "The body is preparing to die. They don't need to eat sustenance anymore."* (PCU Manager)

3.6.3. Beliefs that care should be provided by family

Often close relatives of the patient expressed that they should be doing the caring for the patient at home especially if the patient asks to go home. This is their cultural tradition, and often there was no other option in their country of origin. However, in Australia, they might not have family and friends who can help. The situation can be aggravated by shame at accepting government services because of the belief that care should be provided by the family, even if they are not available.

At the PCU, they have the flexibility to address this by encouraging the family to bring in familiar objects and music to make the environment "more like home." If the care of the person at home is too complex or burdensome, the PCU team may encourage the family to manage extended family/community expectations by explaining it is a medical decision to keep the patient in the hospital:

> *So, you then shift your thinking, shift your care to the family member who's now feeling guilty because they (the patient) didn't get home. So, you then have to work with them, going 'You've brought in all this. This is where* ***you*** *are. They want to be with you. You're here. You just talk to them; you play their music'. We have pictures around—they can decorate the room how they want—so it makes it as home as can be.* (Clinical Nurse Consultant PCU)

3.6.4. Rituals around burial or cremation

For Aboriginal people, funerals and mourning rituals are traditionally important and extensive often taking several days or more. It is difficult for those who work for non-indigenous managers because of the lack of understanding and expectations that "Sorry business" will be dealt with minimally.

*(*Non-indigenous workers*) can go to work at 9am, go to a funeral, an Aboriginal funeral at 10am-11am and then go back to work. (*Aboriginal focus group*)*

Burial rather than cremation was important to many Arabic-speaking and Aboriginal people, but the cost can be prohibitive. There are no dedicated spaces for traditional Aboriginal burials in the city. Some focus group attendees pointed to the historical injustice of dispossession from Aboriginal land:

> *why black fellas have to pay to get buried back on their own country? (*Aboriginal focus group*)*

Many Aboriginal people still have a strong connection to the part of Australia where their people (their mob) came from. Some want to return there at the end of life and others want to be buried there:

> *A few people always want to go back to Country to be buried … and that's important.* (Aboriginal Community Nurse)

For Arabic-speaking people, the dead should be buried within a day, if possible, a fact that is a learning for those working in the palliative care unit:

> *Islamic people last week. We knew that the person needed to be buried within the 24 h so we ensured that family knew that the person could be picked up from the unit, not go to the mortuary straight away, because we knew that those 24 h were important. So, we're learning from them.* (PCU Manager)

However, the cost of burial is a burden. It might be covered by family or friends but in Arabic culture, it is considered a loan that needs to be repaid:

> *I don't want to be dependent on a person or a relative. When something happens in their family, I have to pay back the loan so in the future, it will become another financial burden on me. As a citizen, I should receive this service as part of the services provided by the council.* (Arabic focus group)

Others in the focus group agreed with this, adding that it was shameful to have to ask for money for a burial. However, there was ready community support for organizing the funeral:

> *If there was a death in the family, we gather as an Arabic community. We are an emotional community, we gather, and every person will be saying I will do this, and I will do that. And they leave the family in their sorrows. They call the funeral companies, they call the mosque, and they do everything.* (Arabic focus group)

Hindi participants reported good support from the health services and their community for the funeral. Money is collected at the temple to help the family with the costs. Families reported that they can follow much of their traditional funeral practices with suitable priests in the local area and places where the ashes could be placed in the river:

> *In the Hindu culture actually, it's being burned, and the ashes has been taken to the riverside—and it is our feeling that the whole soul is washed in water and so the person will be clear from the sin. That's people expectations.* (Hindi focus group)

Some migrants also wish to be buried in their country of origin and need to know that it can be organized through their consulate, but they might not know the procedure or be able to pay for the service.

3.7. Theme 7: language barriers

> *it's not just about translating a document into a language that's comprehendible. It's translating a whole idea that might not make sense.* (Volunteer coordinator)

When people do not speak English, there is an obvious language barrier which could be assisted by having more diverse support health workers and interpreters. Interpreters tend to be available in large health facilities and are less likely to be used for counseling and community services which are away from these large facilities. Several respondents found technology very useful:

> *Language is a problem, but we would use pictures and we would also ask the family to translate the words for us [there is also a] new upgrade for the Apple phone has a translation app on it automatically … [so] we can actually communicate better with them.* (PCU Manager)

Telephone interpreting services are available for health services but not for community support services. One difficulty with using telephone interpreters was that there was no opportunity to brief the interpreter beforehand about the patient's circumstances. It was reported that staff was uncomfortable about briefing the interpreter in front of the patient:

> *Because some of the Asian cultures actually are very hesitant, really hesitant, about talking about death … we now drill [the interpreter] before they come in. 'This is what you'll be talking about. You'll be talking about death and dying". …Because we found a couple of them over the years wouldn't tell the patient. The doctor would say something and then [the interpreter] would not interpret that correctly.* (Clinical Nurse Consultant PCU)

In the context of counseling support, there was tension between those counselors wanting a direct translation of their words, and the position of interpreters concerned that ideas do not translate directly. A literal translation could have a very different meaning. Often, interpreters want to explain the significance of what is being said, for example, why the family feels they need to feed the patient. In some instances, there was a lack of trust in interpreters based on this issue:

> *Another dilemma for interpreters is if they are asked if they know of any relevant services, when their role is to simply interpret the words except for the specific cultural-related information. They are not allowed to give personal opinions, but it is difficult to always tell what is culture-specific and what is personal opinion.* (Medical Interpreting Service Manager)

Using interpreting services might also make it difficult to connect with someone more deeply on the level that is needed for counseling. As a result, working with interpreting services on very sensitive matters can be seen as a barrier. The Mandarin focus group participants all had a phone number that gave them direct access to interpreters. However, being one of the most populous migrant groups and knowing there are many doctors and nurses of Chinese background, they expressed a preference for hospitals to put some effort into allotting them, Chinese staff.

With oral and written communications, for example, developing a factsheet, it is not enough to translate from English into another language. Culturally appropriate inclusive language is needed, also recognizing that sometimes this language cannot translate in any straightforward sense. Some roles and activities do not have a translation for other cultures. As already noted, some migrants are not familiar with the concepts of palliative care, volunteering, or counseling so these terms need the skill to translate, and more extensive explanations might be needed.

Language differences can be used as a guide to augment current services. For example, where it is necessary to slow down and explain what is happening in the current palliative situation. It is a reminder that medical language and the jargon in the health services are often not clear to those of non-English-speaking backgrounds:

> *Even if you're born here, you're raised in Australia, the health system in itself is overwhelming let alone with a terminal illness.* (Clinical Nurse Consultant PCU)
>
> *The doctors are very good, and they try really hard but once you give over a couple of pieces of information [to the patient or family], the rest just goes in one ear and out the other. Just bounces off. They can't absorb it all. So, they go home and think about and they may ring back, and we discuss it. It is very overwhelming and culturally for a lot of people . . . it's a shock . . . with anybody, it's not just people who don't have English as their first language.* (Clinical Nurse Consultant PCU)

3.8. Suggestions for addressing the problems

The antidote for many of the sources of distress identified in the above themes was communication and the development of trusted relationships where people are treated as whole persons, not as health conditions. A successful model trialed during the period of this project was employing an Aboriginal Supportive and Palliative Care Worker who comes from the local community. They guide patients and families both within the hospital and in the community, standing up to the health establishment when necessary. Respondents who knew about this role were highly appreciative and those working with CaLD people wanted similar specialist workers:

> *We just need more Nicoles!* (Culturally specific supportive and palliative care worker)

Respondents from interviews and focus groups suggested that community education about EOL and palliative care was needed. To date, the focus of Multicultural Health education teams has been topics requested by communities, and no one had asked for information on palliative care. Indeed, they doubted that anyone would attend an information session due to the cultural resistance to talking about death and dying. However, younger generations are more open, and they could learn more about how to care for their parents. Furthermore, caring in the family is valued so information about palliative care framed as caring could be appreciated.

More diverse and extensive volunteer programs were also suggested. The valuable role of volunteers was recognized especially their freedom to work across health silos and into the community. Indeed, health staff were regretting the lack of volunteers under COVID restrictions. Suggestions included reaching out to communities to recruit volunteers from a wide variety of cultural backgrounds to support the diversity of patients. This includes people willing to be on call to help patients with specific language needs and creating a register for hospital staff. Therefore, a volunteer coordinator is present at each hospital to provide training and support, particularly in CaLD perspectives. Cultural training on Aboriginal perspectives is already a requirement. Furthermore, volunteers need training to understand the roles of social workers, community nurses, and others working in the EOL space so they could better coordinate their efforts. In return, the volunteers should be recognized as an integral part of the hospital team:

> *They do the 4 days of training when they start and then they continually do training . . . they become more Health Literate, so then when they go back to their own families or communities that they can share that insight... I see volunteer service, well particularly my volunteer service, as quite specialized and educated and literate.* (Volunteer Coordinator)

In addition to the hospital-based volunteers, numerous community and religious groups can provide voluntary support. Staff would like an up-to-date and thorough register of Aboriginal and CaLD community support people and services such as not-for-profit groups and religious leaders.

On the issue of funeral expenses, funeral funds were found to be expensive scams whereby people lost everything if they missed one payment. One respondent said his church had a donation box for the costs at every funeral. Another practical suggestion was an agency that gave loans for that purpose:

> *Regarding the funeral services, I say if any association or agency can financially help the family of the deceased. … because death happens suddenly. So, if we can pay them through installments that would be great.* (Arabic focus group)

If these seven themes and suggestions were taken on board by the health and community services, then mainstream medical services would need to reexamine their orientation and priorities and be prepared to change.

4. Discussion

This research offers important insights for the service providers delivering care for people in the last months, weeks, and days of life; similarly for people and groups advocating for the provision of more culturally appropriate palliative and EOL care for their communities. Here, we acknowledge some of the limitations of the study before discussing the evident interrelationships among the research themes identified. The connections between them reinforce the challenges in delivering culturally appropriate services. We also consider some of the practical suggestions for improving EOL care. These include ways to develop trust with people; spatial considerations that also extend the flexibility of care evidently in some palliative care units to other locations and areas of the health service; having dedicated workers with requisite cultural and/or language skills; and ways to develop community knowledge about EOL services. Finally, we return to Rosenberg et al. (26) three principles for Compassionate Communities. We consider what health services might need to do in re-evaluating their organizational values; acknowledging the primacy of caring networks; and transforming the paternalism of health systems.

4.1. Interrelationships among the thematic findings

Notably, yet perhaps not unexpectedly, there is an identifiable interrelationship among the themes in the results. The first three themes tell us that it is important for people to know and trust care providers; there are cultural limitations around discussing death and dying; and there are relatively low levels of knowledge about palliative care and the various services available to assist with care in the last months, weeks, and days of life. The interplay between these three themes is shown to contribute to reduced access to culturally appropriate quality palliative and EOL care. There is a negative cycle among the three themes whereby not talking about death and dying leads to limited knowledge about palliative care. In turn, this meant that patients and families lost the opportunity to develop the relationships of trust which were so important to them. Language barriers cut across the seven themes, aggravating all other issues.

4.2. Suggestions for ameliorating the problems

The research participants had a wide range of practical suggestions for improving EOL care for people from Aboriginal and diverse cultural groups. Many of these suggestions would be valuable for all people in need of EOL services. However, it is important to recognize that there are additional barriers for Aboriginal and CaLD people. Barriers to trust can be one of the most entrenched obstacles in the delivery of all forms of healthcare including palliative and EOL care. The treatment of First Nations peoples and migrants, especially refugees, by many governments, including Australia, is not a record that engenders trust. Migrants might also have had negative experiences with the government in their country of origin. Trust requires a strong relationship with people who can guide them and help them understand the strengths and limitations of the services on offer. Often, this needs to be someone from the same cultural background. Sometimes adult children have the education and resources to fulfill this role or a close relationship with their family doctor is another path for long-term migrants.

Spatial considerations can also be important in building trust. Appropriate spaces with visual symbols and messages in multiple languages help to develop trust by sending the message that Aboriginal and CaLD people are welcome and valued. So too, when spaces allow for the expression of culture. The aspects here are wide-ranging. They include the need for adequately sized spaces that can accommodate family and visitors of sometimes very large numbers; sensitively located spaces that can accommodate cultural rituals, music, or chanting; and dedicated areas for food preparation and consumption. In this research, the only place in the healthcare system identified as possessing flexibility of care allowing for family visits, with suitable food, music, significant images, and rituals, was the palliative care unit. Yet, this flexibility is still very much needed in other parts of the health and community service systems. Given the diversity of places where people die—emergency departments, hospital wards, nursing homes, ambulances, and their own homes—the clear implication is that many more services need to consider a more flexible, culturally safe approach to care at the EOL. An effective palliative care model can pave the way for how the existing health services might respond to culturally specific needs at EOL.

The deployment of dedicated workers, not only with diverse languages but also from the cultural backgrounds of those accessing palliative care and bereavement support, is an urgent need. In the research, there was a clear expression of support for such roles. The new Aboriginal Supportive and Palliative Care Worker demonstrated that many of the problems of understanding the health system, bridging silos in services, and developing trust can be effectively addressed through their role. No doubt that culture-specific Supportive and Palliative Care Workers could help CaLD communities too. However, there are inevitable questions about the feasibility of this suggestion. The provision of culture-specific workers for all of the 170 different language groups in Western Sydney would be costly. Is it viable to provide one Multicultural Supportive and Palliative Care Worker who would coordinate the needs of all CaLD people in the LHD? Could there be several to cover the large language groups? Could people from diverse backgrounds already working within the health system be trained as "care navigators" who can guide others around the system. Given that CaLD people make up over 50% of the WSLHD population, there is a strong case for many more culturally specific workers, and this would assist with improving the equity of palliative and EOL care to significant sections of a diverse community.

Another challenge is presented when considering how to provide culturally appropriate information and education about palliative and EOL care. Many people from culturally diverse groups do not want to talk about EOL, at least not outside their cultural norms. This may also be due to wanting to "hold on to hope," wanting to avoid summoning death by considering it or talking about it, or just being uncomfortable with the topic, as is the case for many in the general population, too. The literature is clear that we cannot engage in cultural stereotyping when considering how best to address EOL and palliative care needs in the setting of life-limiting illness (51). Skillful communication in the setting of a trusted therapeutic alliance is especially important in these cases. Furthermore, considering local strategies within cultural groups to provide information and answer questions about service provision in the setting of age and illness may be a good starting point for conversations about how to best provide EOL information in a culturally safe way.

Mainstream Western culture has encouraged planning and open discussion around dying and provided information about advance care planning, services available, and how to ensure a death that minimizes distress for patients and families. Tapping into existing community programs such as Dying to Know Day and "Death Café's" makes the conversations more normal; less taboo and shocking. Culturally acceptable forums within local community events might serve the same purpose. A strategy to make the education suggestions feasible is to tap into existing resources including, multicultural health services, palliative care education providers, and extending and supporting volunteer programs. Indeed, given the problems with communicating across silos of services, it is better for any new supports to be connected to existing organizations and programs.

The literature reviews of other countries show that the difficulties identified by Aboriginal and CaLD people in this study are not unique to Western Sydney (5–8, 11). Migration to Western countries is expected to continue to increase due to conflict and climate change; and the First Nations people living in neo-colonial countries continue to struggle with disadvantage. However, the suggested strategies for amelioration are also applicable internationally. Countries with Western-developed medical systems all have the resources to meet the suggestions identified in this research. Implementing the flexibility of care evident in some palliative care units in other areas of the health service; developing trust; providing suitable care spaces; employing dedicated workers with requisite cultural and/or language skills; and developing community knowledge about EOL services are all realizable goals. However, they require the will to prioritize equity of access to quality EOL care.

4.3. Toward compassionate communities

The Compassionate Communities model advocates a move from current systems focused on mechanistic physiology and economics (21, 22) to local, civic, and corporate support initiatives for EOL. The aim here is to enable holistic supportive, palliative, and EOL care in and with the community where the patient and family are seen as people who are known and loved. The research results reflect the need for investing in a transition to Compassionate Communities (34, 52) via Rosenberg et al. (26) three principles: re-evaluation of organizational values; recognition of the primacy of caring networks; and realignment of the inherent paternalism in healthcare provision.

In re-orienting their organizational values, health services need to recognize that their assumptions are often not shared with those outside the health system. The adoption of Health Promoting Palliative Care would focus on relationships, respecting each patient as a whole person with their own lived experience and understanding of the world. Health providers, including non-specialists and, in some cases, specialist providers of palliative and EOL care are usually pressed for time and focus on their particular area of treatment. Often "Key Performance Indicator" checklists need to be followed so the service can demonstrate adequate care. Although such checklists can cover actions such as the provision of cultural sensitivity training, they would be challenged to cover the development of relationships and trust. Indeed, it would be unfair for an individual staff member to be held responsible for the lack of trust due to years of societal prejudice and mistreatment. However, there does need to be a palliative and EOL care service delivery model that promotes a relationship of trust, to support the quality care wanted by communities, and care that is not compromised by the suspicion that the person was being abandoned or "left to die" by a biased healthcare system. There needs to be EOL quality of care metrics that can evaluate the capacity of the service to support such relationships.

Most EOL caring takes place at home and social network maps for patients and caregivers depict medical services on the periphery or absent (53). It is, therefore, important for the model of care and the medical services to accommodate the reality that these are occasional contributors to a larger story about culture, community, friends, and family. The primacy of caring networks means that they cannot be set aside by patients and caregivers when the patient is in the hospital. Good connections rather than silos of care are needed so patients can move from home to the hospital when necessary and return without major disruption to their identity and support network. Assistance so cultures can maintain their rituals, provision of appropriate areas with art, music, kitchens, and space to gather, including outdoor space, can all help to support the patient's identity and therefore wellbeing.

By and large, individual healthcare staff are generally dedicated people doing good work often at some personal sacrifice. However, they operate in a system that promotes a paternalistic view of patients and their families. The system dynamic suggests that patients and families should not only be grateful for the care they receive but also accept that it is they who must adjust their expectations and behaviors when they have a problem with the medical system. These messages are not respectful. They do not engender trust. We need to reconsider, for example, whether the dominant narrative of pushing for individual decision-making and open communication and education about EOL is dismissing alternative values and beliefs. People holding different cultural perspectives are unlikely to easily adopt the values and worldview of the medical system.

Indeed, good caring is at odds with seeing people from the perspective of a mechanistic philosophy and public sector management framework that packages and standardizes healthcare in the name of "efficiency" at the cost of diverse individual needs (19). This approach typically guides EOL response and care in health systems across the Western world. However, the results from this research do show that people need guidance to interact in that "foreign territory," preferably from trusted people who know both the patient's culture and the medical system. Such guidance needs to go beyond interpreting the words spoken. It cannot be assumed that people are familiar with palliative and EOL concepts and services, nor can it be assumed that they can, or think they should, ask for the help they need.

4.4. Limitations

The research was comprehensive in its ambitions to reach diverse voices and in its multi-method approach that laid a basis for the triangulation of the findings from different data sets. However, there were also limitations to the research design. The scope of the research was focused on a single local health district (LHD), albeit one with a large and particularly diverse population. This was relevant for this particular study, which was State government funded for the express purpose of conducting a culturally focused bereavement and palliative care needs analysis within the Western Sydney LHD. There is one dedicated palliative care unit within the LHD which is known for its progressive approach to culturally diverse supportive and palliative care. Expressed satisfaction with this service may limit the generalizability of some findings, but it also provides useful data about what works for people, and this was a key goal of the research questions. Furthermore, many participants had experiences with other palliative care units within Australia or their country of origin. Although comparative research across health districts would potentially add to the significance of the findings, the results are, nevertheless, of relevance both locally and internationally.

Participation in the research was limited to the Aboriginal community and the three largest CaLD groups residing within the LHD. This meant that some significant language groups were not allowed to contribute to the research. However, the target groups (Mandarin, Hindi, and Arabic) included in the research are the second, third, and seventh languages spoken worldwide (30), so what they have to say matters. A further limitation was that people were recruited for focus groups through LHD services. Again, while relevant for the project, hearing the voices of those using private or community "services" outside the public health system could potentially have contributed rich data about EOL experiences. The focus group participants were also limited to those who felt able to participate in face-to-face groups in the context of COVID. This no doubt prevented people, such as those with health vulnerabilities, from coming forward to share their views and experiences. Despite these limitations, the qualitative research generated important findings about the cultural needs of significant population groups, in breadth, if not in absolute participant numbers.

5. Conclusion

The changes in service culture and models of care indicated by this research are not necessarily low-cost or simple to implement. However, they are possible with a broader and more nuanced public debate on how diverse multicultural societies want to experience end-of-life and bereavement. The results from this study both prompt and contribute to such a debate. Many of the EOL challenges faced by culturally diverse people and groups can also be faced by those from the dominant culture who are not "death literate." The range of issues raised here are all reasonable requests for bridging such a gap: knowledge of the systems and services; help discussing EOL needs in a respectful way; guidance in making decisions about medical treatment; performing EOL rituals that are important to us; having home comforts such as the food we like; and support of friends and family when in hospital.

Barriers due to language differences and past experiences of discrimination exacerbate the challenge of having one's needs met. Recognizing the needs of diverse and marginalized communities—such as the Aboriginal, Arabic, Mandarin, and Hindi-speaking groups in this research—is an important step toward understanding the diversity of needs and the challenges to managing EOL in a way that minimizes trauma and strengthens the bonds among people. It can be a time for friends and family to gather and connect and show respect to the dying person. The acceptance across society of a Compassionate Communities model would recognize the fundamentally social and cultural, rather than medical, nature of death, dying, and bereavement and remind us that they are, indeed, *everybody's business*.

Data availability statement

The datasets presented in this article are not readily available because our ethics approval does not allow for this. Aboriginal people in particular are very cautious as they have been exploited in the past. Requests to access the datasets should be directed to r.leonard@westernsydney.edu.au.

Ethics statement

The studies involving human participants were reviewed and approved by Western Sydney University Ref: H13743, Aboriginal Health and Medical Research Council of NSW Ref: 1657/20, and Western Sydney LHD Ref: 6530—2020/ETH00559. The patients/participants provided their written informed consent to participate in this study.

Author contributions

RL had the major role in analyzing the data and writing the paper apart from the Method section which was led by the JP. JP also provided substantial input into the Introduction. PH integrated all the input from RL, JP, and SG and was responsible for checking references, formatting, and version control. SG provided significant input into the medical and palliative care system and services in the area. JT was responsible for project management, data collection, translations, and interpreters and transcriptions which were essential for this project. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. World Health Organization (2023). *Health Priorities: Palliative Care.* Available online at: https://www.who.int/health-topics/palliative-care (accessed March 14, 2023).

2. Palliative Care Australia. *What is palliative care*? Available online at: https://palliativecare.org.au/resource/what-is-palliative-care/ (accessed February 7, 2023).

3. McDermott E, Selman LE. Cultural factors influencing advance care planning in progressive, incurable disease: a systematic review with narrative synthesis. *J Pain and Sym Manag.* (2018) 56:613–36. doi: 10.1016/j.jpainsymman.2018.07.006

4. Nelson KE, Wright R, Fisher M, Koirala B, Roberts B, Sloan DH, et al. A call to action to address disparities in palliative care access: a conceptual framework for individualizing care needs. *J Palliat Med.* (2021) 24:177–80. doi: 10.1089/jpm.2020.0435

5. Barwise AK, Nyquist CA, Espinoza Suarez NR, Jaramillo C, Thorsteinsdottir B, Gajic O, et al. End-of-life decision-making for ICU patients with limited english proficiency. *Crit Care Med.* (2019) 47:1380–7. doi: 10.1097/CCM.0000000000003920

6. Abedini NC, Downey L, Engelberg RA, Curtis JR, Sharma RK. End-of-life healthcare utilization and palliative care use among older adults with limited English proficiency. *J Am Geriatr Soc.* (2022) 70:2847–57. doi: 10.1111/jgs.17913

7. Elkan R, Avis M, Cox K, Wilson E, Patel S, Miller S, et al. The reported views and experiences of cancer service users from minority ethnic groups: a critical review of the literature. *Eu J Cancer Care.* (2007) 16:109–21. doi: 10.1111/j.1365-2354.2006.00726.x

8. Six S, Bilsen J, Deschepper R. Dealing with cultural diversity in palliative care. *BMJ Support Palliat Care.* (2020) 13:65–9. doi: 10.1136/bmjspcare-2020-002511

9. Nowara V, Krumm N, Elsner F. Ambulante Palliativversorgung von Patienten mit Migrationshintergrund in der Städteregion Aachen—Perspektiven von Behandelnden und Angehörigen. *Zeitschrift für Palliativmedizin.* (2021) 22:147–54. doi: 10.1055/a-1441-0661

10. Sacchi S, Capone R, Ferrari F, Sforacchi F, Di Leo S, Ghirotto L. "Achieve the best while rushing against time": A grounded theory study on caring for low-income immigrant cancer patients at end of life. *J. Palliat. Med.* (2020) 35:426–36. doi: 10.1177/0269216320974275

11. Shahid S, Taylor EV, Cheetham S, Woods JA, Aoun SM, Thompson SC. Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: a comprehensive review. *BMC Palliative Care.* (2018) 17:72. doi: 10.1186/s12904-018-0325-1

12. Gebauer S, Knox Morley S, Haozous EA, Finlay E, Camarata C, Fahy B, et al. Palliative care for American Indians and Alaska natives: a review of the literature. *J Palliat Med.* (2016) 19:1331–40. doi: 10.1089/jpm.2016.0201

13. Canadian Virtual Hospice. A Literature Review and Environmental Scan of The Experiences of First Nations, Inuit, and Métis Peoples with Advanced Cancer Illness and at the End of Life, Report. Canadian Partnership against Cancer. Available online at: https://www.virtualhospice.ca/Assets/CVH%20IV%20Lit%20review%20final_20201103122024.pdf (accessed April 24, 2023).

14. Gott M, Wiles J, Mason K, Moeke-Maxwell T. Creating 'safe spaces': a qualitative study to explore enablers and barriers to culturally safe end-of-life care. *J Palliat Med.* (2022) 4:8621. doi: 10.1177/02692163221138621

15. Finkelstein EA, Bhadelia A, Goh C, Baid D, Singh R, Bhatnagar S, et al. Cross country comparison of expert assessments of the quality of death and dying 2021. *J Pain Symptom Manage.* (2022) 63:419–29. doi: 10.1016/j.jpainsymman.2021.12.015

16. Productivity Commission. *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Draft Report.* Canberra: Australian Government.

17. Australian Healthcare Associates. *Exploratory Analysis of Barriers To Palliative Care: Literature Review.* Canberra: Australian Government Department of Health (2019).

18. Department of Health. *National Palliative Care Strategy 2018.* Canberra: Australian Government Department of Health.

19. Anjun RL, Copeland S, Rocca E. Introduction: Why is philosophy relevant for clinical practice? in *Rethinking Causality, Complexity and Evidence for the Unique Patient.* Anjum RL, Copeland S, Rocca E. (Eds), Springer, Cham. (2020). doi: 10.1007/978-3-030-41239-5

20. Sunvisson H, Habermann B, Weiss S, Benner P. Augmenting the Cartesian medical discourse with an understanding of the person's lifeworld, lived body, life story and social identity. *Nursing Philosophy.* (2009) 10:241–52. doi: 10.1111/j.1466-769X.2009.00413.x

21. Lupton, D. (2012). Chapter 1: theoretical perspectives on medicine and society. In *Medicine as Culture: Illness, Disease and the Body.* 3rd Ed. Sage Publications Ltd. doi: 10.4135/9781446254530.n1

22. Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. *QJM.* (2013) 106:1071–5. doi: 10.1093/qjmed/hct200

23. Brown L, Walter T. Towards a social model of end-of-life care. *Br J Soc Work.* (2014) 44:2375–90. doi: 10.1093/bjsw/bct087

24. Karapliagkou, A., and Kellehear, A. (2014). *Public health approaches to end of life care: A toolkit.* Public Health England and National Council for Palliative Care. Available online at: http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf (accessed March 22, 2023).

25. Abel J, Kellehear A. Palliative care reimagined: a needed shift. *BMJ Supportive and Palliative Care.* (2016) 6:21–6. doi: 10.1136/bmjspcare-2015-001009

26. Rosenberg J, Horsfall D, Leonard R, Noonan K. Informal care networks' views of palliative care services: Help or hindrance? *Death Studies.* (2018) 42:362–70. doi: 10.1080/07481187.2017.1350216

27. Ma L, Kent JL, Mulley C. Transport disadvantage, social exclusion, and subjective well-being: The role of the neighborhood environment—evidence from Sydney, Australia. *J Transp Land Use.* (2018) 11:31–47. doi: 10.5198/jtlu.2018.1008

28. Hurni A. Transport and Social Disadvantage in Western Sydney: A Partnership Research Project. (2006). Available online at: http://atrf.info/papers/2005/2005_Hurni.pdf (accessed February 8, 2023).

29. ABS. *Snapshot of Australia*, Australian Bureau of Statistics. Available online at: https://www.abs.gov.au/statistics/people/people-and-communities/snapshot-australia/2021 (accessed January 30, 2023).

30. Statistics and Data. *Most spoken languages in the world*. Available online at: https://statisticsanddata.org/data/the-most-spoken-languages-2022/ (accessed March 20, 2023).

31. Anderson I, Devitt J. *Providing Culturally Appropriate Palliative Care to Aboriginal and Torres Strait Islander Peoples: Practice Principles*. Canberra: Australian Government Department of Health and Ageing (2004).

32. ABS. *Australia: Aboriginal and Torres Strait Islander population summary, Australian Bureau of Statistics*. (2022). Available online at: https://www.abs.gov.au/articles/australia-aboriginal-and-torres-strait-islander-population-summary (accessed January 30, 2023).

33. Horsfall D, Leonard R, Noonan K, Rosenberg J. Working together-apart: What role do formal palliative support networks play in establishing, supporting and maintaining informal caring networks for people dying at home? *Prog Palliat Care*. (2013) 21:331–6. doi: 10.1179/1743291X12Y.0000000047

34. Horsfall D, Noonan K, Leonard R. Bringing our dying home: how caring for someone at end-of-life builds social capital and develops compassionate communities. *Health Sociol Rev Spec Issue Cult. Death Dying With Dignity*. (2012) 21:373–82. doi: 10.5172/hesr.2012.21.4.373

35. Leonard R, Noonan K, Horsfall D, Kelly M, Rosenberg J, Rahn A, et al. Developing the death literacy index. *Death Studies*. (2021) 46:2110–2122. doi: 10.1080/07481187.2021.1894268

36. Wang C, Burris MA. Photovoice: concept, methodology, and use for participatory needs assessment. *Health Edu Behav*. (1997) 24:369–87. doi: 10.1177/109019819702400309

37. Booth T, Booth W. In the Frame: Photovoice and mothers with learning difficulties. *Disability and Society*. (2003) 18:431–42. doi: 10.1080/0968759032000080986

38. Tong, A., Sainsbury, P., and Craig J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 19, 349–357. Available online at: http://cdn.elsevier.com/promis_misc/ISSM_COREQ_Checklist.pdf (accessed March 8, 2023). doi: 10.1093/intqhc/mzm042

39. Paton J, Horsfall D, Carrington A. Sensitive inquiry in mental health: a tripartite approach. *Int J Qualit Methods*. (2018). 17:1. doi: 10.1177/1609406918761422

40. CoA. National Health and Medical Research Council. *Ethical Conduct in Research With Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders*. Canberra: Commonwealth of Australia (CoA) (2018).

41. AAG. Australian Association of Gerontology, Federation of Ethnic Communities' Councils of Australia and National Ageing Research Institute. *Developing an ethical Framework for Research With Ageing Culturally and Linguistically Diverse Communities*. Melbourne: Australian Association of Gerontology. (2017) (AAG).

42. Martin K, Mirraboopa B. Ways of knowing, being and doing: a theoretical framework and methods for indigenous and indigenist re-search. *J Aus Stud*. (2003) 27:203–14. doi: 10.1080/14443050309387838

43. Clark-Kazak C. Ethics in Forced Migration Research: Taking Stock and Potential Ways Forward. *Journal on Migration and Human Security*. (2021) 9:125–8. doi: 10.1177/23315024211034401

44. Yeager KA, Bauer-Wu S. Cultural humility: essential foundation for clinical researchers. *App Nurs Res*. (2013) 26:251–6. doi: 10.1016/j.apnr.2013.06.008

45. West R, Stewart L, Foster K, Usher K. Through a critical lens: Indigenist research and the Dadirri method. *Qual Health Res*. (2012) 22:1582–90. doi: 10.1177/1049732312457596

46. Kruger RA, Casey MA. Focus group interviewing. In. *Handbook of Practical Program Evaluation* 4th Ed. Newcomer, K.E., Hatry, H.P. and Wholey J.S. (Eds). (2015). doi: 10.1002/9781119171386.ch20

47. Dewing J. Process consent and research with older persons living with dementia. *Research Ethics*. (2008) 4:59–64. doi: 10.1177/174701610800400205

48. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. (2006) 3:77–101. doi: 10.1191/1478088706qp063oa

49. Braun V, Clarke V. *Thematic Analysis: A Practical Guide*. London: Sage Publications Ltd (2021).

50. Crowe M, Inder M, Porter R. Conducting qualitative research in mental health: Thematic and content analyses. *Aus New Zealand J Psychiatry*. (2015) 49:616–23. doi: 10.1177/0004867415582053

51. Jeong S, Ohr S, Pich J, Saul P, Ho A. 'Planning ahead' among community-dwelling older people from culturally and linguistically diverse background: a cross-sectional survey. *J Clin Nurs*. (2015) 24:244–55. doi: 10.1111/jocn.12649

52. Abel J, Kellehear A. Introduction. In Abel, J. and Kellehear A. (Eds) *Oxford Textbook of Public Health Palliative Care*. UK: OUP. (2022). doi: 10.1093/med/9780198862994.001.0001

53. Leonard RJ, Horsfall D, Noonan K, Rosenberg JP. Carer experience of end-of-life service provision: a social network analysis. *BMJ: Support Palliative Care*. (2020) 10:134. doi: 10.1136/bmjspcare-2017-001344

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Public health palliative care interventions that enable communities to support people who are dying and their carers: a scoping review of studies that assess person-centered outcomes

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Background: Public health palliative care views communities as an integral part of care delivery at the end of life. This community-provider partnership approach has the potential to improve end-of-life care for people who are dying and their carers.

Objective: To identify and appraise the current literature related to public health interventions that enable communities to support people who are dying and their carers.

Methods: A scoping review was conducted, applying Arksey and O'Malley's methods. Data was extracted and synthesized using narrative techniques, and results are reported using PRISMA guidelines.

Results: The search yielded 2,902 results. Eighteen met inclusion criteria and were included in the analysis. Interventions were categorized according to their target population: people with life-limiting illness (ex. facilitated social interaction, helplines and guided discussions about death and dying); carers (ex. social support mapping, psychoeducation, and community resource identification and facilitation); or dyads (ex. reminiscence activities, practical and emotional support from volunteers, online modules to bolster coping mechanisms). Public health palliative care approaches were delivered by key community stakeholders such as community health workers, volunteers, peer mentors, and pre-established support groups. Despite reported challenges in identifying appropriate tools to measure effectiveness, studies report improvement in quality of life, loneliness, social support, stress and self-efficacy.

Conclusion: We found that community-engaged palliative care interventions can lead to appreciable changes in various outcomes, though it was difficult to determine in which contexts this approach works best because of the dearth of contextual information reported. Based on the varied design and implementation strategies, it is clear that no one method for enhancing end of life care will benefit all communities and it is crucial to engage community members at all stages of the design and implementation process. Future research should be grounded in appropriate theory, describe contextual differences in these communities, and should specifically examine how demographics, resource availability, and social capital might impact the design, implementation, and results of public health palliative care interventions.

KEYWORDS

public health, palliative care, end-of-life, interventions, community engaged

What is already known about this topic?

- Public health palliative care is a model of care that views communities as an integral part of care delivery at the end-of-life.
- Some people, like those in rural and coastal communities, people bound to their homes due to disability or transportation limitations, and those from historically underserved populations, might have palliative care needs that are difficult to meet with traditional services.
- Models of palliative care that include public health interventions have the potential to better serve the needs of groups that traditional services are unable to effectively meet.

What does this paper add?

- Though varied in targeted need and approach, each included intervention improved at least one aspect of care for people at the end of life and/or and their carers, demonstrating the utility of a public health palliative care approach in different settings. Despite this, few studies discussed the possible mechanisms of action leading to improved outcomes.
- There was marked heterogeneity in the studies' theoretical underpinnings, methods and outcomes of interest which emphasizes the diversity of the public health palliative care approach and how contextual factors such as demographics, resource availability and social capital likely impact success.
- This review demonstrates the wide number of actors beyond professional services who are involved in end-of-life care, including paid community members, trained volunteers, and peer support mentors.
- Contextual data was not reported consistently among included studies thus limiting our ability to make inferences about which types of approaches work for different communities and why.

Introduction

Palliative care is recognized by the World Health Organization as an essential health service under Universal Health Coverage (1, 2). However, globally only about 14% of people who would benefit from palliative care actually receive it (3). An estimated 56.8 million people around the world require palliative care each year, the majority of whom live in low- and middle-income countries (3). The need to correct the inequitable distribution of end-of-life care services is also evident in high-income countries, where lower socioeconomic position is associated with poorer outcomes in end-of-life care (4, 5). A more integrated approach between healthcare providers and the communities they serve is vital to bridge the gap between demand and supply (6).

Public health palliative care views communities as an integral part of care delivery at the end-of-life (7). The public health palliative care approach is informed by the five pillars for health promotion in the Ottawa Charter (8). It emphasizes the importance of health-centric public policy, supportive environments, community action, personal skill development, and health and social care services reoriented toward health promotion in order to improve the physical, mental, and social well-being of populations, including the context of life-limiting illness. This community-engaged approach has the potential to expand capacity and better serve groups such as rural and coastal communities, people living in economic poverty, people with disability or transportation limitations, and those with limited access to high-quality healthcare services (6). Furthermore, the COVID-19 pandemic shifted care into the home, accelerating new models of care delivery to meet needs beyond resource-limited health and social care institutions (9).

The level of community engagement in supporting the dying falls along a continuum ranging from information provision to consulting, co-producing, collaborating and finally empowerment (where communities lead the work) (10). The public health approach to palliative and end-of-life care ideally involves the input from members of the target community at every stage of design, implementation, and dissemination, thereby ensuring that services are relevant, people feel empowered and supported, with sustainable change. This ecological view of health acknowledges that traditional models of healthcare have limitations, and recognizes that community input is not only valuable, but essential in meeting health needs.

Previous large scale public health initiatives like the Neighborhood Network in Palliative Care in Kerala, India, and Compassionate Communities and Cities have demonstrated that a public health approach can increase the depth and breadth of a palliative and end-of-life care response for those who need it most (11, 12). Working in active partnership with key community stakeholders enables development of community driven support for people with palliative care needs within their networks and neighborhoods (13, 14). The identification and harnessing of community-specific assets with recognition of shared concerns may better reflect and serve the needs and wishes of ethnically and socially diverse populations than traditional service responses alone (10).

All along the spectrum of community engagement, public health palliative care approaches have been found to improve outcomes for both people with life-limiting illness and their carers, including improving quality of life (QoL), reducing fatigue and isolation, and increasing the size of caring networks (6). However, delivery of feasible, acceptable and effective public health palliative care programmes requires greater understanding of what might work, for whom and how, within differing social contexts, and application of robust methods to understand mechanisms and evaluate outcomes (15). This review aimed to identify and appraise the current literature related to public health interventions that enable communities to support people who are dying and their caregivers.

Methods

Design and research questions

A scoping review was undertaken in line with Arksey and O'Malley's methods (16); results were synthesized using narrative synthesis applying a public health palliative care framework (6). The search and screening results are reported according to the PRISMA guidelines.

The review sought to answer the following *a priori* research questions: (1) What are community needs to support those living with terminal illness? (2) What interventions have been developed and what are the theoretical models that underpin them? (3) What is the evidence for effectiveness? (4) What context-specific evidence is available for communities living with economic poverty? (5) What are the mechanisms of action? (6) What research methods are most appropriate to improve support in palliative care? (7) Which process and outcome measures are appropriate to evaluate the impact of these approaches?

The analysis was guided by Sallnow and colleagues' public health palliative care framework (6). In their 2016 systematic review (informed by the tenets of the Ottawa Charter), they explored current evidence at the cross-section of palliative care and public health, specifically seeking interventions in the Charter's community action pillar. For this review, we expanded our conceptualization of public health palliative care approaches to include the personal skill development pillar of the Ottawa Charter as well as community action, acknowledging the overlap that exists in practice. Therefore, we included interventions such as educational materials which had been created specifically for people at the end of life and/or their carers (provided that the materials had been created by or with input from community stakeholders). In their review, Sallnow and colleagues identified and described three main domains which the interventions targeted: "*Making a practical difference*, which describes the impact such work has on the immediate experiences of those facing the end of life and their carers; *Individual learning and growth*, which describes the journey of personal reflection, development and confidence that those involved in delivering the care embark on; and, *Developing community capacity* which refers to the impact of the work beyond the individuals involved, to the wider community where sustainable change can occur." Based on this framework, we sought to assess the methods used in interventions to support the dying and their carers, understand their theoretical underpinnings, and begin to define the mechanism of action which could lead to an improvement in access to and quality of care.

Search strategy

The search strategy is reported in Appendix 1. It was undertaken in September 2022, using the following databases: Medline, Embase, PsycInfo, Cumulative Index to Nursing and Allied Health Literature and Nursing and Allied Health Database. Additionally, we searched similar systematic reviews and publications about community engagement in palliative care for studies we might have missed in the database search. Identified publications were uploaded into Covidence and each assessed for relevance by at least two reviewers (AP, LW, AD, MI, MB). Discrepancies were discussed in weekly team meetings and resolved by consensus. Inclusion criteria were: (1) reporting the results of a public health palliative care intervention targeting the community action or personal skills domain of the Ottawa Charter, (2) the intervention aimed to directly improve the care of adults aged 18 or older at the end of life [within 1 year of dying (17)] and/or their carers, (3) outcomes focused on people at the end of life or their carers, (4) written in English language. Exclusion criteria were: (1) the intervention delivered in a healthcare setting (e.g., hospitals, hospices, skilled nursing facilities) or by healthcare professionals alone, (2) intervention was created with no community input or engagement, (3) outcomes that directly impact people at the end of life or their carers were not evaluated, (4) the intervention was aimed at bereaved individuals only, (5) the publication was a review or meta-analysis of existing literature, (6) full text was not available, or the publication was not peer reviewed (e.g., conference abstracts, gray literature). The full search and screening results are reported in a PRISMA flowchart (Figure 2).

Data extraction and analysis

In line with Arksey and O'Malley's methods (16), the study team extracted data on key aspects of the included studies' settings, designs, theoretical underpinnings, methods, outcome measures and results to address the review's research questions. We used narrative synthesis guided by Sallnow et al.'s public health palliative care framework to identify types of interventions that address the three domains of community-engaged end-of-life care (practical needs, personal growth, and community capacity), to assess the breadth of research on the topic, and to analyse similarities and differences between studies (6). Additionally, we mapped the level of community engagement involved in each of the studies based on Sallnow and Paul's spectrum of engagement in end-of-life

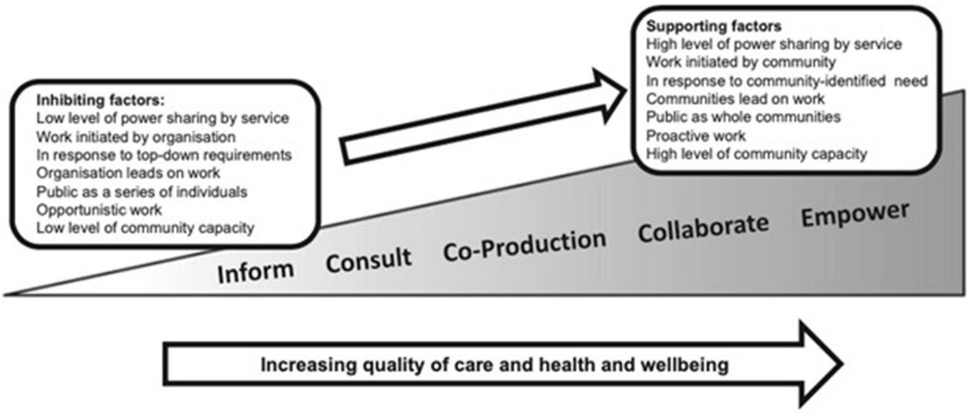

FIGURE 1
Sallnow and Paul's spectrum of engagement in end-of-life care.

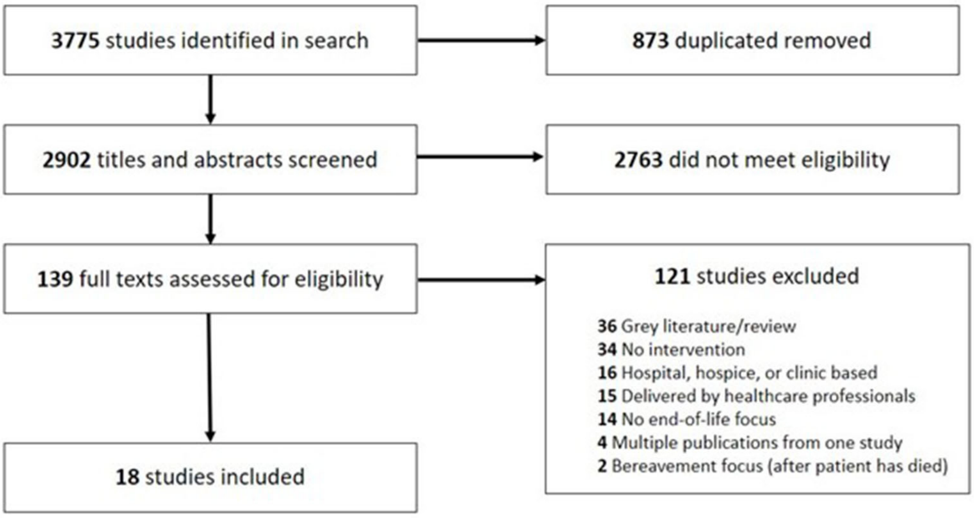

FIGURE 2
PRISMA diagram.

care, seen in Figure 1 (10). We report relevant information from the selected publications according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (18).

Results

Search strategy

The search yielded 2,900 unique results, and two additional studies were identified from reference lists of other similar reviews and from expert consultation. Of those, 2,763 did not meet the eligibility criteria based on title and abstract screening. Subsequently, 139 full text articles were reviewed, and a further 121 did not meet the criteria for inclusion. In total, 18 studies were retained for analysis (see PRISMA flowchart in Figure 2).

Study characteristics

Study summaries are presented in Table 1. Nine studies were conducted in North America, 6 in Europe, 1 in Africa, 1 in Australia and 1 in Asia. Most ($n = 12$) were conducted in large metropolitan areas focusing mainly on urban communities. The majority of these community-based interventions targeted carers of patients with life limiting illness ($n = 10$), three to people at the end-of-life only, and five to dyads. In total, 1,641 patients and 867 carers participated in these intervention studies. In seven of the studies paid community members hired by the research team delivered the intervention, in six volunteers, and in a further five no person delivered the intervention. In the studies with no specified person delivering the intervention, educational materials (i.e., informational booklet, online modules, etc.) were created based on input from community stakeholders and were freely available for community members to utilize as needed. Most of the 18 retained studies were evaluated

TABLE 1 Study details ($n = 18$).

Year	First author	Setting	Study design, sample size	Outcomes	Theoretical underpinnings	Mechanism of action	Delivered by	Delivered to	Main findings
2014	Allen (19)	USA	RCT, 45 dyads	Center for Epidemiological Studies-Depression Scale, Memorial Symptom Assessment Scale-Short Form, Brief Multidimensional Measure of Religiousness and Spirituality, Meaning in Life Scale, Caregiver Stressor Scale, Positive Aspects of Caregiving scale	Folkman's stress process model	Not discussed	Retired Senior Volunteers	Patient-carer dyads	• Patients in the intervention group had a greater reduction in emotional symptoms ($p = 0.02$) and emotional symptom bother ($p = 0.04$) and improved spiritual functioning • Caregivers in the intervention group had better Meaning of Life scale scores ($p = 0.02$)
2022	Chen (20)	China	RCT, 47 dyads	Qualitative Interviews, satisfaction questionnaire, QoL, Zarit Caregiver Burden, Family Adaptability and Cohesion Evaluation Scale II	Erikson's psychosocial development theory and Bowen's family system theory	By improving communication and bidirectional emotional support between patient and carer, encouraging gratitude, and relieving caregivers' stress, the program enabled patients to affirm positive experiences, accept or let negative experiences go, and thus help patients achieve self-integration, and perceive a better QoL	Online modules	Patient-carer dyads	• 5 themes emerged in qualitative interviews: (1) accepting and enjoying the program; (2) better communication; (3) feeling grateful for each other; (4) improved emotional support; and (5) decreased caregivers' stress • QoL ($p < 0.001$), family adaptability($p = 0.001$), and family cohesion ($p < 0.001$) improved • Caregivers' care burden decreased in the intervention group ($p = 0.018$)
2022	Dionne-Odom (21)	USA	RCT, 46 dyads	Intervention completion rates, qualitative interviews, likeliness of recommending intervention, Rini Decision Influence Scale, Hospital Anxiety and Depression Scale	Social Support Effectiveness Theory and the Ottawa Decision Support Framework	Not discussed	Trained PC coaches	Family carers	• Carers completed 78% of intervention sessions • Carers reported a likelihood of recommending the program to others of 9.9 on a scale from 1-Not at all likely to 10-Extremely likely • Some components of the intervention showed potential benefit for effective decision support and caregiver distress

(Continued)

TABLE 1 (Continued)

Year	First author	Setting	Study design, sample size	Outcomes	Theoretical underpinnings	Mechanism of action	Delivered by	Delivered to	Main findings
2014	DuBenske (22)	USA	RCT, 322 dyads	Demographics, Caregiver Quality of Life–Cancer Scale, Short Version Profile of Mood States, Edmonton Symptom Assessment Scale (carer-reported)	Stress and coping theoretical framework	The intervention improved carers appraisal and coping by bolstering cognitive, behavioral and practical support mechanisms. The authors state that more research is needed to understand the mechanism of action	Online modules	Patient-carer dyads	• Carers in the intervention group reported lower burden ($p = 0.021$) and negative mood ($p = 0.006$) than those in the control group • The effect on disruptiveness was not significant
2017	Grande (23)	UK	RCT, 681 people at the end of life	Novel survey with questions related to adequacy of support received by carer, physical and mental wellbeing of carer in bereavement, place of death, carers feelings regarding place of death	Not discussed	Not discussed	Volunteers	Patients	• Intervention group displayed a small but significant reduction in level of early grief and increased physical/mental wellbeing scores compared to control group • No difference in feelings of needs being met between groups
2011	Greene (24)	Australia	Quasi-experimental, 66 carers	Duke Social Support Index, Catholic Health Care Coalition Family Caregiver Questionnaire, AMA Carer Self-check, novel survey questions	Not discussed	Not discussed	Community network facilitators	Carers	• Participants in the intervention group showed improvement in caregiver fatigue, sufficient support from others, decreased resentment in the role, greater confidence in asking for assistance and were better able to find resources and support • No between-group changes were seen
2014	Hanson (25)	USA	Pre-Post, 218 people at the end of life	Novel survey with questions related to support needs and awareness of services to help with pain and symptoms, Functional Assessment of Chronic Illness Therapy–Spiritual Well-being Scale	Socioecological theory of community health promotion using existing social networks	Not discussed	Lay health advisors	Black patients	• Post-intervention 25% of patients identified hospice as source of support for pain/symptom management (pre-intervention = 4%, $p = 0.04$) • 60% of patients reported unmet needs for help with errands or household tasks at enrollment, while only 20% and 15% reported these areas of unmet need after 2 months in the program • QoL scores were unchanged

(Continued)

TABLE 1 (Continued)

Year	First author	Setting	Study design, sample size	Outcomes	Theoretical underpinnings	Mechanism of action	Delivered by	Delivered to	Main findings
2011	Henricksson (26)	Sweden	Descriptive, 29 carers	Qualitative interviews	Not discussed	Not discussed	Peers	Family carers	• Participants reported that the intervention was relevant, the relationships formed were valuable, and the open approach produced a warm and relaxed atmosphere
2012	Jack (27)	Uganda	Descriptive, 21 people at the end of life	Qualitative Interviews	Not discussed	Not discussed	Community volunteers	Patients	• Participants reported that the community volunteers were very beneficial, linking them and their families to practical help, counseling and education, and hospice services when appropriate
2015	Luker (28)	UK	Quasi-experimental, 29 carers	Qualitative interviews	Not discussed	Not discussed	Informational Booklet	Carers and district nurses	• Carers were positive about the booklet, but many reported they would have liked it earlier • Carers reported feeling more positive about caregiving and more reassured and competent in their role • District nurses found the booklet useful and reported receiving fewer phone calls from study carers than others in similar situations
2022	Parker Oliver (29)	USA	RCT, 78 carers	Generalized Anxiety Disorder scale, Patient Health Questionnaire, Caregiver Quality of Life Index-Revised, and the Zarit Burden Interview	Not discussed	Not discussed	Peers	Family carers	• Participating in Facebook support groups was associated with decreased anxiety and depression carers • There was no significant difference in carer QoL or burden
2017	Pesut (30)	Canada	Pre-Post, 21 dyads	Qualitative interviews, novel survey with questions related to self-efficacy and satisfaction with the intervention, McGill Quality of Life Questionnaire	Not discussed	Not discussed	Volunteers	Patients and carers	• Carers were highly satisfied with the intervention • Carers reported that the intervention helped them with decision making, social support, engaging with life, and re-framing the experience of living with illness
2008	Ryan (31)	UK	Descriptive, 81 carers	Qualitative interviews	Not discussed	Not discussed	Lay interventionists	Carers	• Carers appreciated the emotional support, time, practical help, financial advice, and education that the program provided • Carers and health professionals both felt the program provided essential social support

(Continued)

TABLE 1 (Continued)

Year	First author	Setting	Study design, sample size	Outcomes	Theoretical underpinnings	Mechanism of action	Delivered by	Delivered to	Main findings
2009	Steinhauser (32)	USA	RCT, 82 participants	Qualitative interviews	Byock's theory of human development and physical decline	The semi-structured nature of the sessions provided catharsis for participants by empowering them to disclose anything they felt was appropriate. The sessions allowed participants to explore their sense of self with is often interrupted at the onset of illness because crisis supersedes normal roles—by reconnecting to these roles through the personal narrative exercises, participants find emotional and spiritual growth	Lay interventionists	Patients	• Discussions of life completion may improve important health outcomes for patients at the end of life
2016	Walshe (33)	UK	RCT, 179 people at the end of life	World Health Organization QoL Brief Scale, De Jong Gierveld 6-item Loneliness Scale, Medical Outcomes Study Social Support Survey, self-reported healthcare utilization	Not discussed	Not discussed	Volunteers	Patients	• No significant differences in outcomes were found between groups at 4 weeks • Rate of change of QoL slowed in intervention group

(Continued)

TABLE 1 (Continued)

Year	First author	Setting	Study design, sample size	Outcomes	Theoretical underpinnings	Mechanism of action	Delivered by	Delivered to	Main findings
2021	Wang (34)	USA	Descriptive, 22 carers	Qualitative interviews	Body-Mind-Spirit Model	Carers are unable to care for their loved ones if they do not first take care of themselves. The intervention targeted the bodies, minds, and spirits of carers, so they were better equipped with the self-care skills they needed to sustainably car for their loved ones	Online modules	Chinese immigrant carers	• The most beneficial aspects were self-care curriculum related to caregiving stress, lifestyle and health behavior change, community resource support, death education and end-of-life care, and spirituality and spiritual care • Caregivers appreciated the educational aspect of the intervention and wanted more assistance accessing community resources
2011	Williams (35)	Canada	Descriptive, 57 carers	Qualitative interviews	The population health promotion model (outlined in the Ottawa Charter)	When carers feel overburdened by practical concerns (financial strain, missing work, etc) they are unable to effectively care for their loved ones. This intervention helps relieve carers' burden so they have more time and energy to focus on their role in supporting their loved one without feeling burned out	Government	Carers working full time	• Carers discussed social determinants that affected their experience like gender, income and social status, working conditions, health and social services, social support network, and personal health practices and coping strategies • They rated the intervention highly and felt it benefitted them
2004	Witkowski (36)	Sweden	Descriptive, 48 carers	Qualitative interviews	Not discussed	Not discussed	Support group leaders	Carers	• Carers felt that the programme was beneficial to their own health promotion, that it was an important complement to usual palliative home care, and that they benefited from mutual experiences shared among group members

MRC, Medical Research Council; QoL, Quality of life; RCT, Randomized control trial.

using randomized control trials ($n = 8$), six qualitative only, two quasi-experimental, and two pre-post designs.

In terms of reported contextual factors and demographic data, most studies ($n = 16$) reported age and sex of the participants. Nine reported marital status, six reported race and/or ethnicity, five highest level of education, four employment status, three living arrangements, two language proficiency, two religious affiliation, and one time since immigration. Two studies listed no demographic information about the participants. Four studies briefly described the catchment area for recruitment in terms of rurality and healthcare services available.

Included studies fell along the spectrum of community engagement seen in Figure 1 (10), from low levels of consultative engagement [educational materials that were created with community input then passively made available to those who might need it (20, 28)] to relatively high levels of collaborative engagement [researchers created training programs aimed at equipping volunteers with the skills they need to asses needs and then provide tailored support for people at the end of life and their carers (27, 30)]. No studies fell into the extremes of the spectrum, partly because we excluded studies that only informed participants without community engagement at any point in the intervention development.

Interventions focused on people at the end of life

Three of the 18 included studies reported the results of interventions explicitly aimed at supporting people who were dying (25, 32, 33). All aimed to address people's practical needs by providing psychological and social support from trained community volunteers. One targeted personal growth (32) and one addressed community capacity (25). Each approach lasted between 3 weeks and 2 months and were all held in-person. Descriptions of each of the studies and their main components are reported in Table 2. None of the three studies used the same outcome measures.

Hanson et al. developed a peer support group to help meet the practical, emotional and spiritual needs of African Americans with advanced cancer based on the socioecological theory of community health promotion using existing social networks. They measured outcomes using a novel survey of support needs and awareness of services to help with symptoms and the Functional Assessment of Chronic Illness Therapy–Spiritual Well-being Scale. After 2 months people reported less need for practical, emotional, and spiritual support, were more aware of hospice care but had no change in QoL (25). Informed by Byock's theory of human development and physical decline, Steinhauser et al. performed a three-armed RCT comparing a life completion discussion intervention with previously validated relaxation exercises or control. The results form a synopsis of what participants discussed in the three sessions but do not compare the groups in the discussion (32). This was the only study to discuss possible mechanisms of action, and they postulated that their intervention allowed people at the end of life to explore their sense of self and reconnect with their roles outside of illness, thus facilitating personal and spiritual growth. Walshe et al.'s study randomized 196 adults with a terminal diagnosis to receive a volunteer support intervention immediately or after a 4 week wait. They collected the World Health Organization QoL Brief Scale, De Jong Gierveld 6-item Loneliness Scale, Medical Outcomes Study Social Support Survey, and self-reported healthcare utilization from participants. While the intervention produced a positive shift in QoL, loneliness, and perceived social support scores these were not statistically significant (33).

To summarize, two of the three studies used quantitative methods to assess outcomes for people at the end of life [one used a novel survey (25) while the other used validated tools (33)]. One showed improvement in people's needs being met post-intervention (25), but neither showed a statistically significant increase in QoL. One study used qualitative interviews to determine patient satisfaction with the intervention (32). Patients in this study found the interviews to be beneficial in reflecting on their lives and accepting death which the authors stated may have improved their QoL.

Carer-facing interventions

Ten studies focused solely on carers' needs as the person they cared for approached the end-of-life (21, 23, 24, 26, 28, 29, 31, 34–36). Four approaches connected individual carers with trained community members employed by the research team (21, 23, 24, 31) while three joined multiple carers together to form small support groups (26, 29, 36). Three did not utilize interventionists and instead provided standardized support (online modules, information booklet, and government provided financial assistance) aimed at improving carers QoL and self-efficacy (28, 34, 35). All standardized support approaches were informed by community stakeholders and were freely available to community members to use as needed. Interventions lasted between one and 12 weeks and were implemented in a variety of formats, including in-person, online, and hybrid. To assess carer outcomes six studies used qualitative interviews (26, 28, 31, 34–36), two used quantitative methods [two validated tools (24, 29) and one a novel survey (23)], and one used mixed-methods (21). The studies that used validated tools chose the Rini Decision Influence Scale, Hospital Anxiety and Depression Scale, Duke Social Support Index, Catholic Health Care Coalition Family Caregiver Questionnaire, American Medical Association Carer Self-check.

Three of the 10 described the theories that underpinned them, including the Social Support Effectiveness Theory and the Ottawa Decision Support Framework (21), the Body-Mind-Spirit Model (34), and the population health promotion model (35). Two studies discussed possible mechanisms of action leading to improved outcomes. One cited improving physical and emotional well-being of carers allowing them to be better equipped to sustainably care for their loved one (34), and the other postulated that their intervention relieved the burden of practical concerns (financial strain, missing work, etc.,) thereby allowing more time and emotional energy for caring (35, 37). None of the studies that did not state a theoretical framework posited a mechanism of action.

TABLE 2 Intervention components.

Year	First author	Description	Duration	Mode of delivery	Practical needs			Personal growth		Community capacity	
					Physical, psychological, spiritual	Education	Social Support	Knowledge, skills, and attitudes about death and dying	Personal reflection and confidence	Developing community activists	Embedding sustainable change
Interventions focused on people at the end of life ($n = 3$)											
2014	Hanson	Peer-support model designed around pre-existing social networks aimed at extending practical, emotional, and spiritual support	Varied based on patients' needs, up to 2 months	In-person, via phone	Errands, household tasks, personal care, prayer, help organizing paperwork/ records/bills	Resources for help with pain relief, cancer treatment options and life-sustaining treatment	Emails, calls, cards, visits/calls with family members, help finding community resources			Support team model built on pre-existing social networks, often training natural helpers within communities	Support teams have been operating in both intervention locations >1 year after the end of grant funding
2009	Steinhauser	Semi-structured discussion about life story, regrets, heritage, and legacy with the intent of improving QoL	3 weekly sessions, 45 min each	In-person	Spiritual ideas addressed in "Forgiveness" interview e.g., "Are you at peace?"			Attitudes toward death addressed in "Forgiveness", "Heritage and legacy" interviews	All three interviews were reflective around themes of life story, forgiveness, heritage and legacy		
2016	Walshe	Trained volunteers provided tailored support including befriending, practical support and signposting to services	4 weeks	In-person	Practical support and resource signposting		Befriending				
Carer-focused interventions ($n = 10$)											
2022	Dionne-Odom	Coaching family carer to enhance their decision support skills and how to support patient in decision-making process	1–5 weeks, sessions lasted 20–30 minutes	In-person, via phone		Decision making and communication training		Training for how to complete advance directives and POA	Communication training for how to discuss death and dying with loved ones		
2017	Grande	"Carer Support Needs Assessment Tool" which enables end-of-life needs to be identified/prioritized in partnership with the patient	Two 2-h sessions over 2 weeks	In-person	Psychological support, respite care, resource identification	Training for self-care, how to manage meds and symptoms	Training for how to ask for help from others				

(Continued)

TABLE 2 (Continued)

Year	First author	Description	Duration	Mode of delivery	Practical needs			Personal growth		Community capacity	
					Physical, psychological, spiritual	Education	Social Support	Knowledge, skills, and attitudes about death and dying	Personal reflection and confidence	Developing community activists	Embedding sustainable change
2011	Greene	Community network facilitators assessed carers needs, helped mobilize their existing support networks, and connected them to available resources when needed	At least 3 monthly sessions	In-person	Psychological support, carer needs assessment, respite care	Carer role training, relaxation techniques	Training for how to ask for help from others				
2011	Henricksson	Group support program for family members of the dying with educational sessions	6 weeks	In-person		Educational offerings chosen by group members	Peer support	Group sessions focused on how to live with someone who is dying, and the practicalities of death	Group members were encouraged to share experiences and gain insight from others		Group members felt empowered to continue helping peers
2015	Luker	Informational booklet including causes of common patient symptoms, end-of-life considerations, and resources	n/a	Paper leaflet	Psychological and emotional support resources	Symptom management education		Leaflet includes information about death and bereavement			Leaflet is publicly available in perpetuity
2022	Parker Oliver	Online (via Facebook) support groups to educate and provide social support for family carers	4-weeks of content, in group until patient dies	Online		Weeks 1 and 2 provided links to educational material on Hospices and Pain	Peer support from other group members	Week 4 addressed topic of "Dying Process", provided information and group shared perspectives	Each week included reflective practice on topic		Individuals can remain in the group as long as they wish, until their care recipient dies
2011	Williams	Government benefits scheme providing financial support and allowing full-time workers to take leave to care for dying loved one	6 weeks	n/a	Monetary aid (6 weeks of income support up to 55% of regular earnings)						

(Continued)

TABLE 2 (Continued)

Year	First author	Description	Duration	Mode of delivery	Practical needs			Personal growth		Community capacity	
					Physical, psychological, spiritual	Education	Social Support	Knowledge, skills, and attitudes about death and dying	Personal reflection and confidence	Developing community activists	Embedding sustainable change
2008	Ryan	Non-clinical interventionists provided information (care options, accessing resources), emotional support, practical support (form filling, financial/benefit advice) and referral to other agencies	From diagnosis to patient death	In-person, via phone	Offered emotional support and practical (form filling, benefit advice)	Provided information on care options and accessing resources	Check in visits/calls and referral to other agencies				
2021	Wang	Carers interacted with an app containing modules related to self-care, caregiving role, exercise videos, and community resources	n/a	Online (in app)	Curriculum included exercise videos, breathing/relaxation techniques and spiritual care	Education on medication management, resource signposting			Reflection on caregivers' roles and boundaries, diet, exercise, sleep		App currently being reconfigured to address carer feedback
2004	Witkowski	Non-clinical interventionists facilitated peer support groups with carers of advanced cancer patients on topics chosen by carers	5 sessions	In-person	Discussions on psychological reaction to cancer diagnosis in patients and carers	Education on cancer prognosis and treatment options,	Discussion on "living with cancer diagnosis" in group format with coping theories				One group chose to continue meeting as a self-help group after programme completion
Dyadic interventions (*n* = 5)											
2014	Allen	Retired senior volunteers delivered a reminiscence activity intervention aimed at alleviating patient and carer distress	3 sessions	In-person	"Feelings checks" conducted in in-person meetings			"Problem solving" skills addressed in dyad manual	Dyads given reflective manual to complete. During sessions interventionalist discussed feelings evoked from the task		Some dyads expressed the intentional of continuing to work on their projects

(Continued)

TABLE 2 (Continued)

Year	First author	Description	Duration	Mode of delivery	Practical needs			Personal growth		Community capacity	
					Physical, psychological, spiritual	Education	Social Support	Knowledge, skills, and attitudes about death and dying	Personal reflection and confidence	Developing community activists	Embedding sustainable change
2022	Chen	Nursing students led patients and families through experience-based interviews. Participants completed online modules asynchronously	8 sessions over 4 weeks	Online (in app)	"Mind space" module enabled patient expression of emotions.	Health education included in both control/intervention group		"Connecting You and Me" module allowed dyad discussion of their journey and expression of attitudes toward death, with facilitator	Guided reflection based on cancer experience, adulthood, childhood, adolescence and life summary		E-legacy module enabled patients to hand down wishes to others
2014	DuBenske	Dyads received a web-based lung cancer information, communication and coaching intervention	24 months	Online	CHESS website facilitated CBT principles to identify emotional distress and offered coping techniques	CHESS website provided ready and organized access to educational information, resources, news	Monitored discussion groups offering social support. Separate groups for patients, carers and bereaved carers	CHESS website facilitated one-to-one question and answer service with clinician	Aspects of CHESS encourage reflection on goals, obstacles and offer techniques to overcome		Web-based platform is a resource that can be used indefinitely
2011	Jack	Community volunteers trained in palliative care, HIV and cancer, basic nursing tasks and communication, provided tailored care to dyads, including, physical care, practical help, emotional support, and education	Not discussed	In-person, via phone	Physical care provided in management of illness, administration of medicine and cooking. Spiritual support and basic counseling offered to patient/family.	Dyads educated in areas of nutrition, hygiene, infection control and medicine concordance.	Dyad needs identified and referred to appropriate support groups	Stigma around HIV/AIDS addressed, carers trained and supported by volunteers in caring		Talks given within local communities	Programme is still ongoing
2017	Pesut	Trained volunteer navigators provided psychosocial support for dyads and helped connect them to available resources	1 year	In-person, via phone	Volunteers aided clients to identify and access services and resource	Volunteers helped with decision making via discussions of options and education, to empower clients to make their own decision regarding their care	Volunteers visited clients if admitted to hospital/care home, engaged in client hobbies and seniors group activity planning	Discussions about advance care planning and resources available	Strategies to improve client confidence in voicing healthcare related concerns such as via letter writing	Volunteers advocated for their clients at a community level to ensure they received all support available	N-CARE currently being scaled up and delivered across rural communities in Canada

meds, medications; POA, power of attorney.

All 10 interventions addressed at least one aspect of carers' practical needs, from psychological support and education about how to care for someone seriously ill or dying, to financial assistance. Six highlighted the importance of personal growth and encouraged participants to reflect on their experience and their own perceptions of death and dying (21, 23, 24, 26, 28, 29, 34). Five involved community capacity building, often in the form of peer support groups that could continue to meet after the person had died (26, 28, 29, 34, 36). None specifically focused on training community volunteers or activists to continue the program after the intervention study was complete.

As seen in Table 1, there was little overlap in the measures used to assess outcomes, so opportunities for comparison are limited. In all seven of the studies that employed qualitative interviews, carers were satisfied with the intervention and felt it substantially benefitted them. In the studies that used quantitative methods, researchers found that carers were likely to recommend the intervention (21), felt improved mental and physical well-being (21, 23, 29), had decreased anxiety and depression (21, 29), and decreased early grief after the patient had died (23).

Dyadic interventions

Five of the 18 included studies focused on patient-carer dyads (19, 20, 22, 27, 30). The dyadic interventions reported the highest level of community engagement in the development of the intervention and were the most comprehensive in addressing all three domains of the guiding framework. All five touched on at least one aspect within each of the three domains. All paid specific attention to the psychological needs of people at the end of life and their carers, aimed to improve knowledge about and acceptance of dying, and made efforts to embed sustainable change into community networks by bolstering volunteers and resources available to people facing the end of life and their carers. The duration range for dyadic interventions was wide, between 3 weeks and 1 year, and they were delivered in-person, over the phone, online or through apps designed with community input or moderated by community members.

Three of the five stated the theoretical framework that informed the study, including Folkman's stress process model (19), Erikson's psychosocial development theory and Bowen's family system theory (20), and the Stress and coping theoretical framework (22). Two discussed possible mechanisms of action (20, 22). One cited communication and bidirectional emotional support improvements as the key components of improved QoL (20), while the other asserted that the intervention helped improve carers' cognitive, behavioral and practical support mechanisms, thus improving their ability to cope with stressors (22).

Two of the studies evaluated outcomes using quantitative measures only (19, 22), two using mixed methods (20, 30), and one using qualitative methods only (27). There was almost no overlap in outcome measures. Those that used validated measures chose the Center for Epidemiological Studies-Depression Scale, the Memorial Symptom Assessment Scale-Short Form, the Brief Multidimensional Measure of Religiousness and Spirituality, the Meaning in Life Scale, the Caregiver Stressor Scale, the Positive Aspects of Caregiving scale, the Zarit Caregiver Burden scale, the Family Adaptability and Cohesion Evaluation Scale II, the Caregiver Quality of Life–Cancer Scale, the Short Version Profile of Mood States, the Edmonton Symptom Assessment Scale, and the McGill Quality of Life Questionnaire. All four studies using quantitative measures reported statistically significant positive outcomes for both patients and carers. Allen and colleagues reported decreased emotional symptoms and increased spiritual functioning (19). Chen and colleagues reported high satisfaction from both people at the end of life and carers and increased QoL and family cohesion (20). DuBenske and colleagues reported lower caregiving burden and negative mood in the intervention group compared with the control group (22). Finally, Pesut and colleagues reported increased confidence in decision making and perception of social support (30). The studies using qualitative methods similarly all reported positive experiences with the intervention and experiential reports of improved communication, psychosocial functioning and acceptance of death and dying (20, 27, 30).

Discussion

The purpose of this scoping review was to identify and appraise the current literature on public health palliative care interventions aimed at engaging community members in supporting people at the end of life and their carers. The interventions, their theoretical underpinnings, mechanisms of action, measurement strategies and results were heterogeneous. This emphasizes the wide range of interventions that comprise the public health palliative care approach and the importance of co-creating end-of-life care delivery strategies through community action and engagement to fit different contexts. Importantly, most successfully improved at least one aspect of care for people with life limiting illness and their carers, demonstrating the utility of this philosophy of care. This is supportive of the broader literature, which acknowledges the positive impact of engaging communities to improve health and well-being (6, 11, 38).

In terms of supporting people at the end of life and their carers, communities have wide ranging needs that are dependent on context, demographics, and social capital. These needs can be divided into the three distinct categories outlined in the guiding framework: practical needs, personal growth and community capacity (6). Support for practical needs, such as social interaction, symptom management, shopping and financial subsidies, were employed in all studies. For example, most included interventions involved social interaction with trained volunteers or peers in a similar situation and reported benefits for both people at the end of life and their carers. Six studies directed resources to bolstering social networks, while six provided participants with opportunities to interact with community members trained and paid by the research team and volunteers to discuss their needs and challenges. Older adults cite maintaining social well-being as more important to their overall health than their physical and cognitive state (39), however social support is often neglected in the care of older adults with debilitating conditions, leading to social isolation, decreased quality of life, and poorer health outcomes (40). Health professionals often do not have the skills or resources to support the social needs of people at the end of life and carers, nor are they the most appropriate people to do so. Building and supporting sustainable, community-based networks are a more appropriate response to these needs.

Personal growth needs, including education, training, and reflection to strengthen knowledge, skills and confidence around to death and dying, were identified and addressed in 12 of the 18 included studies. These needs were addressed with a range of strategies aimed at improving self-efficacy, such as reflection exercises, decision support coaching, and educational offerings about how to live with and support those with a terminal diagnosis. Death, dying, and loss are universal phenomena, yet strategies and resources to support people to learn and grow as they experience them, and to share this learning within their community networks, are often lacking (41). For both people at the end of life and carers, sharing these interpersonal reflections and experiences with others may provide alternative perspectives and, as found in this review, improved emotional functioning (19) and lower burden (22). Noonan et al. define the outcome of this accumulation of knowledge and skills that carers often develop through practice as 'death literacy', and suggest that death literacy is a resource that strengthens the capacity of individuals and communities for future caring (42).

Lastly, opportunities to build community capacity, including the development of community activist networks, increasing social capital, and partnerships with professional institutions to embed sustainable change, represent an important facet to address community needs in end-of-life care. Eleven of the 18 included studies identified and addressed community capacity building as a need, most often in the form of developing a resource (i.e., educational modules, support groups, volunteer training programme) to be used by the community in perpetuity. Expanding community capacity to support equitable and sustainable end-of-life care is crucial in developing interventions that can continue even after the resources and workforce research teams offer are removed (43). The varied needs addressed in each of the studies supports the idea that public health palliative care approaches work best when they are locally generated in response to community needs and available resources (10).

Other than some similarities in the identified community needs, we found heterogeneity in almost all aspects of the design, implementation, and evaluation of the included intervention studies. Half ($n = 8$) of the publications reported a theoretical framework underpinning the approach taken, though none overlapped. Similarly, authors described differing mechanisms of action leading to improved outcomes in the five studies that reported on it. Interestingly, among the 10 studies that did not describe their theoretical underpinnings, none went on to discuss the mechanisms of action precipitating their outcomes, suggesting that grounding an intervention in a theoretical framework provided critical scaffolding to establish and test the mechanisms of action that are intended to lead to improved outcomes.

Additionally, studies fell all along the spectrum of community engagement (10) but were concentrated in the middle. In 13 of the 18 included studies, community members acted as agents to deliver the intervention, seven as paid members of the research team, and six as unpaid volunteers. Most studies demonstrated progress in consulting community stakeholders in the development of their intervention and co-creating solutions to identified problems, but nearly all fell short of collaborating with communities to promote shared-decision making in the development of new models of care to meet the needs of people at the end-of-life and their carers. None of the studies were considered to fall into the empowerment level of community engagement. While it is possible some aspects of community engagement were not detailed or that continuing efforts have not been reported, this has implications for the sustainability of the approaches. Particularly in burgeoning fields in which theoretical underpinnings are still being established and tested, as with public health palliative care, community engagement is vitally important for defining key concepts, community assets and needs, appropriate outcomes and sustainable solutions (44). Future research should focus on expanding sustainable community engagement approaches in order to more fully empower communities to identify needs and develop strategies to support people at the end of life.

Once needs were identified and interventions to address them were developed, research teams were tasked with developing evaluation strategies that examined key outcomes for people at the end of life and their carers while also acknowledging the importance of individual experiences and contextual nuance. Again, there was wide variability in the chosen outcome measurements which makes it difficult to conclude which methods are best in evaluating intervention efficacy in which contexts. Qualitative interviews were utilized in 14 studies and were the most common data collection method in evaluating the results and efficacy of the included interventions. Six studies used novel, unvalidated quantitative surveys aimed at eliciting satisfaction with the intervention or quality of care. Furthermore, among those that used validated, quantitative measures, few studies used common tools. QoL was measured using seven different tools across seven different studies (ex. Caregiver Quality of Life–Cancer Scale, McGill Quality of Life Questionnaire, World Health Organization Quality of Life Brief Scale), while caregiver burden was measured using four different tools across three different studies (ex. Caregiver Stressor Scale, Zarit Caregiver Burden, American Medical Association Carer Self-check). Many authors cited the lack of validated quantitative outcome measurement tools as a limitation.

The varied outcome measurement strategies represented in the field of included studies may reflect the differing priorities of the communities in which they were implemented. Defining outcomes that are meaningful to community members is as important as co-creating palliative care approaches that fit the community's needs. It is imperative that future research includes systematic evaluation of which measures are meaningful to community members and the co-creation of research strategies with community members to better fit their context. To do this, the WHO recommends beginning community-engaged health services development with exploratory data collection such as qualitative interviews, co-design workshops, or field observation designed to understand context (i.e., community infrastructure, social networks, existing services), encourage stakeholder engagement and buy-in, and identify shared goals and their corresponding outcome metrics (45).

The contextual information, including personal and environmental factors, that was reported varied widely between studies. In terms of personal factors, nearly all studies ($n = 16$)

reported the age and sex of their participants, but other variables such as marital status, race and ethnicity, education level and employment status were collected less consistently. Environmental factors such as location, urbanicity, access to healthcare services, local infrastructure and transportation were rarely reported. Both personal factors (such as age, sex, race, ethnicity, socioeconomic status, education level, disease type or severity, political and religious ideations) and environmental factors (such as access to healthcare services and urbanicity) have been shown to affect engagement with end-of-life services and outcomes (5). As such, these variables have important implications for how interventions are developed and how their results should be interpreted. While an aim of this review was to examine who public health palliative care approaches work for, it was difficult to do so without detailed descriptions of each of the target communities. Understanding the demographic and socioeconomic context of a community is vitally important to designing appropriate end-of-life services that meet their needs. As the field of public health palliative care moves forward, researchers have an imperative to pay particular attention to these social and structural determinants, the context in which they are working, report personal and environmental variables that could impact uptake and examine associations with outcomes if possible. In doing so, we can gain a better understanding of who these approaches work for and in which contexts and move to tackle the significant inequity which exists currently.

As a matter of special interest, we hoped to focus attention on studies that specifically targeted rural and coastal communities or communities living in economic poverty. Rurality and economic status have been shown to impact access to and the delivery of in end-of-life care (4, 5). In this review, very few studies provided sufficient contextual information to determine whether or not their samples included people from these groups, and even fewer included related aims. The majority of studies took place in high-income countries ($n = 16$), and only a few reported any data related to the economic status of their participants such as highest level of education ($n = 5$) and employment status ($n = 4$). The only publication that had an in-depth discussion of economic status and its impact on the intervention was Jack and colleagues' 2011 report of community volunteers in two urban centers in Uganda (27). Here, they discussed the financial strain of the Ugandan population and the national health system and how that impacted the sustainability of the project. While public health and community-engaged palliative care can benefit people with life-limiting illness in all settings, this model of palliative care notably could benefit those living in rural and coastal communities and those in economic poverty who are less likely to receive appropriate palliative and end-of-life care (46). Included studies provided very little specific detail as to the relative economic status or rurality of the subject populations which make it difficult to determine which interventions and models of care would be most beneficial to this population.

Limitations

First, as the aim of this review was to identify publications that report the results of interventions aimed at fostering community engagement in end-of-life care, we only included studies that reported outcomes from people at the end-of-life or their carers. There are multiple public health palliative care initiatives, like the Neighborhood Network in Palliative Care in India and Compassionate Communities in Canada and Australia, that report community level or volunteer outcomes which fell out of the scope of this review (11, 37, 47). Secondly, we excluded gray literature, conference posters or abstracts without full-text publications, and non-peer reviewed literature. Lastly, there is potentially evidence published in languages other than English that we were unable to identify.

Conclusion

In this review, we aimed to gain a better understanding of existing public health palliative care approaches which captured individual outcomes to understand for whom and how they work, and how differing contexts might impact their design and delivery. We found that community-engaged palliative care interventions represent a strong opportunity for improving support at the end of life, and that engaging community members at various stages in the process can lead to appreciable changes in outcomes. There was marked heterogeneity in the studies' theoretical underpinnings, methods, outcomes of interest and results which suggests that this field is developing rapidly. Based on the varied design and implementation strategies and their collective success in improving outcomes, it is likely that different community engagement approaches will support public health palliative care approaches in different communities. Context is a crucial component in understanding community needs and how they might benefit from public health interventions. Future research should define contextual difference in these communities and should specifically examine how demographics, resource availability, and social capital might impact the design, implementation, and results of public health palliative care interventions. Defining these contextual differences and their impact, then adjusting community engagement strategies appropriately, public health approaches can better fit the needs of the communities in which they are situated.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

The review was designed and developed by LW-D, LH, KW, LS, and RH. The search was carried out by LW-D. AP, AD, LW-D, MI, and MB reviewed all items identified in the search and systematically decided which should be included in the final manuscript. All authors contributed to the writing of the manuscript and provided substantial edits to the final draft.

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Conflict of interest

LS was employed by St Christopher's Hospice.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1180571/full#supplementary-material

References

1. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Kwete XJ, et al. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. *Lancet.* (2018) 391:1391–454. doi: 10.1016/S0140-6736(17)32513-8

2. Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, et al. Redefining palliative care-a new consensus-based definition. *J Pain Symptom Manage.* (2020) 60:754–64. doi: 10.1016/j.jpainsymman.2020.04.027

3. Sleeman KE, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health.* (2019) 7:e883–92. doi: 10.1016/S2214-109X(19)30172-X

4. Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, Verne J, Maddocks M, Murtagh FEM. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. *PLoS Med.* (2019) 16:e1002782. doi: 10.1371/journal.pmed.1002782

5. Nelson KE, Wright R, Peeler A, Brockie T, Davidson PM. Sociodemographic disparities in access to hospice and palliative care: an integrative review. *Am J Hosp Palliat Care.* (2021) 38:1378–90. doi: 10.1177/1049909120985419

6. Sallnow L, Richardson H, Murray SA, Kellehear A. The impact of a new public health approach to end-of-life care: a systematic review. *Palliat Med.* (2016) 30:200–11. doi: 10.1177/0269216315599869

7. Kellehear A. Health-promoting palliative care: Developing a social model for practice. *Mortality.* (1999) 4:75–82. doi: 10.1080/713685967

8. Potvin L, Jones C. Twenty-five years after the ottawa charter: the critical role of health promotion for public health. *Public Health.* (2011) 102:244–8. doi: 10.1007/BF03404041

9. Mitchell S, Maynard V, Lyons V, Jones N, Gardiner C. The role and response of primary healthcare services in the delivery of palliative care in epidemics and pandemics: a rapid review to inform practice and service delivery during the COVID-19 pandemic. *Palliat Med.* (2020) 34:1182–92. doi: 10.1177/0269216320947623

10. Sallnow L, Paul S. Understanding community engagement in end-of-life care: developing conceptual clarity. *Crit Public Health.* (2014) 25:231–8. doi: 10.1080/09581596.2014.909582

11. Sallnow L, Kumar S, Numpeli M. Home-based palliative care in Kerala, India: the neighbourhood network in palliative care. *Prog Palliat Care.* (2013) 18:14–7. doi: 10.1179/096992610X12624290276142

12. Quintiens B, D'Eer L, Deliens L, Van den Block L, Chambaere K, De Donder L, et al. Area-based compassionate communities: a systematic integrative review of existing initiatives worldwide. *Palliat Med.* (2022) 36:422–442. doi: 10.1177/02692163211067363

13. Mills J, Abel J, Kellehear A, Patel M. Access to palliative care: the primacy of public health partnerships and community participation. *Lancet Public Health.* (2021) 6:e791–2. doi: 10.1016/S2468-2667(21)00213-9

14. D'Eer L, Quintiens B, Van den Block L, Dury S, Deliens L, Chambaere K, et al. Civic engagement in serious illness, death, and loss: a systematic mixed-methods review. *Palliat Med.* (2022) 36:625–51. doi: 10.1177/02692163221077850

15. De Lima L, Pastrana T. Opportunities for palliative care in public health. *Annu Rev Public Health.* (2016) 37:357–74. doi: 10.1146/annurev-publhealth-032315-021448

16. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol.* (2005) 8:19–32. doi: 10.1080/1364557032000119616

17. Harding R, Higginson IJ. PRISMA: a pan-European co-ordinating action to advance the science in end-of-life cancer care. *Eur J Cancer.* (2010) 46:1493–501. doi: 10.1016/j.ejca.2010.01.035

18. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ.* (2021) 372:n71. doi: 10.1136/bmj.n71

19. Allen RS, Harris GM, Burgio LD, Azuero CB, Miller LA, Shin HJ, et al. Can senior volunteers deliver reminiscence and creative activity interventions? Results of the legacy intervention family enactment randomized controlled trial. *J Pain Symptom Manage.* (2014) 48:590–601. doi: 10.1016/j.jpainsymman.2013.11.012

20. Chen YS, Sun LY, Xiao H, Zheng J, Lin X. Evaluation of a WeChat-based dyadic life review program for people with advanced cancer and family caregivers: a mixed-method feasibility study. *Palliat Med.* (2022) 36:498–509. doi: 10.1177/02692163211066736

21. Dionne-Odom JN, Wells RD, Guastaferro K, Azuero A, Hendricks BA, Currie ER, et al. An early palliative care telehealth coaching intervention to enhance advanced cancer family caregivers' decision support skills: the CASCADE pilot factorial trial. *J Pain Symptom Manage.* (2022) 63:11–22. doi: 10.1016/j.jpainsymman.2021.07.023

22. DuBenske LL, Gustafson DH, Namkoong K, Hawkins RP, Atwood AK, Brown RL, et al. CHESS improves cancer caregivers' burden and mood: results of an eHealth RCT. *Health Psychol.* (2014) 33:1261–72. doi: 10.1037/a0034216

23. Grande GE, Austin L, Ewing G, O'Leary N, Roberts C. Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. *BMJ Support Palliat Care.* (2017) 7:326–34. doi: 10.1136/bmjspcare-2014-000829

24. Greene A, Aranda S, Tieman JJ, Fazekas B, Currow DC. Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: community facilitator pilot. *Palliat Med.* (2012) 26:917–23. doi: 10.1177/0269216311421834

25. Hanson LC, Green MA, Hayes M, Diehl SJ, Warnock S, Corbie-Smith G, et al. Circles of care: implementation and evaluation of support teams for African Americans with cancer. *Health Educ Behav.* (2014) 41:291–8. doi: 10.1177/1090198113512127

26. Henriksson A, Benzein E, Ternestedt BM, Andershed B. Meeting needs of family members of persons with life-threatening illness: a support group program during ongoing palliative care. *Palliat Support Care.* (2011) 9:263–71. doi: 10.1017/S1478951511000216

27. Jack BA, Kirton J, Birakurataki J, Merriman A. 'A bridge to the hospice': the impact of a Community Volunteer Programme in Uganda. *Palliat Med.* (2011) 25:706–15. doi: 10.1177/0269216310397566

28. Luker K, Cooke M, Dunn L, Lloyd-Williams M, Pilling M, Todd C. Development and evaluation of an intervention to support family caregivers of people with cancer to provide home-based care at the end of life: a feasibility study. *Eur J Oncol Nurs.* (2015) 19:154–61. doi: 10.1016/j.ejon.2014.09.006

29. Oliver DP, Washington KT, Benson J, White P, Oliver DC, Smith JB, et al. Facebook online support groups for hospice family caregivers of advanced cancer patients: protocol, facilitation skills and promising outcomes. *J Soc Work End Life Palliat Care.* (2022) 18:146–59. doi: 10.1080/15524256.2022.2046236

30. Pesut B, Duggleby W, Warner G, Fassbender K, Antifeau E, Hooper B, et al. Volunteer navigation partnerships: Piloting a compassionate community approach to early palliative care. *BMC Palliat Care.* (2017) 17:2. doi: 10.1186/s12904-017-0210-3

31. Ryan P, Howell V, Jones J, Hardy E. Lung cancer, caring for the caregivers. A qualitative study of providing pro-active social support targeted to the carers of patients with lung cancer. *Palliat Med.* (2008) 22:233–8. doi: 10.1177/0269216307087145

32. Steinhauser KE, Alexander SC, Byock IR, George LK, Tulsky JA. Seriously ill patients' discussions of preparation and life completion: an intervention to assist with transition at the end of life. *Palliat Support Care.* (2009) 7:393–404. doi: 10.1017/S147895150999040X

33. Walshe C, Dodd S, Hill M, Ockenden N, Payne S, Preston N, et al. How effective are volunteers at supporting people in their last year of life? A pragmatic randomised wait-list trial in palliative care (ELSA). *BMC Med.* (2016) 14:203. doi: 10.1186/s12916-016-0746-8

34. Wang Y, Liu M, Chi I. An evaluation of self-care and caregiving training curriculum content for Chinese immigrant caregivers: a participatory design approach. *J Appl Gerontol.* (2021) 40:1818–27. doi: 10.1177/0733464820987920

35. Williams AM, Eby JA, Crooks VA, Stajduhar K, Giesbrecht M, Vuksan M, et al. Canada's compassionate care benefit: is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? *BMC Public Health.* (2011) 11:335. doi: 10.1186/1471-2458-11-335

36. Witkowski A, Carlsson ME. Support group programme for relatives of terminally ill cancer patients. *Support Care Cancer.* (2004) 12:168–75. doi: 10.1007/s00520-003-0518-9

37. Librada-Flores S, Nabal-Vicuna M, Forero-Vega D, Munoz-Mayorga I, Guerra-Martin MD. Implementation models of compassionate communities andcompassionate cities at the end of life: a systematic review. *Int J Environ Res Public Health.* (2020) 17:6271. doi: 10.3390/ijerph17176271

38. O'Mara-Eves A, Brunton G, McDaid D, Oliver S, Kavanagh J, Jamal F, et al. Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. *Public Health Res.* (2013) 1. doi: 10.3310/phr01040

39. Ten Bruggencate T, Luijkx KG, Sturm J. To meet, to matter, and to have fun: the development, implementation, and evaluation of an intervention to fulfil the social needs of older people. *Int J Environ Res Public Health.* (2019) 16:2307. doi: 10.3390/ijerph16132307

40. Mehrabi F, Beland F. Effects of social isolation, loneliness and frailty on health outcomes and their possible mediators and moderators in community-dwelling older adults: a scoping review. *Arch Gerontol Geriatr.* (2020) 90:104119. doi: 10.1016/j.archger.2020.104119

41. Kellehear A. The end of death in late modernity: an emerging public health challenge. *Crit Public Health.* (2007) 17:71–9. doi: 10.1080/09581590601156365

42. Leonard R, Noonan K, Horsfall D, Kelly M, Rosenberg JP, Grindrod A, et al. Developing a death literacy index. *Death Stud.* (2022) 46:2110–22. doi: 10.1080/07481187.2021.1894268

43. Azeez A. Social capital and sustainable health care: an analysis of community based palliative care model of Kerala. *Ind J Sustain Dev.* (2015) 1. doi: 10.21863/ijsd/2015.1.1.001

44. Brunton G, Thomas J, O'Mara-Eves A, Jamal F, Oliver S, Kavanagh J. Narratives of community engagement: a systematic review-derived conceptual framework for public health interventions. *BMC Public Health.* (2017) 17:944. doi: 10.1186/s12889-017-4958-4

45. WHO. *WHO Community Engagement Framework for Quality, People-Centred and Resilient Health Services.* Geneva: WHO (2017).

46. Castleden H, Crooks VA, Schuurman N, Hanlon N. "It's not necessarily the distance on the map…": using place as an analytic tool to elucidate geographic issues central to rural palliative care. *Health Place Mar.* (2010) 16:284–90. doi: 10.1016/j.healthplace.2009.10.011

47. Howard M, Pfaff K, Sattler D, Dolovich L, Marshall D, Zwarenstein M, et al. Achieving holistic, quality-of-life focused care: description of a Compassion Care Community initiative in Canada. *Health Promot Int.* (2022) 37:daac067. doi: 10.1093/heapro/daac067

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Dignity promotion in people with advanced chronic diseases: contributions for a value-based healthcare practice

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1. Introduction

Since human dignity interpretations depend on culture and fluctuate over time, they are historically, politically, and culturally rooted. The term dignity comes from the Latin terms *dignitus*, which means competent, and *dignus*, which means derived worth (1). Even though the phrase "human dignity" has been used in several research, its definition remains unclear (2). A basic definition of human dignity is an individual's intrinsic value as a result of being human. The United Nations [(3), p. 1948] emphasizes that all human beings have inherent dignity: "All human beings are born free and equal in dignity and rights." Individuals develop a feeling of this value via their interactions with others (4). Human dignity has long been valued in all countries and faiths and serves as the cornerstone for human rights (5). Professional codes of conduct for healthcare workers promote care that safeguards patients' dignity and emphasizes that respect for others is a fundamental human right. At this point, the International Council of Nurses' (ICN) Code of Ethics [(6), p. 1] states "inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect."

According to some researchers, it is often simpler for practitioners to express undignified care than it is to define dignified care (7, 8). Illness trajectory, power imbalance, a loss of privacy, and being treated or hospitalized can all have an impact on human dignity. Human dignity violations can harm patients' bodies, spirits, morality, and spirituality, exposing them to stress and anguish (9). As we become older, we want to know that we will be loved and respected, that the person taking care of us is compassionate and understands that we are unique individuals with important lives. We seek attention. A growing number of patients are given life-limiting illnesses each year. Responsive care is ethically necessary since people with advanced diseases depend on others for their wellbeing. We determined that the foundation of what patients and their caregivers believe to be responsive care is the preservation and advancement of what Nordenfeldt (10) refers to as the "dignity of identity."

Human dignity is linked to the property of being human, and it is critical in health, medicine or healthcare systems (11). Chronic patients may be among the most vulnerable social groups, since they have not only lost physical capacities, but also face unique psychological, social, and economic demands as a result of their condition.

Healthcare practitioners must maintain open lines of contact with patients while also respecting their personal rights and professional principles such as human dignity, as well as being sensitive to existing disparities (12). Respect for patients' dignity is essential in their care and improves their quality of life. Furthermore, healthcare system-related characteristics such as patient-provider communication may promote drug adherence, as well as patient dignity (13). As a result, the researchers looked at the possible link between human dignity preservation and incentives to promote patient adherence to medical advice.

This essay discusses the value of dignity and personhood for those suffering from life-limiting illnesses such as advanced chronic diseases. Before discussing our theoretical framework for comprehending the contextual character of the dignity of identity, we first give background literature on the relational operations of dignity of identity. Increasing professionals' ethical awareness allows them to see the complexities of patient requirements and circumstances, from which possible ethical conflicts eventually arise, and address them. This is one way to empower professionals to behave as moral agents and provide patients with safe and ethical care. Amidst public interest in the tragic outcomes of the COVID-19 pandemic, this paper is a timely reminder of the relevance of ethical awareness of healthcare professionals and the need to foster human dignity as the last goal pursued by value-based health care.

2. Dignity in a historical perspective

No other notion has had as much resonance in the history of ethical philosophy as the concept of human dignity. However, defining the term has resulted in intense scholarly arguments in a variety of fields of moral reflection (14). We all know that the concept of human dignity is quite old and has its origins in classical culture. Cicero's *dignitas romana* mirrors a notion already known to Greek philosophy, however, the focus in these texts is mostly on the socio-political dimensions of personal activity within the society. The essence of a person's dignity is the dignity with which he builds and lives his life in society. Against this historical backdrop, Christianity examines another aspect of human dignity in-depth, offering a more specific anthropological viewpoint. A theological definition of human dignity must include a reference to the notion of the *imago Dei*.

Despite philosophical and disciplinary differences, researchers conceptualize dignity as dualistic (15), so there are essentially two approaches to dignity (16). One approach is to think of it as intrinsic and ontological, or as what some writers refer to as fundamental or absolute dignity. According to this perspective, dignity is an unchangeable aspect of personality that does not change or rely on the situation. Absolute dignity refers to principles such as human worth, freedom, responsibility, and helping others that are impossible to compromise. The second viewpoint speaks of what is referred to as dynamic or relative dignity, which is a characteristic of a person that is connected to how they view themselves and the environment in which they live, is impacted by culture, and has both rigid and flexible values. On the other hand, relative dignity derives from cultural factors in which individuals find themselves, such as educational level and social network (17, 18). In the absence of these cultural conditions, there is a risk of violation of dignity, so health professionals must be aware of the ethical principles, values and actions necessary for the maintenance/promotion of dignity. What dignity means in practice will depend on how patients see themselves and are perceived by others, as well as how the nature of the illness in question affects the person's life and identity. Nonetheless, dignity is generally thought to be a fundamentally intrinsic feature of the human individual (19).

Dignity is also a cultural concept, whose definition and maintenance is both social and culturally dictated (20). Individual attitudes, values, and perceptions shape an individual's norms and expectations about the maintenance of dignity (21). However, the term "dignity" intersects with other terms such as pride, self-respect, quality of life, wellbeing, hope, self-esteem, autonomy, respect, empowerment, and communication.

To advance thinking on the matter, a more responsive concept of dignity is required, one capable of capturing individual perspectives of personhood over time and in diverse settings. In this sense, the Ring Theory of Personhood (RToP) (22, 23) is widely used to evaluate current ideas on dignity. The RToP is composed of four concentric and interrelated rings: —the Innate, Individual, Relational, and Societal rings. A core feature of the RtoP is the fluid nature of interactions between the rings, which capture the dynamic/evolving nature of self-concepts of personhood (24). In order to construct domain-based identities, which in turn shape personal concepts of dignity, each ring incorporates particular beliefs, moral values, ethical principles, family mores, cultural norms, attitudes, thoughts, decisional preferences, duties, and obligations. Thus, giving primacy to a patient's personhood and dignity requires that professionals attend very carefully to the meaning of the illness.

2.1. Dignity in patients with advanced chronic diseases

Chronic diseases such as heart disease, cancer, and diabetes are major and universal public health problems. Poor health status, failing bodies, an increase in symptom burden, functional incapacity, and cognitive decline are all consequences of declining physical function brought on by chronic diseases (25, 26). Patients with chronic diseases spend more of their lives with limitations induced by the disease, have higher symptom severity (27, 28), and must cope with unexpected mortality. Even though everyone will eventually die, losing one's dignity does not only happen at the end of life (25). Many of these patients feel agitated and have limited control over their symptoms, especially in the later stages of the disease. As a result, the major objective of care for individuals is to increase their life expectancy. As a result, palliative care is crucial for these patients, and one of the fundamental components of this palliative care is respect for dignity and human rights, regardless of nationality, ethnicity, religion, color, age, gender, disabilities, or socio-political circumstances. There is increasing research on dignity using several instruments, particularly the Patient Dignity Inventory, a rigorous tool that has been translated into many languages (29). Identifying and enhancing the patient's dignity can boost their confidence and contentment with treatment, enhance care, minimize hospitalization length, and improve patient outcomes. In contrast, the loss of a patient's dignity can have a negative impact on the patient's physical and mental health (30).

Dignity-conserving care offers an approach that clinicians can use to explicitly target the maintenance of dignity as a therapeutic objective and as a principle of bedside care for patients nearing death (31). In the challenge launched by this author, current Medicine must dedicate itself to a culture of caring (to advance a culture of caring). In clinical practice, dignity must be the value, not a value, capable of overestimating personhood (relating to the person, personality) over the so usual and undignified patient hood (relating to the strict condition of being sick, to the disease) (32). For this author, clinical practice should focus on the sick person and not on the person's diseases, following the care philosophy of Cicely Saunders of making the disease peripheral to the person. If the patient's dignity is not upheld, needless and maybe excruciating suffering will befall them (33). In this sense, the caregiver has an ethical obligation to ensure that the patient is treated as a friend and fellow human being when they come into contact. According to Lévinas responsibility ethics entails that one is not free in relation to the other and that the ethical need has an endless scope (33).

Harvey Chochinov, promoter of the concept of the tonality of care (care tenor), developed the mnemonic A, B, C, and D of Conservative Care of Dignity (34) in analogy to the A, B, C of cardio-respiratory resuscitation (A-airway, B- breathing, and C-circulation). In this work, the author postulates that all health professionals dedicated to the holistic care of the person and their dignity must develop specific skills that can be listed through the simple mnemonic A (Attitude); B (Behavior); C (Compassion), and D (Dialogue). This entails being sensitive to and respecting the presented concerns, aspirations, and goals (35, 36). Individualized care, restoration of control, respect, advocacy, and careful listening are all required for dignity in care. Other variables that support dignity include a caring culture, staff attitudes and behavior, and the performance of specialized care tasks (15). Along with more tangible and precise care acts, perceptiveness, openness, listening, and respect are elements of a complete approach to dignity-conserving care for patients (35). As a result, enhancing one's sense of self involves conserving it or regaining it, sustaining one's identity, and ensuring and maintaining one's self-esteem. Self-responsibility, participation in decision-making regarding their own treatments and care, attention to patient rights (37), and cultivating a pedagogical climate of mutual understanding all supported the autonomy of people with chronic progressive disease.

Health professionals also play a crucial role in lowering stigma views and helping people manage stigma, which helps them get support by protecting them from shame. Health professionals must reassure patients that their inner sense of self is unaffected by their illness and that they will always be the same person in order to provide them with a feeling of continuity in their identity. Improvements in patients' self-esteem, a deeper understanding of their purpose and meaning in life, maintaining and improving their quality of life, and providing relief from multifaceted distress through the interaction between patients and nurses are all necessary outcomes of dignity-centered care (25). Recognizing these dynamics helps understand how patients retain their dignity when facing changes and losses, and can help deliver proactive and dignity-sustaining care to lead patients through the illness's trajectory (38). Indeed, some factors should be addressed to uphold a person's dignity (Table 1).

TABLE 1 Core principles to support dignity in patient care.

Throughout every stage of human existence, value and accept each person as a unique individual "being seen and being heard" (39).
Safeguard and respect each individual's right to self-determination as a fundamental human right (39).
Protect and promote patient autonomy by respecting their needs, preferences, alternatives, beliefs/values, privacy, and advocating against stigma (25, 40).
Acknowledge and guarantee that the rights and best interests of the incapacitated are central to all decision-making processes pertaining to their care and welfare. Open communication, patient engagement in developing care plans, and shared decision-making can minimize many ethical conundrums, especially in end-of-life care (41).
In the quest for more dignified treatment, provide knowledgeable, empathetic, compassionate, and non-possessive care (40).
To avoid undignified treatment, promote advanced care planning by people with chronic progressive diseases (25).

The challenge is therefore to combine the importance of obtaining the best clinical results with the need to satisfy the specific expectations of each individual, simultaneously ensuring that the necessary resources are organized and used, and the costs involved are managed, as far as that is strictly necessary. The concept of value in health care allows for greater involvement and accountability of all stakeholders, from health systems and organizations to professionals and citizens themselves, who thus contribute, in synergy and actively, to improving the health of each person and optimize the functioning of health systems (42).

3. Final remarks

Although present in several codes of conduct and standards for patient care, dignity is still a contentious idea that is hard to define, quantify, and apply to the field of healthcare. Dignity is a value-based and humanistic concept that emerged within the field of ethics, associated with the main attributes of personhood (intrinsic), sociability (relational/behavioral), respect, and autonomy. RToP allows healthcare professionals to determine which of the Innate, Individual, Relational, and Societal rings dominate thinking and need greater attention at a particular moment and context. Developing ethical awareness can empower professionals to act as moral agents in providing patients with safe and ethical care. An ethical awareness knows no enemies, no strangers. It represents an integrating and regulating principle that can establish relationships between particular issues and the universalist and formal claim, without the intention of becoming, itself, absolute. In fact, it could not feed this absolutist claim since, as an integrating principle, its validity is restricted to the attempt to interpret transcendental moral expectations for the context of individuals, on whose agreement, ultimately, it will depend. This ethical consciousness is a dialectical process of the reflected balance between the places (physical environment and organizational culture), the people (the attitudes and behavior of professionals and others), and the processes (care activities) which are crucial to foster value-based healthcare practices.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Matiti M, Bailey L. *Dignity in Healthcare A Practical Approach for Nurses and Midwives*. London: Routledge (2020).

2. Borhani F, Abbaszadeh A, Rabori R. New vision for the dignity: understanding the meaning of patient dignity in Iran. *Br J Med Med Res.* (2015) 9:1–11. doi: 10.9734/BJMMR/2015/18886

3. United Nations. *Universal Declaration of Human Rights*. Now York, NY: United Nations (2015).

4. van Gennip I, Pasman H, Oosterveld-Vlug M, Willems DL, Onwuteaka-Philipsen BD. The development of a model of dignity in illness based on qualitative interviews with seriously ill patients. *Int J Nurs Stud.* (2013) 50:1080–9. doi: 10.1016/j.ijnurstu.2012.12.014

5. Borhani F, Abbaszadeh A, Rabori RM. Facilitators and threats to the patient dignity in hospitalized patients with heart diseases: a qualitative study. *Int J Community Based Nurs Midwifery.* (2016) 4:36–46.

6. International Council of Nurses. *The ICN Code of Ethics for Nurses.* (2012). Available online at: https://www.icn.ch/sites/default/files/inline-files/ICN_Code-of-Ethics_EN_Web.pdf (accessed September 4, 2022).

7. Barclay L. In sickness and in dignity: a philosophical account of the meaning of dignity in health care. *Int J Nurs Stud.* (2016) 61:136–41. doi: 10.1016/j.ijnurstu.2016.06.010

8. Ostaszkiewicz J, Dickson-Swift V, Hutchinson A, Wagg A. A concept analysis of dignity-protective continence care for care dependent older people in long-term care settings. *BMC Geriatr.* (2020) 20:266. doi: 10.1186/s12877-020-01673-x

9. Peičius E, Urbonas G, Harrison WD, Urboniene A, Kuznecoviene J, Butkevičiene R, et al. Dignity violations and barriers to dignity assurance for terminally ill patients at the end of life: a cross-sectional analysis. *Medicina.* (2022) 58:294. doi: 10.3390/medicina58020294

10. Nordenfelt L. The varieties of dignity. Health care analysis. *J Health Philos Policy.* (2004) 12:69–89. doi: 10.1023/B10.1023/B:HCAN.0000041183.78435.4b

11. Winter SF, Winter SF. Human dignity as leading principle in public health ethics: a multi-case analysis of 21st century german health policy decisions. *Int J Health Policy Manag.* (2018) 7:210–24. doi: 10.15171/ijhpm.2017.67

12. Zirak M, Ghafourifard M, Aliafsari Mamaghani E. Patients' dignity and its relationship with contextual variables: a cross-sectional study. *J Caring Sci.* (2017) 6:49–51. doi: 10.15171/jcs.2017.006

13. Fahlberg B. Promoting patient dignity in nursing care. *Nursing.* (2014) 44:14. doi: 10.1097/01.NURSE.0000450788.72731.82

14. Galvin K, Todres L. Dignity as honour-wound: an experiential and relational view. *J Eval Clin Pract.* (2015) 21:410–8. doi: 10.1111/jep.12278

15. Stephen Ekpenyong M, Nyashanu M, Ossey-Nweze C, Serrant L. Exploring the perceptions of dignity among patients and nurses in hospital and community settings: an integrative review. *J Res Nurs.* (2021) 26:517–37. doi: 10.1177/1744987121997890

16. Rodríguez-Prat A, Monforte-Royo C, Porta-Sales J, Escribano X, Balaguer A. Patient perspectives of dignity, autonomy and control at the end of life: systematic review and meta-ethnography. *PLoS ONE.* (2016) 11:e0151435. doi: 10.1371/journal.pone.0151435

17. Choo P, Tan-Ho G, Dutta O, Patinadan P, Ho A. Reciprocal dynamics of dignity in end-of-life care: a multiperspective systematic review of qualitative and 168 mixed methods research. *Am J Hosp Palliat Care.* (2020) 37:385–98. doi: 10.1177/1049909119878860

18. Franco H, Caldeira S, Nunes L. Dignity in nursing: a synthesis review of concept analysis studies. *Nurs Ethics.* (2021) 28:734–49. doi: 10.1177/0969733020961822

19. Sulmasy DP. The varieties of human dignity: a logical and conceptual analysis. *Med Health Care Philos.* (2013) 16:937–44. doi: 10.1007/s11019-012-9400-1

20. Dakessian Sailian S, Salifu Y, Saad R, Preston N. Dignity of patients with palliative needs in the Middle East: an integrative review. *BMC Palliat Care.* (2021) 20:112. doi: 10.1186/s12904-021-00791-6

21. Bagheri H, Yaghmaei F, Ashktorab T, Zayeri F. Test of a Dignity Model in patients with heart failure. *Nurs Ethics.* (2018) 25:532–46. doi: 10.1177/0969733016658793

22. Chan NPX, Chia JL, Ho CY, Ngiam LXL, Kuek JTY, Ahmad Kamal NHB, et al. Extending the ring theory of personhood to the care of dying patients in intensive care units. *Asian Bioeth Rev.* (2021) 14:71–86. doi: 10.1007/s41649-021-00192-0

23. Radha Krishna LK, Alsuwaigh R. Understanding the fluid nature of personhood - the ring theory of personhood. *Bioethics.* (2015) 29:171–81. doi: 10.1111/bioe.12085

24. Chua KZY, Quah ELY, Lim YX, Goh CK, Lim J, Wan DWJ, et al. A systematic scoping review on patients' perceptions of dignity. *BMC Palliat Care.* (2022) 21:118. doi: 10.1186/s12904-022-01004-4

25. Igai Y. Concept analysis of dignity-centered care for people with chronic progressive disease. *Jpn J Nurs Sci.* (2020) 17:e12302. doi: 10.1111/jjns.12302

26. Holmberg B, Godskesen T. Dignity in bodily care at the end of life in a nursing home: an ethnographic study. *BMC Geriatr.* (2022) 22:593. doi: 10.1186/s12877-022-03244-8

27. Xu J, Nolan M, Heinze K, Yenokyan G, Hughes M, Johnson J, et al. Symptom frequency, severity, and quality of life among persons with three disease trajectories: cancer, ALS, and CHF. *Appl Nurs Res.* (2015) 28:311–5. doi: 10.1016/j.apnr.2015.03.005

28. Laranjeira C, Dourado M. "Dignity as a small candle flame that doesn't go out!": An interpretative phenomenological study with patients living with advanced chronic obstructive pulmonary disease. *Int J Environ Res Public Health.* (2022) 19:17029. doi: 10.3390/ijerph192417029

29. Bagnasco A, Zanini M, Dasso N, Rossi S, Timmins F, Galanti M, et al. Dignity, privacy, respect and choice-a scoping review of measurement of these concepts within acute healthcare practice. *J Clin Nurs.* (2020) 29:1832–57. doi: 10.1111/jocn.15245

30. Fuseini AG, Rawson H, Ley L, Kerr D. Patient dignity and dignified care: a qualitative description of hospitalised older adults perspectives. *J Clin Nurs*. (2022) 2022:16286. doi: 10.1111/jocn.16286

31. Chochinov HM. Dignity-conserving care–a new model for palliative care: helping the patient feel valued. *JAMA*. (2002) 287:2253–60. doi: 10.1001/jama.287.17.2253

32. Chochinov HM. Dignity in care: time to take action. *J Pain Symptom Manage.* (2013) 46:756–9. doi: 10.1016/j.jpainsymman.2013.08.004

33. Lindwall L, Lohne V. Human dignity research in clinical practice—a systematic literature review. *Scand J Caring Sci.* (2021) 35:1038–49. doi: 10.1111/scs.12922

34. Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *Br Med J.* (2007) 335:184–7. doi: 10.1136/bmj.39244.650926.47

35. Harstäde CW, Blomberg K, Benzein E, Östlund U. Dignity-conserving care actions in palliative care: an integrative review of Swedish research. *Scand J Caring Sci.* (2018) 32:8–23. doi: 10.1111/scs.12433

36. Sandsdalen T, Hov R, Hoye S, Rystedt I, Wilde-Larsson B. Patients' preferences in palliative care: a systematic mixed studies review. *Palliat Med.* (2015) 29:399–419. doi: 10.1177/0269216314557882

37. Karami-Tanha F, Moradi-Lakeh M, Fallah-Abadi H, Nojomi M. Health system responsiveness for care of patients with heart failure: evidence from a university hospital. *Arch Iran Med.* (2014) 17:736–40.

38. van Gennip IE, Pasman HR, Oosterveld-Vlug MG, Willems DL, Onwuteaka-Philipsen BD. Dynamics in the sense of dignity over the course of illness: a longitudinal study into the perspectives of seriously ill patients. *Int J Nurs Stud.* (2015) 52:1694–704. doi: 10.1016/j.ijnurstu.2015.06.010

39. Clancy A, Simonsen N, Lind J, Liveng A, Johannessen A. The meaning of dignity for older adults: a meta-synthesis. *Nurs Ethics.* (2021) 28:878–94. doi: 10.1177/0969733020928134

40. Dutra PE, Quagliato LA, Nardi AE. Improving the perception of respect for and the dignity of inpatients: a systematic review. *Br Med J Open.* (2022) 12:e059129. doi: 10.1136/bmjopen-2021-059129

41. Akdeniz M, Yardimci B, Kavukcu E. Ethical considerations at the end-of-life care. *SAGE Open Med*. (2021) 9:20503121211000918. doi: 10.1177/20503121211000918

42. Teisberg E, Wallace S, O'Hara S. Defining and implementing value-based health care: a strategic framework. *Acad Med.* (2020) 95:682–5. doi: 10.1097/ACM.0000000000003122

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Effects of ozone therapy on anxiety and depression in patients with refractory symptoms of severe diseases: a pilot study

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Background: Patients with refractory symptoms of severe diseases frequently experience anxiety, depression, and an altered health-related quality of life (HRQOL). Some publications have described the beneficial effect of ozone therapy on several symptoms of this kind of patient. The aim of this study was to preliminarily evaluate, in patients treated because of refractory symptoms of cancer treatment and advanced nononcologic diseases, if ozone therapy has an additional impact on self-reported anxiety and depression.

Methods: Before and after ozone treatment, we assessed (i) anxiety and depression according to the Hospital Anxiety and Depression Scale (HADS); (ii) the HRQOL (according to the EQ-5D-5L questionnaire), which includes a dimension on anxiety and depression and a visual analog scale (VAS) measuring self-perceived general health.

Results: Before ozone therapy, 56% of patients were on anxiolytic and/or antidepressant treatment. Before and after ozone therapy, the anxiety and depression HADS subscales (i) significantly correlated with the anxiety/depression dimension of the EQ-5D-5L questionnaire and (ii) inversely correlated with the health status as measured by the VAS. After ozone therapy, we found a significant improvement in anxiety and depression measured by both the (i) HADS subscales and (ii) EQ-5D-5L questionnaire.

Conclusion: The addition of ozone therapy for patients with refractory symptoms of cancer treatment and advanced chronic nononcologic diseases can decrease anxiety and depression severity levels. Additional, more focused studies are ongoing to provide the needed explanatory information for this finding.

KEYWORDS

ozone therapy, anxiety and depression, health-related quality of life, advanced diseases, chemotherapy-induced side effects, radiation-induced side effects, cancer survivors, chemotherapy-induced neuropathy

1. Introduction

Patients with refractory symptoms of cancer treatment and advanced nononcologic diseases frequently experience anxiety, depression, and an altered health-related quality of life (HRQOL). Fortunately, the improvements in diagnostics and treatments over the last decades have increased survival rates in patients with cancer or advanced chronic diseases. In the European Union (EU), the relative average number of cancer survivors was more than 50% within 5 years of diagnosis during 2000–2007 in both sexes (European Commission, 2000) and the prevalence of depression is approximately 20% in cancer survivors (Boyes et al., 2013). In addition, the general population frequently reports chronic anxiety and depression (7.2%) (European Commission, 2023), with increased levels in patients with advanced chronic disease (DeJean et al., 2013; Li et al., 2019) or cancer (Greer et al., 2011; Gotze et al., 2020; Ji et al., 2020). However, in these patients, anxiety and depression can be associated with an increased risk of all-cause mortality (Lloyd et al., 2019), which relevantly impacts the results of symptom management and their HRQOL.

Anxiety and depression are associated with higher levels of oxidative stress markers and pro-inflammatory cytokines as well as with decreased levels of antioxidants (Ng et al., 2008; Maes et al., 2011; Leonard and Maes, 2012; Lindqvist et al., 2017). Furthermore, the success of antidepressant treatment is associated with changes in those parameters over the course of treatment (Lindqvist et al., 2017). Interestingly, most of the scientific reports about ozone and anxiety and depression have been focused on "ozone inhalation" to induce oxidative stress as a mechanism of production of anxiety and depression (Gonzalez-Pina and Paz, 1997; Avila-Costa et al., 1999; Santiago-Lopez et al., 2010; Mokoena et al., 2015).

However, (i) medical ozone treatment (O_3T) must specifically avoid the inhalation of ozone, and (ii) an appropriate ozone concentration and route of administration look for the induction of a controlled, limited and transient oxidative stress that can overregulate nuclear factor erythroid 2-related factor 2 (Nrf2), which is the key for a further enhancement of the antioxidant defenses in the body with further and favorable modulation of oxidative stress and inflammation (Re et al., 2014; Bocci and Valacchi, 2015; Galie et al., 2019; Viebahn-Haensler and Leon Fernandez, 2021).

In cancer survivors with refractory symptoms, adjuvant O_3T can reduce several chronic symptoms such as ischemic and metabolic issues (Clavo et al., 2011), pelvic pain (Clavo et al., 2021), radiation-induced hematuria (Clavo et al., 2005) or hemorrhagic proctitis (Clavo et al., 2013, 2015), chemotherapy-induced peripheral neuropathy (Clavo et al., 2022), and lymphedema (Waked et al., 2013).

In a recent study of cancer survivors with chronic symptoms, we found that O_3T could decrease the grade of toxicity secondary to cancer treatments as well as improve HRQOL using the EQ-5D-5L questionnaire, which includes an anxiety/depression dimension that also showed improvement after O_3T (Clavo et al., 2023). However, the EQ-5D-5L questionnaire assesses anxiety and depression with only one question and it seemed justified the evaluation with a specific questionnaire focused on anxiety and depression.

The aim of this study was to assess (in patients treated because of refractory symptoms of severe diseases) if O_3T has an additional impact on self-reported anxiety and depression using a specifically focused questionnaire: the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).

2. Materials and methods

2.1. Patients

This is a retrospective case series of 16 patients submitted to our Chronic Pain Unit between November 2019 and October 2022, with these inclusion criteria: (i) they were treated with O_3T because of chronic and refractory symptoms of severe diseases and (ii) they had completed HADS questionnaires before and after O_3T. They were 13 cancer survivors with chronic side effects of cancer treatment (8 because of chemotherapy-induced peripheral neuropathy and 5 because of local toxicity induced by radiochemotherapy) and 3 noncancer patients with chronic symptoms of advanced diseases (because of cardiopathy, cerebellar syndrome, and post-COVID-19 syndrome). Informed written consent was obtained from all patients, according to the Declaration of Helsinki of 1975. The administration of O_3T in our hospital was assessed by the Health Care Ethics Committee. This research study was approved by the Provincial Research Ethics Committee of Las Palmas, Spain (Ref 2019–288-1) on 2 December 2022. Table 1 shows patient's clinical characteristics.

2.2. Ozone therapy

O_3T was administered on an outpatient basis, always avoiding the inhalation of ozone by patients or by staff. Ozone (an O_3/O_2 mixture) was obtained from clinical-grade oxygen using two medical ozone generators (Ozonosan Alpha-plus®, Dr. Hänsler GmbH, Iffezheim, Germany; Ozonobaric P®, Sedecal, Madrid, Spain).

TABLE 1 Patient's clinical characteristics.

#	Age, years	Sex	O3T	Anxio. Tx	Depre. Tx	Clinical characteristics
1	73	F	S	Yes	No	Uterine carcinoma: Surg. + CT + RT. O_3T for CIPN. Tx: Bromazepam, Pregabalin
2	56	M	S	Yes	No	Ischemic cardiopathy grade III. O_3T for physical fatigue. Tx: Diazepam
3	54	M	L*	No	No	Rectal Kaposi's sarcoma: Surg. + CT + RT. O_3T for wound dehiscence.
4	72	M	S	Yes	No	Unknown cerebellar syndrome. O_3T for instability and movement disturbances. Tx: Clonazepam, Pregabalin
5	67	F	S + L	No	No	Uterine cervical carcinoma: RT + CT. O_3T for radiation-induced hematuria.
6	45	F	S	No	No	Ovarian carcinoma + uterine carcinoma: Surg. + RT. O_3T for CIPN.
7	69	M	S	No	No	Head and neck carcinoma + cutaneous melanoma: Surg. + CT. O_3T for CIPN.
8	65	F	S + L	No	No	Relapsed vaginal carcinoma: RT + CT. O_3T for vulvar and vaginal wounds.
9	62	M	S	Yes	Yes	Colon carcinoma: Surg. + CT. O_3T for CIPN. Tx: Alprazolam
10	53	F	S	Yes	Yes	Non-Hodgkin lymphoma: Surg. + RT + CT. O_3T for CIPN. Tx: Pregabalin, Amitriptyline, Citalopram
11	53	F	L*	Yes	Yes	Relapsed carcinoma of uterine cervix and vagina: RT + CT. O_3T for vulvar and vaginal wounds. Tx: Pregabalin, Duloxetine
12	71	M	S	No	Yes	Pancoast carcinoma of the lung: CT + RT. O_3T for CIPN + refractory post-herpetic neuralgia. Tx: Duloxetine
13	68	M	S	No	No	Pancoast carcinoma of the lung: CT + RT. O_3T for CIPN.
14	76	F	S	Yes	No	Uterine carcinosarcoma: Surg. + CT + RT. O_3T for CIPN. Tx: Alprazolam
15	69	F	L*	Yes	Yes	Rectum carcinoma: Surg. + CT + RT. O_3T for wound dehiscence. Tx: Clonazepam, Venlafaxine
16	49	M	S	No	No	COVID-19 disease: Prolonged hospital stay. O_3T for secondary polyneuropathy.

#: Patients. O_3T, ozone therapy; S, systemic ozone therapy; L, local ozone therapy; S+ L, systemic and local ozone therapy; Tx, treatment; Anxio. Tx, anxiolytic treatment; Depre. Tx., antidepressant treatment; CIPN, chemotherapy-induced peripheral neuropathy. All symptoms treated with ozone therapy were chronic and refractory symptoms. Surg., surgery; CT, chemotherapy; RT, radiotherapy. * "Local ozone administration alone" was used only for superficial wounds or wound dehiscences with localized symptoms.

O_3T was administered according to the symptoms of the patients. A total of 13 patients (81%) received systemic ozone treatment, 11 by rectal insufflation (1 with additional topical treatment), and 2 by autohemotherapy (1 with additional local treatment). Five patients (31%) received local O_3T, three (19%) as an exclusive procedure, and two with additional systemic treatment. We have previously described the procedures followed for rectal insufflation (Clavo et al., 2013) and autohemotherapy (Clavo et al., 2013); the O_3/O_2 concentrations were progressively increased from 10 to 30 μg/mL and from 30 to 50 μg/mL, respectively. For topical administration, O_3/O_2 concentrations usually ranged between 10 and 40 μg/mL according to patient tolerance or based on the absence or presence of local infection. In cancer survivors, O_3T was administered if evidence of tumor progression was lacking.

2.3. Anxiety and depression assessment

The aim of this study was the assessment of anxiety and depression using the Spanish version of the HADS (Zigmond and Snaith, 1983; Herrero et al., 2003; Quintana et al., 2003; Mitchell et al., 2010). The HADS questionnaire includes 14 questions, which can be scored from 0 (best) to 3 (worst). It includes seven questions assessing for anxiety (HADS-A) and seven questions assessing for depression (HADS-D). The maximum score for each subscale is 21: 0–7, normal; 8–10, mild; 11–15, moderate; 16–21, severe.

We also assessed the HRQOL with the Spanish version (v1.0, 2009) of the EQ-5D-5L questionnaire. Their cultural adaptation was carried out following the methodology recommended by the EuroQol Group (Rabin et al., 2014), and its validity for Spain and the United Kingdom has been demonstrated in different studies (Herdman et al., 2011; Hernandez et al., 2018; Ramos-Goni et al., 2018). The EQ-5D-5L assesses five different dimensions scored from 1 ("I have no problems") to 5 ("I have a lot of problems"): (i) mobility, (ii) self-care, (iii) activities of daily living, (iv) pain and discomfort, and (v) anxiety/depression. The EQ-5D-5L also includes a visual analog scale (VAS) measuring self-perceived general health status (EQ VAS), scored from "0" (worst health status) to "100" (best health status).

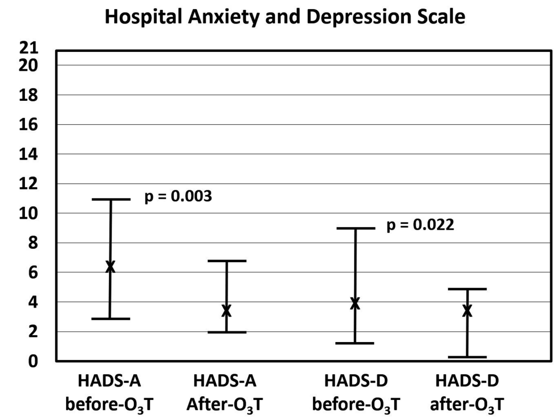

FIGURE 1
Hospital anxiety and depression scale (HADS). After ozone therapy (O_3T), we found a significant decrease in: (i) HADS-Anxiety (HADS-A) from 6.5 (Q1–Q3 = 3–10.8) to 3.5 (Q1-Q = 2–6.8), p = 0.003 and (ii) HADS-Depression (HADS-D) from 4 (Q1–Q3 = 1.3–9) to 3.5 (Q1–Q3 = 0.3–5) after O3T (p = 0.022). X: median value. Bars: interquartile range.

2.4. Statistical analysis

The SPSS software package (version 15 for Windows) was used for statistical analyses. All data are described as median (quartile 2) and quartiles 1 and 3 (Q1–Q3). The correlation between the grade of toxicity and EQ-5D-5L dimensions was assessed with Spearman's rho. Paired comparisons (before/after O_3T) were conducted with the exact (significance) Wilcoxon rank test. Unpaired comparisons (before/after O_3T) were conducted with the exact (significance) Mann–Whitney *U*-test. Qualitative variables were compared with the exact (significance) McNemar's test. Though more conservative than asymptotic tests, exact tests were used due to the small sample size. *p*-values of <0.05 were considered statistically significant.

3. Results

The sex distribution included eight men and eight women. The median age was 66 years (Q1–Q3 = 53.3–70.5). Symptoms treated with O_3T were previously present for a median of 14.5 months (Q1–Q3 = 8.3–20). Overall, the median number of systemic O_3T sessions was 40 (Q1–Q3 = 40–40), and the number of local O_3T sessions was 40 (Q1–Q3 = 25–61.5). The median duration of O_3T was 20 weeks (Q1–Q3 = 17–25).

Before the commencement of O_3T, nine patients (56%) were taking anxiolytics (eight patients) or antidepressants (five patients), with four patients taking both therapies. Patients were treated with O_3T because of chronic and refractory symptoms and treatment for anxiety and depression was not prescribed nor modified in our Chronic Pain Unit during O_3T.

Anxiety assessed by the HADS-A did not show significant differences between the patients without or with anxiolytic treatment (i) before O_3T, 4.5 (Q1–Q3 = 3–9.5) vs. 9.5 (Q1–Q3 = 6–13), $p = 0.207$ or (ii) after O_3T, 2.5 (Q1–Q3 = 1.8–4.5) vs. O_3T, 7 (Q1–Q3 = 1.5–10.3), $p = 0.204$. Depression assessed by HADS-D did not show significant differences between the patients without or with antidepressant treatment: (i) before O_3T, 3 (Q1–Q3 = 0.8–9.3) vs. 5 (Q1–Q3 = 2.5–9), $p = 0.688$ or (ii) after O_3T, 3 (Q1–Q3 = 0.8–5.3) vs. O_3T, 4 (Q1–Q3 = 0–6.3), $p = 0.826$.

Overall, the median HADS-A score was 6.5 (Q1–Q3 = 3–10.8) before O_3T and 3.5 (Q1-Q = 2–6.8) after O_3T ($p = 0.003$). The median HADS-D was 4 (Q1–Q3 = 1.3–9) before O_3T and 3.5 (Q1–Q3 = 0.3–5) after O_3T ($p = 0.022$) (Figure 1). In the group of 13 cancer patients: (i) the median HADS-A was 5 (Q1–Q3: 3–10.5) before O_3T and 3 (Q1–Q3: 1.6–6.5) after O_3T ($p = 0.016$); and (ii) the median HADS-D was 4 (Q1–Q3: 1–9) before O_3T and 3 (Q1–Q3: 0–4.5) after O_3T ($p = 0.070$).

The HADS-A results showed mild or higher anxiety levels (values ≥8) in eight (50%) patients before O_3T and in three (18.8%) patients after O_3T, ($p = 0.063$). The HADS-D results showed mild or higher depression levels in six patients (38%) before O_3T and two patients (13%) after O_3T ($p = 0.125$).

After O_3T, the EQ-5D-5L questionnaire showed: *(i) a significant improvement (decreased values) in the anxiety/depression dimension, from a median value of 1.5 (Q1–Q3: 1–3) to 1 (Q1–Q3: 1–2), $p = 0.047$; and (ii) a significant improvement (increased values) in the EQ VAS, from a median value of 52.5 (Q1–Q3: 43–78) to 75 (Q1–Q3: 60–90), $p = 0.015$ (Figure 2). In the group of 13 cancer patients, the EQ-5D-5L questionnaire showed changes in: the anxiety/depression dimension from a median value of 1 (Q1–Q3: 1–3) to 1 (Q1–Q3: 1–2), $p = 0.188$; and (ii) the EQ VAS, from a median value of 65 (Q1–Q3: 45–87.5) to 75 (Q1–Q3: 62.5–90), $p = 0.033$.

Before O_3T, the HADS-A results showed a strong correlation with the anxiety/depression dimension of the EQ-5D-5L questionnaire (rho = 0.866, $p < 0.001$) and an inverse correlation with the EQ VAS (rho = −0.554, $p = 0.026$). Additionally, the HADS-D subscale results significantly correlated with age (rho = 0.521, $p = 0.039$) and the anxiety/depression dimension of the EQ-5D-5L (rho = 0.852, $p < 0.001$), and inversely with the EQ VAS (rho = −0.644, $p = 0.007$).

After O_3T, the HADS-A results correlated with the anxiety/depression dimension of the EQ-5D-5L questionnaire (rho = 0.874, $p < 0.001$) and inversely with the EQ VAS (rho = −0.627, $p = 0.009$). The HADS-D results correlated with the anxiety/depression dimensions of the EQ-5D-5L (rho = 0.673, $p = 0.004$), and inversely with the EQ VAS (rho = −0.812, $p < 0.001$).

Table 2 shows a summary of the main results of the study group.

4. Discussion

Anxiety and depression are frequent disorders experienced by patients with severe disease, especially in those with chronic or refractory symptoms, producing a relevant impact on their HRQOL. In our study, adjuvant treatment with O_3T of chronic and refractory symptoms in cancer survivors and patients with advanced diseases was associated with improvement in anxiety and depression, assessed by the specific HADS subscales.

In a recent study, we found that O_3T could improve HRQOL using the EQ-5D-5L questionnaire (Clavo et al., 2023). However, the EQ-5D-5L questionnaire assesses the anxiety/depression dimension with only one question and it seemed justified to evaluate this dimension with a specific questionnaire focused on anxiety and depression. We used the Spanish version of the HADS, which is frequently used in our Chronic Pain Unit. In patients with different diagnoses, the Spanish HADS version has showed: (i) high test–retest reliability, with correlation coefficients above 0.85; (ii) high internal consistency, with a Cronbach's alpha of 0.85 for anxiety and above 0.84 for depression; and (iii) high concurrent validity, with the Beck Depression Inventory and State–Trait Anxiety Inventory and with the mental domains of the Short-Form Health Survey (Herrero et al., 2003; Quintana et al., 2003).

The prevalence of depression is approximately 20% in cancer survivors, although the prevalence of self-reported depression using the HADS-D subscale seems to be lower, at approximately 13% (Boyes et al., 2013). We previously described that 34.9% of patients submitted to our Chronic Pain Unit had been prescribed anxiolytic or antidepressants treatment. Of them, 24.2% were on anxiolytics only, 40.2% were on antidepressants only, and 35.5% were on both treatments. In that review, no patient had an antidepressant prescription for pain management (usually duloxetine or amitriptyline) (Caramés et al., 2021). In our study group, before O_3T, nine patients (56%) were on anxiolytic (38%) or antidepressant (38%) treatment, and three (19%) were on treatment for both disorders.

The treatment of anxiety and depression in cancer survivors and in patients with refractory symptoms of advanced diseases is similar to that of different patient populations, including pharmacologic treatment and cognitive behavioral therapy. However, the patient fears the formal diagnosis of anxiety and depression due to the social stigma surrounding mental illness. So, patients are hesitant to express a desire for psychiatric evaluation and consider that treatment is not essential or a priority (Kim et al., 2015). As such, in the EU, most patients reported neither provider discussions nor the use of professional psychosocial counseling or support groups (Forsythe et al., 2013). Additionally, anxiety and depression were not fully controlled in our

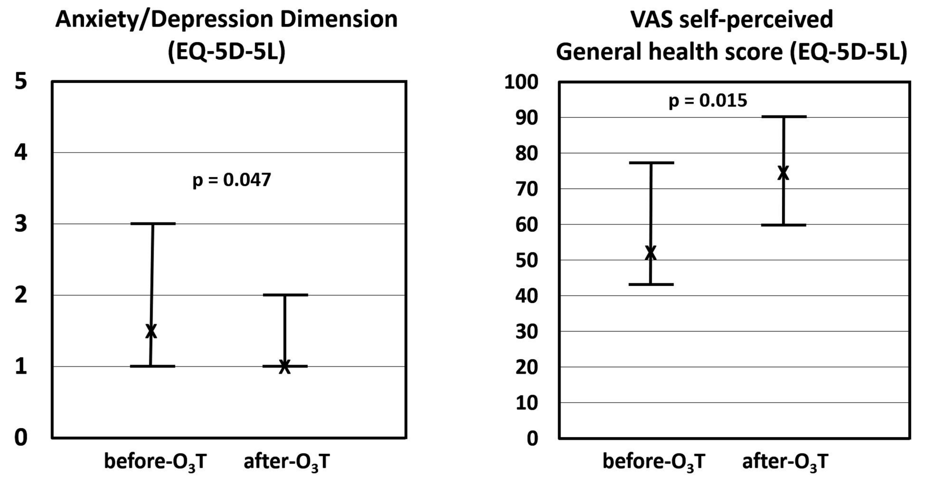

FIGURE 2
Assessment with the EQ-5D-5L questionnaire. (Left) Results on the anxiety/depression dimensions of the EQ-5D-5L significantly decreased after ozone therapy (O_3T) from 1.5 (Q1–Q3: 1–3) to 1 (Q1–Q3: 1–2), $p = 0.047$. (Right) Visual analog scale results of self-perceived general health score significantly increased after O_3T from 52.5 (Q1–Q3: 43–78) to 75 (Q1–Q3: 60–90), $p = 0.015$. X: median value. Bars: interquartile range.

TABLE 2 Summary of the main results of the study group.

	Before-O_3T median (Q1–Q3)	After-O_3T median (Q1–Q3)	*p*-value
HADS-A (from 0 to 21)	6.5 (3–10.8)	3.5 (2–6.8)	0.003
HADS-D (from 0 to 21)	4 (1.3–9)	3.5 (0.3–5)	0.022
EQ-5D-5L: Anxiety/depression (from 1 to 5)	1.5 (1–3)	1 (1–2)	0.047
EQ-5D-5L: EQ VAS (from 0 to 100)	52.5 (43–78)	75 (60–90)	0.015

	Before-O_3T Correlations (rho)	After-O_3T Correlations (rho)	*p*-value before/after
HADS-A-EQ-5D-5L Anxiety/Depression-EQ-5D-5L, EQ VAS	0.866, −0.554	0.874, −0.627	< 0.001/< 0.001 0.026/0.009
HADS-D-EQ-5D-5L Anxiety/Depression-EQ-5D-5L, EQ VAS	0.852, −0.644	0.673, −0.812	< 0.001/0.004 0.007/<0.001

O_3T, ozone therapy; Q1–Q3: quartiles 1 and 3; HADS, Hospital Anxiety and Depression Scale; HADS-A, HADS-Anxiety; HADS-D, HADS-Depression; EQ VAS, EQ-5D-5L Visual Analog Scale self-perceived general health status.

group of patients, and these symptoms remained despite half of the patients already being on anxiolytic and/or antidepressant treatment.

Affective disorders and depression are associated with high levels of oxidative stress markers [such as 8-hydroxydeoxyguanosine (8-OHdG)], proinflammatory cytokines (such as interleukins (IL) IL-1 and IL-6 and tumor necrosis factor alpha (TNFα)), as well as with decreased levels of antioxidants (such as coenzyme Q10, glutathione peroxidase, and zinc) (Ng et al., 2008; Maes et al., 2011; Leonard and Maes, 2012; Lindqvist et al., 2017). Additionally, oxidative stress is associated with low brain-derived neurotrophic factor (BDNF) and subsequent decreases in Nrf2 activity (Bouvier et al., 2017). Clinically, in comparison with healthy controls, patients with major depressive disorder have significantly higher levels of proinflammatory cytokines such as IL-6, TNFα, 8-OHdG, and F2-isoprostanes. Furthermore, those parameters are associated with the success of antidepressant treatment. Over the course of treatment, patients without response to selective serotonin reuptake inhibitors (SSRIs) showed an increase in 8-OHdG levels, whereas patients showing a response to SSRIs showed a decrease in IL-6 levels (Lindqvist et al., 2017).

Several studies on the impact of oxidative stress on brain function have been based on experimental models of ozone “inhalation,” which described changes in brain neurotransmitters and increases in dopamine and noradrenaline (Gonzalez-Pina and Paz, 1997), oxidized dopamine species (Santiago-Lopez et al., 2010), memory alterations (Avila-Costa et al., 1999; Mokoena et al., 2015), anxiety, and depression, even with antidepressant treatment (Mokoena et al., 2015). Clinically, a detrimental effect of environmental ozone exposure has also been associated with increased psychiatric emergency services admissions (Bernardini et al., 2019), depression (Kioumourtzoglou et al., 2017), and other psychiatric disorders (Gladka et al., 2018). However, some systematic reviews with meta-analyses did not find a statistically significant association between the role of ozone and depression (Zhao et al., 2018; Fan et al., 2020; Borroni et al., 2022). Further clinical studies in this field are required. Notably, we highlight that medical ozone administration must specifically avoid the inhalation of ozone, so, these studies would not apply to O_3T.

Conversely, clinical O_3T is based on appropriate: (i) routes of ozone administration (inhalation must be avoided) and (ii) ozone concentrations. We previously described the relationship between oxidative stress and inflammation and the toxicity of chemotherapy in detail (Clavo et al., 2021, 2022). When low/moderate ozone concentrations are properly administered by systemic routes, a relevant part of ozone will be removed by the antioxidant defenses of the medium (rectal mucosa when rectal insufflation is used or the blood when autohemotherapy is used). The remaining ozone will interact with biomolecules as polyunsaturated fatty acids from cell membranes or blood cells, or other components of rectal mucosa or plasma, to generate reactive species of oxygen, second messengers and lipid peroxides, which can reach distant tissues. This way, O_3T produces a controlled and transient oxidative stress that indirectly will induce an adaptive response of the organism, with overregulation of Nrf2 (which leads to potentiation of antioxidant systems) and downregulation of NF-kβ and proinflammatory cytokines (Re et al., 2014; Bocci and Valacchi, 2015; Galie et al., 2019; Viebahn-Haensler and Leon Fernandez, 2021). These actions are in the opposite direction that those involved in the production of anxiety and depression that were described in the two previous paragraphs about “ozone inhalation.” Thus, the enhancement in Nrf2 levels and antioxidant systems by O_3T may be of interest in the management of anxiety or depression, as supported by the described (i) antioxidant properties for some antidepressants such as desvenlafaxine, desipramine, and venlafaxine (Gaur and Kumar, 2010; Silva et al., 2016); (ii) decreased oxidative stress damage induced by chronic mild stress by the modulation of Nrf2 in the prefrontal cortex by antidepressants (Martin-Hernandez et al., 2016); and (iii) beneficial effect of O_3T (avoiding inhalation) in experimental models on aging and neurodegenerative disorders (El-Mehi and Faried, 2020; Scassellati et al., 2020) and a clinical study on depression in older patients (Coppola et al., 2010).

After O_3T, the patients in our study showed a decrease in anxiety and depression in (i) the anxiety/depression dimension of the EQ-5D-5L questionnaire and (ii) the HADS-A and HADS-D subscales. Both HADS subscales showed: (i) a marked correlation with the anxiety/depression dimension of the EQ-5D-5L questionnaire, and (ii) the correlation was higher with anxiety than with depression. These results in our study agree with a previous larger study with 245 patients comparing the same anxiety/depression dimension of the EQ-5D-3L questionnaire with the HADS subscales (Thayabaranathan et al., 2022). HADS-A and HADS-D subscales also showed a significant correlation with the VAS self-perceived general health status. However, here, the correlation was higher with depression than with anxiety. These results agree with the findings of studies showing that a high prevalence of anxiety and depression predicts a low HRQOL in cancer patients, but also that depression has a more pervasive association with multiple other domains of HRQL (Brown et al., 2010). On the other hand, our results with O_3T in patients with refractory symptoms of cancer treatment and advanced nononcologic diseases, agree with the results of O_3T on anxiety and depression in three previous reports using systemic O_3T in different kinds of patients: (i) in older patients with mild to moderate depression and mild cognitive impairment, assessed by the Hamilton and Montgomery scales (Coppola et al., 2010), in patients with fibromyalgia assessed by the Beck Depression Inventory and the State and Trait Anxiety Inventory (Hidalgo-Tallon et al., 2013), and (ii) in patients with insomnia and coronary heart disease, assessed by the HADS questionnaire (Li et al., 2021).

Among the limitations of this study, we highlight the following: (i) This study had a small sample size. Currently, the assessment of anxiety and depression is a specific aim of our larger ongoing studies with O_3T in cancer (NCT04299893) and noncancer (NCT05417737) patients. (ii) The improvement in anxiety and depression could have been partially related to the improvement in physical symptoms in most patients, especially in the three patients only treated with topical O_3 administration. (iii) This is a nonrandomized clinical trial, so a potential placebo effect could not be completely ruled out, including the potential effect on anxiety and depression of closer follow-up during the ozone treatment period. However, two relevant aspects should be considered regarding the potential placebo effect in points (ii) and (iii): (a) patients in this study suffered advanced disease and chronic symptoms for many months before O_3T; (b) as mentioned above, the role of oxidative stress in anxiety and depression has been well-described (Ng et al., 2008; Maes et al., 2011; Leonard and Maes, 2012; Lindqvist et al., 2017). So, the well-described effect of O_3T in modulating oxidative stress and inflammation overall (Re et al., 2014; Bocci and Valacchi, 2015; Galie et al., 2019; Viebahn-Haensler and Leon Fernandez, 2021) and at the brain level (Coppola et al., 2010; El-Mehi and Faried, 2020; Scassellati et al., 2020) probably played a direct role in our patients, especially in those treated with systemic O_3T (most of them). Finally, we would like to mention two additional limitations: (iv) the study was focused on patients with severe diseases treated with O_3T because of refractory symptoms, but they were treated different cancer-related and noncancer-related symptoms and diagnosis, and (v) anxiety, depression, or treatment for anxiety and depression were not present in all patients. Results could be conditioned by these clinical parameters. Further specifically addressed studies are required, and our ongoing studies will more thoroughly assess the role of O_3T in anxiety and depression.

4.1. Conclusions

In this preliminary study, using the Hospital Anxiety and Depression Scale questionnaire, patients with refractory symptoms of cancer treatment and advanced disease showed decreased mild or higher levels of both anxiety and depression after ozone therapy. The effect of ozone therapy on the psychological field merits focused research, and related studies are ongoing.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Provincial Research Ethics Committee of Las Palmas, Spain. The patients/participants provided their written informed consent to participate in this study.

Author contributions

BC, DR-A, JD-G, PS-A, and FR-E: conceptualization. BC, YR-F, and PS-A: formal analysis. BC, YR-F, PS-A, and FR-E: methodology. DR-A, MF, and SG: initial management and oncology follow-up. BC, AC-M, CG-L, DG-B, and MC: treatment with ozone therapy. JD-G, SC, HL, and JH-F: evaluation of HADS questionnaire. BC, JD-G, YR-F, HL, JH-F, PS-A, and FR-E: writing—original draft. BC, AC-M, JD-G, SC, YR-F, HL, MF, DR-A, SG, CG-L, DG-B, MC, JH-F, PS-A, and FR-E: writing—review and editing and approval of the final version. BC and DR-A: funding acquisition. All authors have read and agreed to the published version of the manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

Avila-Costa, M. R., Colin-Barenque, L., Fortoul, T. I., Machado-Salas, P., Espinosa-Villanueva, J., Rugerio-Vargas, C., et al. (1999). Memory deterioration in an oxidative stress model and its correlation with cytological changes on rat hippocampus CA1. *Neurosci. Lett.* 270, 107–109. doi: 10.1016/S0304-3940(99)00458-9

Bernardini, F., Attademo, L., Trezzi, R., Gobbicchi, C., Balducci, P. M., Del Bello, V., et al. (2019). Air pollutants and daily number of admissions to psychiatric emergency services: evidence for detrimental mental health effects of ozone. *Epidemiol. Psychiatr. Sci.* 29:e66. doi: 10.1017/S2045796019000623

Bocci, V., and Valacchi, G. (2015). Nrf2 activation as target to implement therapeutic treatments. *Front. Chem.* 3:4. doi: 10.3389/fchem.2015.00004

Borroni, E., Pesatori, A. C., Bollati, V., Buoli, M., and Carugno, M. (2022). Air pollution exposure and depression: a comprehensive updated systematic review and meta-analysis. *Environ. Pollut.* 292:118245. doi: 10.1016/j.envpol.2021.118245

Bouvier, E., Brouillard, F., Molet, J., Claverie, D., Cabungcal, J. H., Cresto, N., et al. (2017). Nrf2-dependent persistent oxidative stress results in stress-induced vulnerability to depression. *Mol. Psychiatry* 22:1795. doi: 10.1038/mp.2016.211

Boyes, A. W., Girgis, A., D'Este, C. A., Zucca, A. C., Lecathelinais, C., and Carey, M. L. (2013). Prevalence and predictors of the short-term trajectory of anxiety and depression in the first year after a cancer diagnosis: a population-based longitudinal study. *J. Clin. Oncol.* 31, 2724–2729. doi: 10.1200/JCO.2012.44.7540

Brown, L. F., Kroenke, K., Theobald, D. E., Wu, J., and Tu, W. (2010). The association of depression and anxiety with health-related quality of life in cancer patients with depression and/or pain. *Psychooncology* 19, 734–741. doi: 10.1002/pon.1627

Caramés, M. A., Navarro, M., Pérez-Lehmann, C., Hernández-Rodríguez, J., Lázaro-Archilla, J., and Clavo, B. (2021). Descriptive study on the profile of patients sent to the chronic pain treatment unit of the University Hospital of Gran Canaria Dr. Negrín (UTDC-HUGCDN) as a basis for the reorganization of this. [Estudio descriptivo sobre el perfil de los pacientes derivados a la Unidad de Tratamiento del dolor Crónico del Hospital Universitario de gran Canaria Dr. Negrín (UTDC-HUGCDN) Como base Para la reorganización de esta]. *Rev. Soc. Esp. Dol.or* 25, 254–263. doi: 10.20986/resed.2021.3939/2021

Clavo, B., Canovas-Molina, A., Ramallo-Farina, Y., Federico, M., Rodriguez-Abreu, D., Galvan, S., et al. (2023). Effects of ozone treatment on health-related quality of life and toxicity induced by radiotherapy and chemotherapy in symptomatic Cancer survivors. *Int. J. Environ. Res. Public Health* 20:1479. doi: 10.3390/ijerph20021479

Clavo, B., Ceballos, D., Gutierrez, D., Rovira, G., Suarez, G., Lopez, L., et al. (2013). Long-term control of refractory hemorrhagic radiation proctitis with ozone therapy. *J. Pain Symptom Manag.* 46, 106–112. doi: 10.1016/j.jpainsymman.2012.06.017

Clavo, B., Gutierrez, D., Martin, D., Suarez, G., Hernandez, M. A., and Robaina, F. (2005). Intravesical ozone therapy for progressive radiation-induced Hematuria. *J. Altern. Complement. Med.* 11, 539–541. doi: 10.1089/acm.2005.11.539

Clavo, B., Martinez-Sanchez, G., Rodriguez-Esparragon, F., Rodriguez-Abreu, D., Galvan, S., Aguiar-Bujanda, D., et al. (2021). Modulation by ozone therapy of oxidative stress in chemotherapy-induced peripheral neuropathy: the background for a randomized clinical trial. *Int. J. Mol. Sci.* 22:2802. doi: 10.3390/ijms22062802

Clavo, B., Navarro, M., Federico, M., Borrelli, E., Jorge, I. J., Ribeiro, I., et al. (2021). Long-term results with adjuvant ozone therapy in the Management of Chronic Pelvic Pain Secondary to Cancer treatment. *Pain Med.* 22, 2138–2141. doi: 10.1093/pm/pnaa459

Clavo, B., Rodríguez-Abreu, D., Galván, S., Federico, M., Martínez-Sánchez, G., Ramallo-Fariña, Y., et al. (2022). Long-term improvement by ozone treatment in chronic pain secondary to chemotherapy-induced peripheral neuropathy: a preliminary report. *Front. Physiol.* 13:935269. doi: 10.3389/fphys.2022.935269

Clavo, B., Santana-Rodriguez, N., Gutierrez, D., Lopez, J. C., Suarez, G., Lopez, L., et al. (2013). Long-term improvement in refractory headache following ozone therapy. *J. Altern. Complement. Med.* 19, 453–458. doi: 10.1089/acm.2012.0273

Clavo, B., Santana-Rodriguez, N., Llontop, P., Gutierrez, D., Ceballos, D., Mendez, C., et al. (2015). Ozone therapy in the Management of Persistent Radiation-Induced Rectal Bleeding in prostate Cancer patients. *Evid. Based Complement. Alternat. Med.* 2015:480369. doi: 10.1155/2015/480369

Clavo, B., Suarez, G., Aguilar, Y., Gutierrez, D., Ponce, P., Cubero, A., et al. (2011). Brain ischemia and hypometabolism treated by ozone therapy. *Forsch. Komplementmed.* 18, 283–287. doi: 10.1159/000333795

Coppola, L., Luongo, C., Pastore, A., Masciello, C., Parascandola, R. R., Mastrolorenzo, L., et al. (2010). Ozonized autohaemotransfusion could be a potential rapid-acting antidepressant medication in elderly patients. *Int. J. Geriatr. Psychiatry* 25, 208–213. doi: 10.1002/gps.2322

DeJean, D., Giacomini, M., Vanstone, M., and Brundisini, F. (2013). Patient experiences of depression and anxiety with chronic disease: a systematic review and qualitative meta-synthesis. *Ont. Health Technol. Assess. Ser.* 13, 1–33.

El-Mehi, A. E., and Faried, M. A. (2020). Controlled ozone therapy modulates the neurodegenerative changes in the frontal cortex of the aged albino rat. *Ann. Anat.* 227:151428. doi: 10.1016/j.aanat.2019.151428

European Commission (2000). European Comission: Estimates of survival, by country and cancer site, 2000–2007. Available at: https://ecis.jrc.ec.europa.eu/explorer.php?$0-2$1-AEE$2-All$4-1,2$3-0$6-0,14$5-2000,2007$7-1$CRelativeSurvivalAgeGroup$X0_14-$X0_15-RSC$CRelativeSurvivalFollow$X1_14-$X1_-1-$X1_15-RSC.In (accessed February 14th, 2023).

European Commission (2023). Persons reporting a chronic disease, by disease, sex, age and educational attainment level. Available at: https://ec.europa.eu/eurostat/databrowser/view/HLTH_EHIS_CD1E/bookmark/table?lang=en&bookmarkId=2d249b06-f173-48b3-b6ed-e90b57e6f683&page=time:2019 (accessed February 14th, 2023),

Fan, S. J., Heinrich, J., Bloom, M. S., Zhao, T. Y., Shi, T. X., Feng, W. R., et al. (2020). Ambient air pollution and depression: a systematic review with meta-analysis up to 2019. *Sci. Total Environ.* 701:134721. doi: 10.1016/j.scitotenv.2019.134721

Forsythe, L. P., Kent, E. E., Weaver, K. E., Buchanan, N., Hawkins, N. A., Rodriguez, J. L., et al. (2013). Receipt of psychosocial care among cancer survivors in the United States. *J. Clin. Oncol.* 31, 1961–1969. doi: 10.1200/JCO.2012.46.2101

Galie, M., Covi, V., Tabaracci, G., and Malatesta, M. (2019). The role of Nrf2 in the antioxidant cellular response to medical ozone exposure. *Int. J. Mol. Sci.* 20:4009. doi: 10.3390/ijms20164009

Gaur, V., and Kumar, A. (2010). Protective effect of desipramine, venlafaxine and trazodone against experimental animal model of transient global ischemia: possible involvement of NO-cGMP pathway. *Brain Res.* 1353, 204–212. doi: 10.1016/j.brainres.2010.07.004

Gladka, A., Rymaszewska, J., and Zatonski, T. (2018). Impact of air pollution on depression and suicide. *Int. J. Occup. Med. Environ. Health* 31, 711–721. doi: 10.13075/ijomeh.1896.01277

Gonzalez-Pina, R., and Paz, C. (1997). Brain monoamine changes in rats after short periods of ozone exposure. *Neurochem. Res.* 22, 63–66. doi: 10.1023/A:1027329405112

Gotze, H., Friedrich, M., Taubenheim, S., Dietz, A., Lordick, F., and Mehnert, A. (2020). Depression and anxiety in long-term survivors 5 and 10 years after cancer diagnosis. *Support Care Cancer* 28, 211–220. doi: 10.1007/s00520-019-04805-1

Greer, J. A., Solis, J. M., Temel, J. S., Lennes, I. T., Prigerson, H. G., Maciejewski, P. K., et al. (2011). Anxiety disorders in long-term survivors of adult cancers. *Psychosomatics* 52, 417–423. doi: 10.1016/j.psym.2011.01.014

Herdman, M., Gudex, C., Lloyd, A., Janssen, M., Kind, P., Parkin, D., et al. (2011). Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual. Life Res.* 20, 1727–1736. doi: 10.1007/s11136-011-9903-x

Hernandez, G., Garin, O., Pardo, Y., Vilagut, G., Pont, A., Suarez, M., et al. (2018). Validity of the EQ-5D-5L and reference norms for the Spanish population. *Qual. Life Res.* 27, 2337–2348. doi: 10.1007/s11136-018-1877-5

Herrero, M. J., Blanch, J., Peri, J. M., De Pablo, J., Pintor, L., and Bulbena, A. (2003). A validation study of the hospital anxiety and depression scale (HADS) in a Spanish population. *Gen. Hosp. Psychiatry* 25, 277–283. doi: 10.1016/S0163-8343(03)00043-4

Hidalgo-Tallon, J., Menendez-Cepero, S., Vilchez, J. S., Rodriguez-Lopez, C. M., and Calandre, E. P. (2013). Ozone therapy as add-on treatment in fibromyalgia management by rectal insufflation: an open-label pilot study. *J. Altern. Complement. Med.* 19, 238–242. doi: 10.1089/acm.2011.0739

Ji, X., Cummings, J. R., Gilleland Marchak, J., Han, X., and Mertens, A. C. (2020). Mental health among nonelderly adult cancer survivors: a national estimate. *Cancer* 126, 3768–3776. doi: 10.1002/cncr.32988

Kim, J. L., Cho, J., Park, S., and Park, E. C. (2015). Depression symptom and professional mental health service use. *BMC Psychiatry* 15:261. doi: 10.1186/s12888-015-0646-z

Kioumourtzoglou, M. A., Power, M. C., Hart, J. E., Okereke, O. I., Coull, B. A., Laden, F., et al. (2017). The association between air pollution and onset of depression among middle-aged and older women. *Am. J. Epidemiol.* 185, 801–809. doi: 10.1093/aje/kww163

Leonard, B., and Maes, M. (2012). Mechanistic explanations how cell-mediated immune activation, inflammation and oxidative and nitrosative stress pathways and their sequels and concomitants play a role in the pathophysiology of unipolar depression. *Neurosci. Biobehav. Rev.* 36, 764–785. doi: 10.1016/j.neubiorev.2011.12.005

Li, Y., Feng, X., Ren, H., Huang, H., Wang, Y., and Yu, S. (2021). Low-dose ozone therapy improves sleep quality in patients with insomnia and coronary heart disease by elevating serum BDNF and GABA. *Bull. Exp. Biol. Med.* 170, 493–498. doi: 10.1007/s10517-021-05095-6

Li, H., Ge, S., Greene, B., and Dunbar-Jacob, J. (2019). Depression in the context of chronic diseases in the United States and China. *Int. J. Nurs. Sci.* 6, 117–122. doi: 10.1016/j.ijnss.2018.11.007

Lindqvist, D., Dhabhar, F. S., James, S. J., Hough, C. M., Jain, F. A., Bersani, F. S., et al. (2017). Oxidative stress, inflammation and treatment response in major depression. *Psychoneuroendocrinology* 76, 197–205. doi: 10.1016/j.psyneuen.2016.11.031

Lloyd, S., Baraghoshi, D., Tao, R., Garrido-Laguna, I., Gilcrease, G. W., et al. (2019). Mental health disorders are more common in colorectal Cancer survivors and associated with decreased overall survival. *Am. J. Clin. Oncol.* 42, 355–362. doi: 10.1097/COC.0000000000000529

Maes, M., Galecki, P., Chang, Y. S., and Berk, M. (2011). A review on the oxidative and nitrosative stress (O&NS) pathways in major depression and their possible contribution to the (neuro)degenerative processes in that illness. *Prog. Neuro-Psychopharmacol. Biol. Psychiatry* 35, 676–692. doi: 10.1016/j.pnpbp.2010.05.004

Martin-Hernandez, D., Bris, A. G., MacDowell, K. S., Garcia-Bueno, B., Madrigal, J. L., Leza, J. C., et al. (2016). Modulation of the antioxidant nuclear factor (erythroid 2-derived)-like 2 pathway by antidepressants in rats. *Neuropharmacology* 103, 79–91. doi: 10.1016/j.neuropharm.2015.11.029

Mitchell, A. J., Meader, N., and Symonds, P. (2010). Diagnostic validity of the hospital anxiety and depression scale (HADS) in cancer and palliative settings: a meta-analysis. *J. Affect. Disord.* 126, 335–348. doi: 10.1016/j.jad.2010.01.067

Mokoena, M. L., Harvey, B. H., Viljoen, F., Ellis, S. M., and Brink, C. B. (2015). Ozone exposure of Flinders sensitive line rats is a rodent translational model of neurobiological oxidative stress with relevance for depression and antidepressant response. *Psychopharmacology* 232, 2921–2938. doi: 10.1007/s00213-015-3928-8

Ng, F., Berk, M., Dean, O., and Bush, A. I. (2008). Oxidative stress in psychiatric disorders: evidence base and therapeutic implications. *Int. J. Neuropsychopharmacol.* 11, 851–876. doi: 10.1017/S1461145707008401

Quintana, J. M., Padierna, A., Esteban, C., Arostegui, I., Bilbao, A., and Ruiz, I. (2003). Evaluation of the psychometric characteristics of the Spanish version of the hospital anxiety and depression scale. *Acta Psychiatr. Scand.* 107, 216–221. doi: 10.1034/j.1600-0447.2003.00062.x

Rabin, R., Gudex, C., Selai, C., and Herdman, M. (2014). From translation to version management: a history and review of methods for the cultural adaptation of the EuroQol five-dimensional questionnaire. *Value Health* 17, 70–76. doi: 10.1016/j.jval.2013.10.006

Ramos-Goni, J. M., Craig, B. M., Oppe, M., Ramallo-Farina, Y., Pinto-Prades, J. L., Luo, N., et al. (2018). Handling data quality issues to estimate the Spanish EQ-5D-5L value set using a hybrid interval regression approach. *Value Health* 21, 596–604. doi: 10.1016/j.jval.2017.10.023

Re, L., Martinez-Sanchez, G., Bordicchia, M., Malcangi, G., Pocognoli, A., Morales-Segura, M. A., et al. (2014). Is ozone pre-conditioning effect linked to Nrf2/EpRE activation pathway *in vivo*? A preliminary result. *Eur. J. Pharmacol.* 742, 158–162. doi: 10.1016/j.ejphar.2014.08.029

Santiago-Lopez, D., Bautista-Martinez, J. A., Reyes-Hernandez, C. I., Aguilar-Martinez, M., and Rivas-Arancibia, S. (2010). Oxidative stress, progressive damage in the substantia nigra and plasma dopamine oxidation, in rats chronically exposed to ozone. *Toxicol. Lett.* 197, 193–200. doi: 10.1016/j.toxlet.2010.05.020

Scassellati, C., Galoforo, A. C., Bonvicini, C., Esposito, C., and Ricevuti, G. (2020). Ozone: a natural bioactive molecule with antioxidant property as potential new strategy in aging and in neurodegenerative disorders. *Ageing Res. Rev.* 63:101138. doi: 10.1016/j.arr.2020.101138

Silva, M. C., de Sousa, C. N., Gomes, P. X., de Oliveira, G. V., Araujo, F. Y., Ximenes, N. C., et al. (2016). Evidence for protective effect of lipoic acid and desvenlafaxine on oxidative stress in a model depression in mice. *Prog. Neuro-Psychopharmacol. Biol. Psychiatry* 64, 142–148. doi: 10.1016/j.pnpbp.2015.08.002

Thayabaranathan, T., Andrew, N. E., Stolwyk, R., Lannin, N. A., and Cadilhac, D. A. (2022). Comparing the EQ-5D-3L anxiety or depression domain to the hospital anxiety and depression scale to identify anxiety or depression after stroke. *Top. Stroke Rehabil.* 29, 146–155. doi: 10.1080/10749357.2021.1895494

Viebahn-Haensler, R., and Leon Fernandez, O. S. (2021). Ozone in medicine. The low-dose ozone concept and its basic biochemical mechanisms of action in chronic inflammatory diseases. *Int. J. Mol. Sci.* 22:7890. doi: 10.3390/ijms22157890

Waked, I. S., Nagib, S. H., and Omar, M. T. A. (2013). A single blinded randomized controlled clinical trial on the efficacy of ozone therapy on breast cancer-related lymphedema. *Cancer Clin Oncol* 2, 93–106. doi: 10.5539/cco.v2n2p93

Zhao, T., Markevych, I., Romanos, M., Nowak, D., and Heinrich, J. (2018). Ambient ozone exposure and mental health: a systematic review of epidemiological studies. *Environ. Res.* 165, 459–472. doi: 10.1016/j.envres.2018.04.015

Zigmond, A. S., and Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatr. Scand.* 67, 361–370. doi: 10.1111/j.1600-0447.1983.tb09716.x

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Dementia care in gerontological social work: emerging issues and challenges in Saudi Arabia

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The issues and challenges in the current state of gerontological social work policy, practice, and education related to dementia care in Saudi Arabia are discussed in this article. The following primary issues were explored: (1) the impact of the biomedical model's global dominance on gerontological social work policy and research for dementia care and health promotion; (2) the position of the older adults in Middle Eastern nations and its connection to the lack of gerontological social work policies, programs, and care services for older adults with dementia and their family caregivers; (3) the effect of the profession of social work's lack of recognition on the potential evolution of gerontological social work practice in dementia care; (4) the state of dementia patients' rights, dementia patients' safety, and dementia patients' rights to self-determination on the gerontological social work support provided for older adults with dementia; (5) the unequal distribution of dementia care resources and gerontological social work; and (6) the social work education programs' inability to supply the market with sufficient number of skilled gerontological social workers and its effect on the advancement of dementia care in gerontological social work practice. Approaches for advancing policy, practice, and education are provided to support the evolution of gerontological social work in dementia care in the region.

KEYWORDS
dementia, social work in gerontology, older adults, care challenges, Saudi Arabia

1. Introduction

In Saudi Arabia, there were more than one million and a half individuals aged 60 and over in 2022 (1). By 2050, ten million people are anticipated to be over the age of 60 in the country (2). With the Saudi population's anticipated move toward old age, chronic diseases, particularly dementia, are anticipated to become more prevalent (3). There are currently no published studies in the nation that evaluate the incidence and prevalence rate of dementia. Dementia is a term that refers to a specific set of symptoms, including memory, language, problem-solving, and other thinking skills impairments. These symptoms are linked to many problems that make life more stressful for older adults with dementia and their family caregivers, such as physical decline, personality change, poor oral intake, depression, anxiety, and sleep disturbance (3–5).

Generally, formal care and services for older adults in the country has enhanced recently *via* introduction of various care and services by government and private sector, such as health services (therapeutic programs, geriatric clinics, and discount cards for medical services), social services (free transportation services, housing programs, and social entertainment programs), educational services (literacy programs, vocational training programs, and teaching Quran reading programs), and spatial services (seating for the older adults, private parking, and wheelchair services) (6). However, more attention and efforts are still needed to address the gaps in diagnosis, health, social, and educational services and care programs specific to older adults with dementia in Saudi Arabia and their informal caregivers (7, 8).

Although there is no official data that show the exact number of informal caregivers for older adults with dementia in the country, Saudi experts predict that most of the care for this population is provided by unpaid informal caregivers due to the cultural and religious belief that caring for older adults is a family responsibility (9). The majority of informal caregivers of older adults with dementia are women, 50 years of age or younger, married, caring for parents, employed, with modest incomes, provide care all the time, and live with the care recipient (10–12).

By offering dementia care, primarily social, psychological, emotional, financial, and spiritual support and care, gerontological social workers, may enhance the quality of life for this population and their family caregivers while also improving the experience of living with dementia. For instance, gerontological social workers might provide this population the proper educational resources to deal with dementia and navigate the challenges associated with it. Gerontological social workers may also encourage older adults with dementia and the people who care for them to join social support groups in order to deal with dementia-related stress. Gerontological social workers may also educate society about dementia in order to lessen the stigma associated with it, which may negatively affect the quality of life for those living with it and their families. To address societal, cultural, and workforce issues associated with dementia care, Gerontological social workers may also promote social policies and programs for this particular population. These duties and responsibilities necessitate a thorough understanding of the disease, expertise in developing interventions that support older adults with dementia and the family caregivers in making emotional adjustments, and familiarity with the available services and practical resources for this population (13, 14).

Although there are many opportunities for gerontological social workers to improve the quality of life for older oldest with dementia and their families, there is still confusion about how to perform gerontological social work with this group, and there is no core set of competencies for such practice in Saudi Arabia. Dementia care and gerontological social work practice and policy for this population are negatively impacted by the global roles within the healthcare system that is informed by the biomedical disease model of dementia, the status of the older adults in Middle Eastern countries, the local lack of recognition of the social work profession, and the lack of gerontological social work education programs (9). The following sections address issues and challenges in gerontological social work policy, practice, and education linked to dementia care. A set of recommendations is also provided to overcome remaining gaps in social work and dementia care.

2. Policy issues and challenges related to dementia care in gerontological social work in Saudi Arabia

Middle Eastern cultures, particularly Saudi culture, place high importance on the older adults. They are respected and regarded as a source of blessing, wisdom, and affection. Furthermore, in Middle Eastern culture, taking care of the older adults is a religious and familial obligation. Therefore, it is seen to be a violation of family and religious obligations to send older adults with dementia to nursing homes or long-term care facilities. This viewpoint, which led to a gap in policies, programs, and services for the older adults with dementia and their families, is problematic because it presumes that families can care for their loved ones with dementia without official assistance and support (9). The desire of the family to care for their loved ones with dementia at home should be respected. However, it is also essential to guarantee high-quality care and support for this vulnerable population. Therefore, it is crucial to develop particular gerontological social work policies that offer educational, emotional, social, and financial support and assistance to families caring for older adults with dementia at home.

Because of the belief that focusing on medical research will result in discovering a cure, saving money and patients' lives, the biomedical model's popularity around the world has led to an emphasis on helping medical experts and funding their research (4, 7). This assumption needs to be challenged for several reasons. First, it undervalues the high price of developing a dementia cure and the anticipated high cost of the promised treatments (15). Second, because of this assumption, gerontological social work research on non-pharmacological therapies, which is expected to be more successful and cost-effective in improving the quality of life, care, and satisfaction of older adults with dementia and their families until finding a cure, has been underfunded (16). This assumption also fails to consider the challenging living conditions that older adults with dementia and those who care for them currently face, including their emotional, social, and financial challenges. Additionally, it undermined social care policies intended to improve assistance for older adults with dementia and their families by underfunding gerontological social work research programs that explore the psychological and social aspects of dementia (7). It is more appropriate to address dementia and its impacts by concentrating on raising the standard of social care and living for older adults with dementia while working to discover a cure.

The biological trend toward developing a cure to treat dementia resulted in the belief that doing so is the best method to deal with dementia, which encourages medical researchers to request more funding for their work in this field (17). There are several reasons why this assumption has to be challenged. First, it ignores the need for social care research, regulations, and initiatives to advance health, especially brain health, which can help reduce cognitive, functional, and psychological impairments brought on by aging and improve overall body health (18, 19). Second, this assumption ignores the advantages of multidomain lifestyle interventions, including gerontological social work interventions in lowering the risk of cognitive decline in older adults with a high risk of dementia (20, 21). Therefore, it is essential to invest in supporting a healthy lifestyle and brain health for those who are at high risk of dementia while trying to develop a cure to treat dementia.

3. Practice issues and challenges related to dementia care in gerontological social work in Saudi Arabia

The number of social work practitioners working in many important social work areas, including gerontological social work area remains deficient due to the need for more recognition of social work as a profession and the scarcity of policies limiting social work jobs to certified social workers. This reality resulted in a shortage of gerontological social workers who offer services and promote care for older adults with dementia and their families (22). The problem is that most employees lack gerontological social work training, which undoubtedly affects dementia services and care across the nation. To fully realize the potential of gerontological social workers in dementia care, initiatives for educating and recruiting more of them in hospitals and social institutions must be promoted.

Gerontological social workers are employed in hospitals to collaborate with multidisciplinary care teams that include medical professionals, formal caregivers, and other non-physician health care providers to extend effective dementia care and services for older adults and family caregivers (23–25). However, gerontological social workers in the region face limitations and barriers that affects their ability to perform their duties appropriately. For instance, they face strong resistance when they try to participate in a patient's treatment due to the ineffective assumption made by medical physicians that dementia is a medical issue and that social workers' engagement in dementia cases is unnecessary (26, 27).

In order to ensure that gerontological social workers participate actively and collaborate as a cohesive team in an interdisciplinary healthcare team and achieve the best possible support and care outcomes for older adults with dementia, it is crucial to empower gerontological social workers and raise awareness of hospitals administrations and medical professionals about the significance of the social work profession. This is done by connecting the complex biological components of dementia with the psychological, emotional, social, and cultural factors that contribute to the stressful living experience with dementia.

Disagreement over treatment and care decisions, made by professional physicians among people with dementia, family caregivers, and health care providers, including social workers, is also one of the most critical issues in dementia care (28). The right to self-determination of older adults with dementia, especially those with severe dementia, is threatened by this issue. Additionally, it affects the standard of dementia care and increases moral distress of social workers, especially when; (1) the autonomy of older adults with dementia, such as their decision where to live conflicts with family caregivers, healthcare professionals, and social workers' desire to keep them safe, (2) the difficulty to assess and understand autonomy of older adults with dementia due to cognitive decline lead to conflict among family caregivers, healthcare professionals, and social workers about what they consider is best for the older adults with dementia's well-being, and (3) the autonomy of older adults with dementia, such as their decision not to go to a nursing home conflicts with the self-interests of family caregivers (29). This issue, which becomes more complicated with the unclarity of job descriptions (28), needs to be addressed with respect to the right to self-determination for the older adults with dementia.

Despite the fact that social workers have an ethical duty to protect patient's rights, especially older adults with dementia who are particularly susceptible to physical and medical harms because of their vulnerability (30), the issue of dementia patients' rights is one of the challenges facing social work providers in the country, especially gerontological social workers. Although the Saudi Patient's Bill of Rights and Responsibilities included the general rights for older adults patients, (31), the specific rights for dementia patients were not discussed. It is crucial to create and endorse a Dementia Bill of Rights that ensured the rights of older adults with dementia, such as the rights to be informed of their diagnosis, to receive quality medical care and treatment, and to be provided with information and support they need to participate as fully as possible in care decisions in all stages of dementia.

Another concern that hospital social workers and medical personnel must address is patient safety (32). Some of the hospitals in the country place a low priority on patient safety, which includes providing adequate assessment, treatment, and intervention, reporting error events, responding to errors, being open with patients, ensuring impartiality, and providing adequate management support for patient safety (33). Patient's psychological, emotional, and social well-being is in risk as a result of the violations of patient safety-related issues, especially older people with dementia (32). Promoting and advocating for policies to reinforce the patient safety culture in hospitals is imperative to alleviate concerns and enhance the quality and safety of care for older adults with dementia and their family caregivers.

Access to resources is also one of the critical issues related to dementia care in Saudi Arabia. For instance, the majority of medical and healthcare resources are located in urban cities, which makes it difficult for gerontological social workers to provide those living in rural areas with appropriate resources to deal with dementia challenges (32). For citizens and residents to have access to high-quality medical care and services, there must be an equitable allocation of resources across the nation.

4. Education issues and challenges related to dementia care in gerontological social work in Saudi Arabia

Due to several reasons, social work education programs could not adequately equip their students to meet this demand and need of gerontological social workers who are specialized in providing care and services to older adults with chronic diseases, such as dementia. First, few faculty members in the country specialize in geriatric social work. Furthermore, social work education programs in the universities do not offer foundational courses to train students who want to focus on serving and caring for senior populations, particularly those with chronic illnesses like dementia. Furthermore, there are not enough graduate students specializing in gerontology and dementia care research in Saudi Arabia because there are not enough academic mentors in the field (34). To fill the urgent market demand for gerontological social workers and researchers, it is crucial to hire faculty members from other countries with expertise in geriatric social work while also intending to increase the number of faculty members with gerontological social work specialization in Saudi Arabia. Along with that, social work education programs at universities need to create fundamental courses that educate future social workers about aging and chronic illnesses like dementia and its related effects.

The absence of social work scientific literature and knowledge that discuss social difficulties linked with chronic diseases, such as dementia, is also one of the challenges that social work education in Saudi Arabia faces (17, 35). This fact heightens the propensity of academics to use outdated materials and information that are not culturally relevant, which has an impact on student learning outcomes and the establishment of a gerontological social work education foundation in the country that fits its unique culture and addresses the escalating social issues related to aging and chronic diseases like dementia (36). It is significant to develop a foundation for culturally appropriate gerontological social work education and increase the quantity of high-quality social work geriatric research in Saudi Arabia that tackles the most prevalent geriatric health disorders with psychological and social effects, such as dementia.

The limited options for social work students to receive dementia care training in health and social institutions is also one of the issues facing social work education in the country. There are various reasons for this. First, few public and private health/social institutions are eager to offer social work students internship opportunities due to the unfounded concern that they will interfere with these organizations' principal missions and expose ethical misbehavior and negligence. The lack of field practicum programs in social work education programs that outline student and agency obligations, offer high-quality supervision, and establish a connection between theoretical knowledge, field practicum, and market needs complicates the situation (34). Development of field practicum programs in the social work education programs in Saudi Arabia that gives high priority to field practicum as part of the academic curriculum and addresses the issues related to field practicum education is significant to increase the number of trained and highly skilled gerontological social workers, including those who are specialized in providing care for older adults with dementia and their family caregivers.

5. Theoretical perspectives of dementia care and their impacts on dementia care and gerontological social work

The development of dementia-related practice and policy is influenced by how society views and understands dementia. Therefore, changing social work policy, practice, and education related to dementia requires changing the dominant way of understanding it. There are several theoretical models to understand dementia. Each model uniquely affects dementia-specific care practices, policies, and research related to discipline of social work and other disciplines. Theoretical models of understanding dementia can be categorized into four conceptual models: biological model, socio-psychological model, disability model, and social gerontological model (37, 38).

According to the biological approach, dementia is diagnosed as a pathological disorder with treatable symptoms. Thus, in accordance with this model of understanding, dementia is a condition that results in a steady degeneration of the brain. Consequently, medical control is the best strategy for dealing with dementia. Therefore, it is crucial to recognize the signs of this disease in order to ascertain its underlying causes. The development of dementia treatments or preventative measures should be the main focus of all research. Healthcare providers should concentrate on reducing dementia symptoms. The goal of the policymakers should be to create laws that will make it possible to cure dementia. However, the biological approach has been criticized for prioritizing dementia research over offering patients and their families the assistance and care required to deal with the illness. Social-psychological and disability models, which prioritize enhancing the health and quality of life of people with dementia, were developed in response to this critique of the biology paradigm (37, 38).

The social-psychological model focuses on how dementia affects both the individuals with dementia and the family members who provide care for them. Because of this, this paradigm perceives dementia as an individual-level experience that affects people differently. This perspective view assisted people living with dementia and their carers manage the condition and its consequences. According to this paradigm, the research aims to develop treatments and preventative measures for dementia patients. It is the duty of healthcare providers, including social workers and caretakers, to work with older adults with dementia to provide activities that take into account their preferences and needs. By taking into account the unique experiences of older adults with dementia and family caregivers, the social psychological approach focuses on creating social policies intended to promote medical and non-medical interventions (37, 38).

According to the disability paradigm, dementia is a disorder that causes a disability. However, it does not consider disability as a problem. Instead, by neglecting to change social attitudes and the environment for dementia patients, society has problematized impairment and excluded older adults with dementia from fully participating in society. In order to properly stimulate and engage older adults with dementia in social situations, environmental adjustments are needed. As a result, the fundamental objective of the research, treatment strategies, and legislation should be to maintain the independence of older adults with dementia for as long as feasible by promoting non-medical interventions (37, 38).

The social gerontological model indicates that life with dementia can remain fulfilling if society does not exclude and isolate older adults with dementia and perceive them as a burden. Thus, societies' social, environmental, and structural contexts influence the living experience with dementia. Therefore, dementia research, healthcare practices, and policies should focus on understanding the broader social and structural factors that impact the living experience with dementia, thus promoting positive images of aging to decrease their stressful experience with the disease (37, 38).

The biological paradigm of understanding dementia continues to predominate in the region, despite the fact that other nations, including the United States, have begun to push an integrative model to understand dementia (37). The supremacy of the biological model has an impact on social services, policies, and social work practice with older adults with dementia and their family caregivers. It undermined the social services and assistance provided to older adults living with dementia to lessen the emotional, social, psychological, and economic strain of the disease. It also led to the lack of national guidelines, educational programs, and social service initiatives for older adults with dementia and their family caregivers. It also contributed to the lack of financing for dementia care research and long-term care facilities or nursing homes for older adults with dementia. It also expanded the gap between gerontologists and healthcare professionals who focus on providing care for the older adults, such as gerontological social workers and other healthcare providers (4, 5, 7, 11). The following recommendations should be implemented in order to overcome the gerontological social work policy, practice, and education gaps related to dementia care:

6. Approaches and recommendations

Integrative biological, psychological, disability, and gerontological models should be used to understand dementia as a condition. To foster a deeper understanding of the nature of living with dementia, social work policy, education, practice, and policy efforts should be concentrated on macro and micro levels. Gerontological social workers should take neurological impairment and social structural limitations into account while providing older adults with dementia and their family caregivers with high-quality care. Social work policymakers should incorporate biomedical information as well as behavioral, social, and structural issues when drafting policies for senior citizens with dementia and the family caregivers who support them.

The country needs to prepare for the increased financial, social, and health burden that will come with the rise in dementia cases. The Ministries of Health and Human Resource and Social Development, social service organizations, medical and non-medical professionals, and researchers should collaborate to assess the current level of all aspects of care for people with dementia and their families and to formulate recommendations for addressing the health, societal, economic, and workforce issues related to dementia. The prior recommendation should be incorporated into the Saudi Vision 2030 by working with the Council of Economic and Development Affairs. Saudi Arabia must also develop and maintain a national plan to deal with dementia, with the explicit goals of identifying long-term care assistance and service gaps, enhancing the standard of social care and quality of life for older adults with dementia and their families, and enhancing social workers' roles in dementia care.

To meet the needs of older adults with dementia and family caregivers, it is essential to provide social workers with well-designed gerontological social work education programs. In order to provide patient-centered care to people with dementia and their family caregivers, Saudi Arabia should prepare to increase the number of healthcare service providers, including social workers, and establish geriatrics-specific training programs. In order to provide appropriate dementia care and services, Saudi hospitals must establish multidisciplinary care teams that include social workers and other medical professionals. Through promoting a positive image of the older adults with dementia and the caregivers who support them, social work education programs should raise public acceptance and enhance integration. Additionally, it is crucial to use social media to reach a large audience and to take advantage of other media platforms to raise awareness of dementia related concerns and the roles of social workers. Creating dementia-related content and incorporating information on aging, its societal impacts, and the roles of social work in dementia care into university and school curricula is significant.

Author contributions

The author confirms being the sole contributor of this work and has approved it for publication.

Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. General Authority of Statistics (2022). Population by Detailed Age. Available at: https://portal.saudicensus.sa/portal/public/1/15/100647?type=TABLE (Accessed July 5, 2023).

2. Abusaaq H. I. (2015). SAMA Working Paper: Population Aging in Saudi Arabia. Saudi Arabian Monetary Agency. Available at: https://www.sama.gov.sa/en-US/EconomicResearch/WorkingPapers/population%20aging%20in%20saudi%20arabia.pdf (Accessed July 9, 2023).

3. 2022 Alzheimer's disease facts and figures. *Alzheimers Dement*. (2022) 18:700–89. doi: 10.1002/alz.12638

4. Albugami M, Qadi N, Almugbel F, Mohammed A, Alttas A, Elamin A, et al. The demographic characteristics and the risk factors of dementia in Saudi elderly. *Hypertension*. (2018) 314:71–53. doi: 10.11648/j.ajpn.20180601.11

5. Ogunniyi A, Daif AK, Al-Rajeh S, AbdulJabbar M, Al-Tahan AR, Al-Bunyan M, et al. Dementia in Saudi Arabia: experience from a university hospital. *Acta Neurol Scand*. (1998) 98:116–20. doi: 10.1111/j.1600-0404.1998.tb01729.x

6. Saudi Elderly Support Organization "WAQAR" (2017). Directory of Elderly Services in Saudi Arabia. Available at: https://waqar.org.sa/uploads/files/bfa5361_1592544386.pdf (Accessed June 23, 2023).

7. Abyad A. Alzheimer's in the Middle East. *JSM Alzheimers Dis Relat. Demen*. (2015) 2:1012–5. doi: 10.4172/2161-0460.1000241

8. Alshahri MZ. Regional report from Saudi Arabia. Stand-alone palliative care facilities: a cultural viewpoint. *IAHPC NEWS Hosp Palliat Care News Events*. (2009) 10

9. Abyad A. Alzheimer's in the Middle East: the future. *Middle East J. Psychiatry Alzheimers*. (2017) 84:1–4. doi: 10.5742/MEPA.2017.93005

10. Alfakhri AS, Alshudukhi AW, Alqahtani AA, Alhumaid AM, Alhathlol OA, Almojali AI, et al. Depression among caregivers of patients with dementia. *Inquiry*. (2018) 55:0046958017750432. doi: 10.1177/0046958017750432

11. Almoajel A, Alsadhan NM, Almasoud N, Alseraia L, Alanazi S, Almotari A. The impact of Alzheimer's disease on family caregivers in Saudi Arabia. *Life Sci J*. (2019). 16:44

12. Alqahtani MS, Alshbriqe AA, Awwadh AA, Alyami TA, Alshomrani MS, Alhazzani A. Prevalence and risk factors for depression among caregivers of Alzheimer's disease patients in Saudi Arabia. *Neurol Res Int*. (2018) 2018:2501835–5. doi: 10.1155/2018/2501835

13. Ely EM, Fawzi AS. The effectiveness if the intervention programming the framework of professional general practice to educate social workers working in the elderly patients field treated for Alzheimer's and their families. *Res Humanit Soc Sci*. (2015) 5:99–107.

14. Yaghmour SM, Bartlett R, Brannelly T. Dementia in eastern mediterranean countries: a systematic review. *Dementia*. (2019) 18:2635–61. doi: 10.1177/1471301217753776

15. Wong G, Knapp M. Should we move dementia research funding from a cure to its care? *Expert Rev Neurother*. (2020) 20:303–5. doi: 10.1080/14737175.2020.1735364

16. Klimova B, Maresova P, Kuca K. Non-pharmacological approaches to the prevention and treatment of Alzheimer's disease with respect to the rising treatment costs. *Curr Alzheimer Res*. (2016) 13:1249–58. doi: 10.2174/1567205013666151116142302

17. Alamri SH. Geriatric research in Saudi Arabia: a bibliometric analysis. *J Adv Med Med Res*. (2019) 31:1–9.

18. Song D, Yu DSF, Li PWC, Lei Y. The effectiveness of physical exercise on cognitive and psychological outcomes in individuals with mild cognitive impairment: a systematic review and meta-analysis. *Int J Nurs Stud*. (2018) 79:155–64. doi: 10.1016/j.ijnurstu.2018.01.002

19. Shah TM, Weinborn M, Verdile G, Sohrabi HR, Martins RN. Enhancing cognitive functioning in healthly older adults: a systematic review of the clinical significance of commercially available computerized cognitive training in preventing cognitive decline. *Neuropsychol Rev*. (2017) 27:62–80. doi: 10.1007/s11065-016-9338-9

20. Kivipelto M, Mangialasche F, Ngandu T. Lifestyle interventions to prevent cognitive impairment, dementia and alzheimer disease. *Nat Rev Neurol*. (2018) 14:653–66. doi: 10.1038/s41582-018-0070-3

21. Rosenberg A, Ngandu T, Rusanen M, Antikainen R, Lars B, Havulinna S, et al. Multidomain lifestyle intervention benefits a large elderly population at risk for cognitive decline and dementia regardless of baseline characteristics: the finger trial. *Alzheimers Dement*. (2018) 14:263–70. doi: 10.1016/j.jalz.2017.09.006

22. Albrithen APD, Yalli NPD. A discussion of professional issues of hospital social workers in Saudi Arabia. *Soc Work Health Care*. (2013) 52:20–42. doi: 10.1080/00981389.2012.728559

23. Chen C, Huang Y, Liu C, Xu Y, Zheng L, Li J. Effects of an interdisciplinary care team on the management of alzheimer's disease in China. *J Gerontol Nurs*. (2019) 45:39–45. doi: 10.3928/00989134-20190318-01

24. Fazio S, Pace D, Maslow K, Zimmerman S, Kallmyer B. Alzheimer's association dementia care practice recommendations. *The Gerontologist*. (2018) 58:9. doi: 10.1093/geront/gnx182

25. Koskas P, Pons-Peyneau C, Romdhani M, Houenou-Quenum N, Tigue-Wato A, Galleron S, et al. Effectiveness of multidisciplinary consultation for older adults with alzheimer's disease in response to acute situations. *L'Encéphale*. (2018) 44:491–5. doi: 10.1016/j.encep.2018.01.008

26. AlAhmadi H, Roland M. Quality of primary health care in Saudi Arabia: a comprehensive review. *Int J Qual Health Care*. (2005) 17:331–46. doi: 10.1093/intqhc/mzi046

27. Albrithen A, Yalli N. Social workers: peer interaction and hospital integration. *Int Soc Work*. (2016) 59:129–40. doi: 10.1177/0020872815594859

28. Almoallem AM, Almudayfir MA, Al-Jahdail YH, Ahmed AE, Al-Shaikh A, Baharoon S, et al. Top ethical issues concerning healthcare providers working in Saudi Arabia. *J Epidemiol Glob Health*. (2020) 10:143–52. doi: 10.2991/jegh.k.191211.001

29. Smebye KL, Kirkevold M, Engedal K. Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study. *BMC Health Serv Res*. (2016) 16:21–1. doi: 10.1186/s12913-015-1217-1

30. Beresford HR. Severe neurological impairment: legal aspects of decisions to reduce care. *Ann Neurol*. (1984) 15:409–14. doi: 10.1002/ana.410150502

31. Ministry of Health (2021). Patient's Bill of Rights and Responsibilities. Available at: https://www.moh.gov.sa/en/HealthAwareness/EducationalContent/HealthTips/Documents/Patient-Bill-of-Rights-and-Responsibilities.pdf (Accessed July 7, 2023).

32. Alkabba AF, Hussein GMA, Albar AA, Bahnassy AA, Qadi M. The major medical ethical challenges facing the public and healthcare providers in Saudi Arabia. *J Fam Community Med*. (2012) 19:1–6. doi: 10.4103/2230-8229.94003

33. Mahrous MS. Patient safety culture as a quality indicator for a safe health system: experience from almadinah almunawwarah, ksa. *J Taibah Univ Med Sci*. (2018) 13:377–83. doi: 10.1016/j.jtumed.2018.04.002

34. Ibrahim QA, Hreish KM, Hantoosh KS, Benson OG, Galalh AA, al-Halalat K, et al. Social work education in the Middle East and North Africa: students' perspectives at 13 universities in 10 countries. *Egypt J Soc Work*. (2020) 9:189–204. doi: 10.21608/ejsw.2020.68765

35. Kokaliari E, Berzoff J, Byers DS, Fareed A, Berzoff-Cohen J, Hreish K. Teaching clinical social work under occupation: listening to the voices of Palestinian social work students. *J Teach Soc Work*. (2016) 36:140–59. doi: 10.1080/08841233.2016.1142490

36. Albrithen A. Social work education in Saudi Arabia: a review. *Soc Dev Issues*. (2014) 36:52–66.

37. Cuijpers Y, Van Lente H. Early diagnostics and Alzheimer's disease: beyond 'cure' and 'care'. *Technol Forecast Soc Chang*. (2015) 93:54–67. doi: 10.1016/j.techfore.2014.03.006

38. Innes A, Manthorpe J. Developing theoretical understandings of dementia and their application to dementia care policy in the UK. *Dementia*. (2013) 12:682–96. doi: 10.1177/1471301212442583

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Population-level, patient-reported outcomes: a case study regarding a public health intervention that involves patients with life-limiting illnesses

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Introduction: Dying and death are public health concerns, but little is known about public health interventions that target populations living with life-limiting illnesses. This gap makes it difficult to identify best-practice public health interventions for this population and to achieve public health objectives. The study aimed to describe a public health intervention that intends to improve population-level outcomes using point-of-care and patient-reported outcomes.

Methods: A case study approach, informed by the Organization for Economic Co-operation and Development's (OECD) Best-Practice Public Health Framework, was used to describe coverage, effectiveness, and equity using mixed methods. Data from 2012 to 2022 were analyzed.

Results: Over the 10-year period, the number of deaths recorded in the programme (n = 16,358 to 32,421, +98.2%) as well as the percentage of the population that might benefit from palliative care increased (14.8% to 25.1%). The median age of those admitted for care (74 to 77 years) and the proportion of services participating in the programme located in outer regional and remote areas of Australia increased (2012: 59; 2022: 94; +5.4%). The access by patients that experience the greatest socioeconomic disadvantage decreased (2012: 18.2% n = 4,918; 2022: 15.9% n = 9,525). Improvements in relation to moderate distress related to pain were identified (2012: 63% n = 8,751, 2022: 69% n = 13,700), and one in five instances of severe distress related to pain did not improve (2012: 20% n = 781; 2022: 19% n = 635).

Conclusion: Population-level, patient-reported outcome data are useful and necessary in addressing public health objectives in populations with life-limiting illnesses. Our application of the OECD's Best-Practice Public Health Framework has helped to identify and describe a national intervention that may be transferred to other settings to address health promotion objectives. This may help improve the targeting of treatments to improve pain and issues related to equity.

KEYWORDS

palliative care, aged care, health status disparities, public health, mixed methods

Introduction

Public health and palliative care have much in common. Both disciplines include a commitment to achieving the optimal health for everyone in society and rely on data and evidence-informed strategies to achieve this aim (1, 2). Population-level data are also key to advancing both disciplines.

Population-level data, or big data, provide valuable insights into public health objectives. They can assist with health planning, the prediction of risk (including risks related to under-served populations), the targeting of interventions, the understanding of disease (including its trajectory), and issues related to safety and harm (3). Examples of the use of big data within palliative care include the use of national death indices to estimate populations (4), hospital activity information to derive risks (5), government-subsidized pharmaceutical dispensing data to illuminate inequities regarding palliative-care-related medicines (6), surveys to investigate bereavement needs (7), differential impacts on caregivers when specialist palliative care services are and are not accessed (8), and the needs of caregivers who did or did not use a specialist palliative care service (9).

However, population-level data that report on patient-reported outcome measures that closely align with clinical care are rarely available. This gap hinders public health evaluation of populations with life-limiting illnesses and the monitoring of the effectiveness of health systems. Populations with life-limiting illnesses often require the use of a specialized, multidisciplinary care in which the primary aim is to optimize the person's functioning (to maintain independence for as long as possible) and quality of life. Routinely collected clinical data, which capture information about symptom burden, performance, and clinical acuity are therefore useful for promoting the health of populations at the end of life (3). Patient-reported outcome indicators ensure that the users of the health systems (i.e., the patients themselves) can directly influence the evaluation of the health systems that they use. There is a growing recognition of the need to incorporate patient experience measures (e.g., ease of access to information) and patient preferences (e.g., place of care) but less recognition of the need to report on patient-reported outcomes, including the extent of distress that patients may experience.

Close partnerships between clinician communities, patients and their caregivers, and key groups, such as universities, are likely to be key to the successful development and adoption of public health interventions in palliative care (10). Despite this, the focus of partnerships in public health has often included an emphasis on partnerships with community organizations and faith-based groups, as well as members of the public (11). Less emphasis has been placed on partnerships from within the professional healthcare system (e.g., communities of practices inclusive of palliative care service providers), and the involvement of patients, their caregivers, and the public is also often neglected. Typically, the involvement of patients, caregivers, and the public has evolved by including them as the target audience of public health initiatives rather than as partners that can help shape and inform the programme itself (11).

Whilst the recognition of the need for public health for populations with life-limiting illnesses is growing, the descriptions of population-based, public health interventions are lacking. Describing public health interventions is a critical first step to identifying public health interventions that may be useful for national implementation (2). This study aims to assess a national initiative that intends to improve population-level outcomes for people with life-limiting illnesses. The initiative is called the Australian National Palliative Care Outcomes Collaboration (PCOC) (12). PCOC has previously been demonstrated as feasible, desirable, and useful in addressing public health objectives (12, 13) although scant accounts with respect to describing how PCOC may explicitly align with the available public health methodology. This study aims to help address this gap in knowledge.

Methods

We used the Organization for Economic Co-operation and Development (OECD) Best-Practice Public Health Intervention Framework to assess the PCOC intervention (2). A case study approach was used to inform the evaluation of the PCOC intervention in line with the OECD 5E Framework. The areas assessed included the extent of coverage, effectiveness, and equity (2). Descriptive statistics were used to describe changes over time to compare the proportions in 2012 and 2022, and the percentage increases or decreases between these two points.

Extent of coverage

Coverage was assessed using two measures. Change was calculated for the period 2012–2022 regarding the volume of services registered with the programme and in relation to a range of service characteristics. This was to be presented as the total number of services divided by care setting (inpatient and community), service size, and location. The size of the service was derived by examining episodes of care in each service, with an episode of care defined as a continuous period of care for a patient in one setting.

The second measure involved the use of a well-established method of estimating the need for palliative care, developed by Murtagh et al. (14). This measure was used to provide an indication of the extent of coverage of the intervention over time in relation to the estimated need within the total population. This methodology was selected for use due to its expanded inclusion of ICD-10 codes and its more comprehensive consideration of underlying and contributory causes of death and inpatient admission patterns prior to death as compared to other methodologies (15, 16).

For the analysis, the deaths recorded in the PCOC programme were calculated as a proportion of people who could potentially benefit from palliative care and analysis of this with the Australian Bureau of Statistics Cause of Death Data from 2012 to 2021. The estimate included using the number of people with a selected underlying cause of death plus a contributing cause of death for selected conditions (to estimate co-morbidities). The conditions included were all-cancer deaths (C00-C97—malignant neoplasms only included) and selected non-cancer deaths (*ICD-10*: I00-I52, I60-I69, N17, N18, N28, K70-K77, J06-J18, J20-J22, J40-J47 and J96, G10, G20, G35, G122, G903, G231, F01, F03, G30, R54, B20-B24) (14). The most recent and complete 10-year period was included in the analysis, that is, from January 2012 to December 2021. As 2022 data were not available at the time of our analysis, we derived an estimate based on data from previous years.

Effectiveness

In relation to effectiveness, improvements in a key symptom area were examined to describe population-level changes, that is, pain. The OECD's expert guidance is that intervention-specific health indicators can be used to assess effectiveness if there is a need to assess the extent to which an intervention's desired outcomes were achieved in a real-world setting. The trends in the ways in which distress related to pain was managed over the 10-year period were examined. Distress was measured using the patient-reported PCOC Symptom Assessment Scale (PCOC SAS) (17), which is a derivative of earlier scales (18–21). PCOC SAS is an 11-point numerical rating scale with the response options on the scale grouped into six categories. Each category has a corresponding descriptor, color, and facial expression for assisting the patient in reporting their distress. Higher scores represent higher levels of distress. Descriptive statistics were used to describe a 1-point change in the 11-point scale. Instances of positive, negative, or no change from scores were also derived. This was calculated by using the scores that varied from the absent (a score of 0) to mild (scores 1–3), moderate (scores 4–7), and severe (scores 8–10) ranges of the scale.

Equity

In relation to equity, a measure of socioeconomic disadvantage was calculated for each patient that accessed care over the 10-year period. This was completed to report trends by the socioeconomic disadvantage. The measure we used is the Socio-Economic Indexes for Areas (SEIFA) quintiles (22), which are based on the ABS Index of Relative Socio-Economic Disadvantage. Each SEIFA quintile represents ∼20% of the national population, with quintile one being the most disadvantaged and quintile five being the most advantaged.

Results

Extent of coverage

The extent of coverage of the programme increased in relation to palliative care services registered, patient outcomes captured, the proportion of patients in Australia that may benefit from palliative care, and the proportion of those that die in Australia.

In relation to the coverage of palliative care services, the absolute number of palliative care services registered with the programme increased from 135 to 215 services (+59%). An increase in the proportion of larger services (i.e., 300+ episodes of care per 6 months) was observed, primarily including an increase in the growth in larger community services in the country (Table 1).

TABLE 1 Characteristics of palliative care services registered with the PCOC programme in 2012, 2022, and the percentage increase and decrease observed.

Characteristics	2012	2022	Percentage increase or decrease
	n (%)	*n* (%)	
Services			
Number of services	135	215	+59.3%
Location of service			
Major city	76 (56.3)	121 (56.3)	+0.0%
Inner regional	43 (31.9)	57 (26.5)	−5.3%
Outer regional/remote	16 (11.9)	37 (17.2)	+5.4%
Care setting			
Inpatient	81 (60.0)	129 (60.0)	0.0%
Community	54 (40.0)	86 (40.0)	0.0%
Size of service			
Small (<100 episodes)	47 (34.8)	75 (34.9)	+0.1%
Medium (100–299 episodes)	44 (32.6)	65 (30.2)	−2.4%
Large (300+ episodes)	44 (32.6)	75 (34.9)	+2.3%
Care setting by the size of service			
Inpatient			
Small (<100 episodes)	26 (19.3)	47 (21.9)	+2.6%
Medium (100–299 episodes)	24 (17.8)	38 (17.7)	−0.1%
Large (300+ episodes)	31 (23.0)	44 (20.5)	−2.5%
Community			
Small (<100 episodes)	21 (15.6)	28 (13.0)	−2.5%
Medium (100–299 episodes)	20 (14.8)	27 (12.6)	−2.3%
Large (300+ episodes)	13 (9.6)	31 (14.4)	+4.8%

In relation to the extent of coverage of patients, the absolute number of patients in the programme increased by 110% (n = 28,528 annually to n = 60,032 annually), and the overall median age of patients observed by the services increased from 74 years to 77 years. An increase in the proportion of patients diagnosed with a principal life-limiting illness other than cancer, a decrease in the proportion of pediatric patients, and an increase in the proportion of adolescents, young adults, and older adults (+85 years) were evident (Table 2).

The number of deaths reported in PCOC increased each year both in absolute terms and as a percentage of patients who might potentially benefit from palliative care (14.8% to 25.1%). In 2012, the national initiative reported 16,358 deaths, which increased to 32,421 deaths in 2022 (+98.2%) (Figure 1).

Effectiveness

In relation to distress related to pain (as measured by the PCOC SAS), the trends remained broadly the same over the 10-year period (Table 3). Further examination identified substantial improvements in relation to moderate distress related to pain over the same period. An increase in the proportion that improved was observed (63% to 69%), whilst the proportion that got worse decreased (16% to

11%). In relation to absent and mild scores, the proportion of outcomes (that got worse, stayed the same, or improved) remained constant. One in five reports of severe distress stayed the same or got worse over the 10-year period (18% in 2012 and 20% in 2022) (Figure 2).

Equity

The proportion of services participating in the programme located in outer regional and remote areas of Australia increased by +5.4% (Table 1). A substantial decrease in the proportion of patients that experience the greatest disadvantage within Australia was observed. This group was under-represented in 2012 (18.2%) and even more so by 2022 (15.9%). The proportion of patients in the services within the top quintile reduced from 33.4% to 29.4% (Table 2).

Discussion

The public recognizes the importance of dying and death; they are often concerned about any perceived prioritization of the quantity of life over the quality of life with respect to people with life-limiting illnesses; and they call for improved quality of end-of-life care and palliative care for patients, especially for older adult populations and their carers (e.g., families and friends) (23). Given these public priorities, our study provides useful insights into a public health concern as we present effectiveness, coverage, and equity data from a national initiative focused on those with life-limiting illnesses. Improved coverage of the population living with life-limiting illnesses within the national programme was evident over the 10-year period although trends revealed that those that experience the greatest disadvantage within Australia are the ones less likely to be admitted to care. Our analysis of data from the national initiative has also shown that gains have been made in relation to the health of those living with moderate distress related to pain; however, there is little evidence of improved resolution of severe distress related to pain. An unexpected finding was the increase in the median age of patients admitted to care, which may be explained by the increase in life expectancy within Australia. Life expectancy increased by 0.9 years [from 82.3 years (24) to 83.2 years (25)] over the 10-year period studied in the study, with the volume of the highest annual increase in the population growth of the 75 to 84-year-old age group estimated to peak in the early years of 2020 (26). The increase in the median age of patients accessing care may be explained by this growth within society (25).

TABLE 2 Characteristics of palliative care patients admitted to services registered with the PCOC programme in 2012, 2022, and the percentage increase and decrease observed.

Characteristics	2012	2022	Percentage increase or decrease
	n (%)	*n* (%)	
Age group			
≤15	120 (0.3)	62 (0.1)	−0.2%
16–25	1,083 (2.9)	3,773 (4.8)	+1.9%
26–39	552 (1.5)	1,132 (1.4)	0.0%
40–64	9,210 (24.8)	14,332 (18.2)	−6.6%
65–79	14,132 (38.1)	27,325 (34.7)	−3.4%
≥80	12,036 (32.4)	32,121 (40.8)	+8.4%
Median age in years (IQR)	74 (63–82)	77 (67–85)	
Sex			
Men	15,202 (53.3)	31,191 (52.0)	−1.3%
Women	13,297 (46.7)	28,778 (48.0)	+1.3%
Not stated/other	29	63	
Country of birth			
Australia	17,885 (64.9)	37,755 (64.5)	+0.4%
Not Australia	9,663 (35.1)	20,787 (35.5)	−0.4%
Preferred language			
English	13,871 (88.9)	52,900 (89.4)	+0.5%
Other than English	1,739 (11.1)	6,275 (10.6)	−0.5%
Primary diagnosis			
Cancer	22,654 (80.6)	36,942 (63.2)	−17.5%
End-stage organ failure	2,645 (9.4)	8,770 (15.0)	+5.6%
Other non-cancers	1,834 (6.5)	6,541 (11.2)	+4.7%
Neurodegenerative disease	946 (3.4)	3,117 (5.3)	+2.0%
Alzheimer's Disease and other dementias	17 (0.1)	3,121 (5.3)	+5.3%
SEIFA—IRSAD quintile			
1 (greater disadvantage)	4,918 (18.2)	9,525 (15.9)	−2.3%
2	3,769 (14.0)	8,907 (14.9)	+0.9%
3	4,721 (17.5)	11,450 (19.1)	+1.6%
4	4,645 (17.2)	12,404 (20.7)	+3.5%
5 (greater advantage)	8,913 (33.1)	17,606 (29.4)	−3.7%

Our study also showed that the number of deaths reported in PCOC increased each year both in absolute terms and as a percentage of patients who might potentially benefit from palliative care (14.8% to 25.1%). In 2012, the national initiative reported 16,358 deaths, which increased to 32,421 deaths in 2022 (+98.2%). Whilst this coverage represents a major achievement by the national voluntary initiative, it is important to emphasize that the methodology we used to estimate the need for palliative care relies on the assumption that people who are missing out on accessing palliative care have unmet needs (14, 15, 27). Whilst this methodology has been useful, the assumption underpinning the model has limitations (9). The limitations include how it fails to account for the effectiveness of other providers of care (e.g., primary palliative care) and patient preference. The range of methodologies that were available for us to estimate the need for palliative care for our study all failed to address these underlying assumptions. Higginson et al.'s disease-specific methodology includes a range of cancer diagnoses and six non-cancer diagnoses, with the consideration of symptom prevalence (14). Rosenwax et al.'s method relies on routine mortality statistics to estimate the need

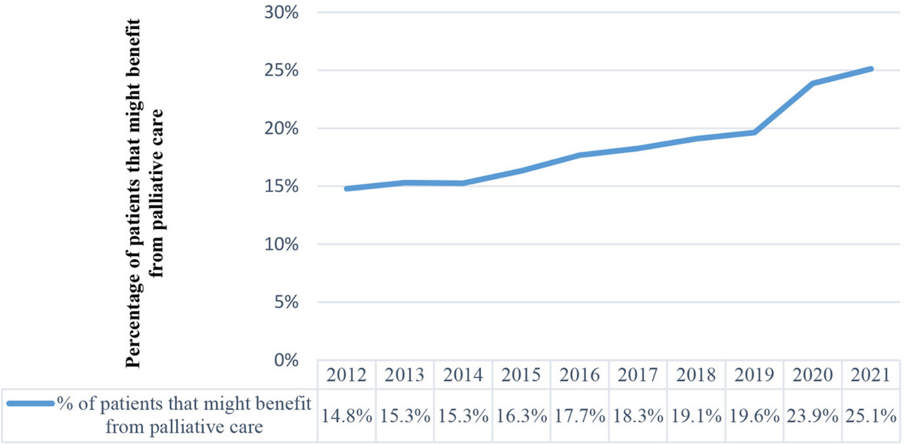


FIGURE 1
Proportion of patients in Australia that may benefit from palliative care and the proportion of deaths in Australia reported in the national programme.

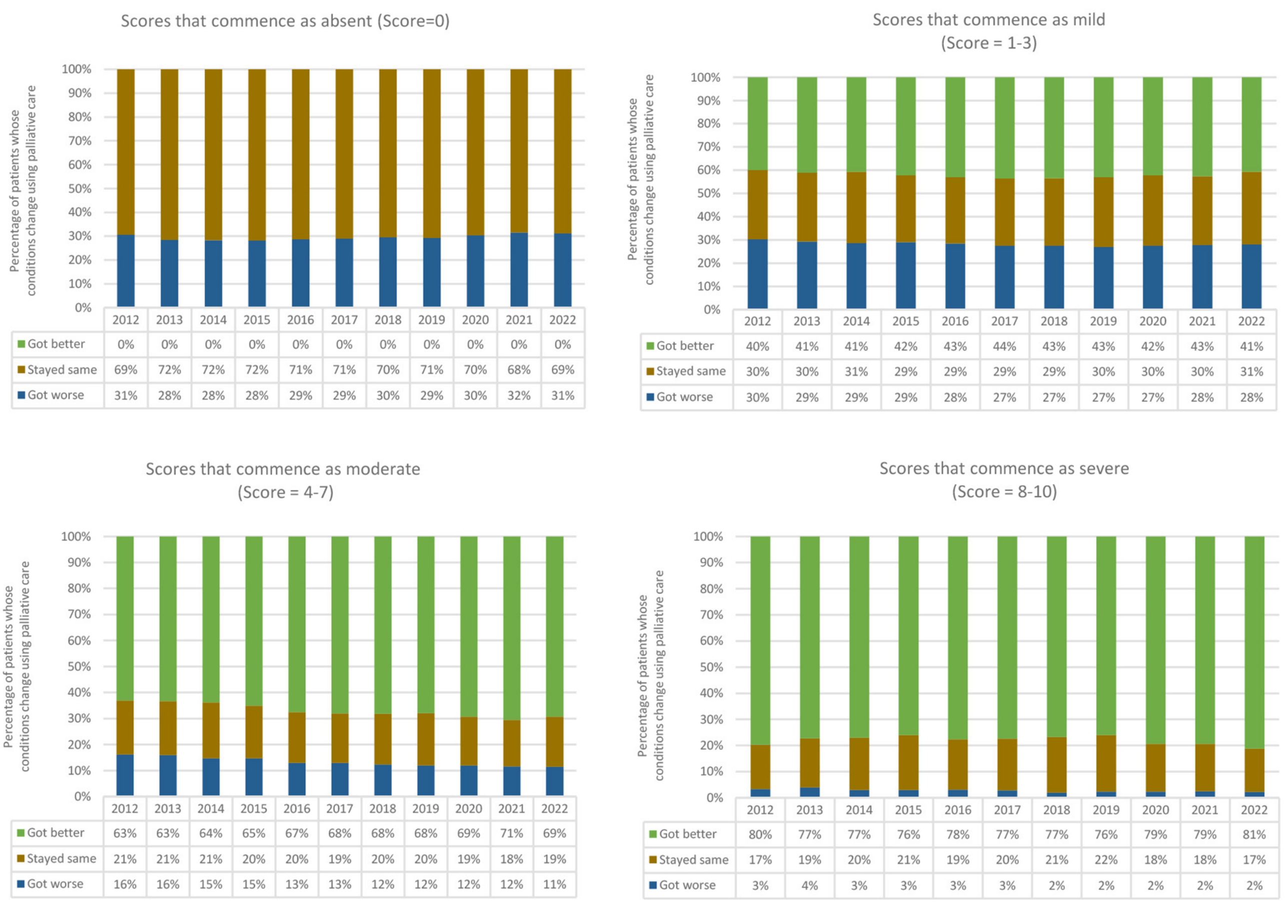
TABLE 3 Number and proportion of patient outcomes that worsened, stayed the same, or improved over time: distress related to pain.

Year	Distress related to pain (PCOC SAS)		
	Worsened *n* (%)	Stayed the same *n* (%)	Improved *n* (%)
2012	7,558 (22%)	8,626 (25%)	18,565 (53%)
2013	9,633 (22%)	11,264 (25%)	23,797 (53%)
2014	10,616 (21%)	13,232 (26%)	26,554 (53%)
2015	11,692 (21%)	13,645 (25%)	29,440 (54%)
2016	12,139 (21%)	14,290 (25%)	31,484 (54%)
2017	12,279 (21%)	14,716 (25%)	31,637 (54%)
2018	13,131 (21%)	16,039 (26%)	33,354 (53%)
2019	14,181 (21%)	18,025 (26%)	35,875 (53%)
2020	16,317 (21%)	19,981 (26%)	39,716 (52%)
2021	16,770 (22%)	19,635 (26%)	39,862 (52%)
2022	16,503 (22%)	20,222 (27%)	37,008 (50%)

for palliative care for cancerous and non-cancerous populations, using all deaths from 10 specific disease groups (16). Gómez-Batiste et al.'s methodology is informed by the estimated proportion of deaths from chronic progressive diseases and its prevalence (15). Whilst we selected Murtagh et al.'s method because of its expanded inclusion of ICD-10 codes and its more comprehensive consideration of underlying and contributory causes of death and inpatient admission patterns prior to death, it is important to discuss these assumptions.

An alternative approach that we could have used involves the recognition that a referral to a service may not necessarily equate with a need and that unmet or perceived needs may not necessarily equate to a referral or a preference to be referred (9). This means that a lack of admission to a palliative care service may not equate to an unmet need. As described elsewhere, an alternative approach that incorporates this alternative view could allow for the identification of a group that had used a service and benefited from it (e.g., primary palliative care ± specialist palliative care), a group that had used a service but not benefited from the service (e.g., primary palliative care or specialist palliative care, or a combination of both), a group in the population where a service was not used (e.g., primary or specialist palliative care) but it would not have added value, and a group where a service was not used (e.g., as it was not available or the patient preferred not to use the service) but yet the service may have added benefit (e.g., primary or specialist palliative care, or a combination of both) (9, 28). The continued surveillance of the accessibility of palliative care services can allow for a population-based gap analysis to be completed, especially as the coverage of PCOC in primary palliative care expands. Continued growth in the programme may allow for the analysis of those that access specialist palliative care and/or primary care (with or without primary palliative care) and changes in outcomes of these groups. One of the original aspirations of the PCOC programme was to improve outcomes at scale, and this also includes the monitoring of outcomes across the country (12). At present, the PCOC programme can begin to achieve this goal as the PCOC dataset has matured. This development was also anticipated by the founders of the programme as early as 2008 (12).

A key objective of public health is to ensure the promotion of health for all in society and not just those that can afford to access care or the majority within society. Our study reports trends related to the socioeconomic disadvantage indicative of growing inequities in relation to service entry. It suggests that resource use by patients continues to be inequitable (assuming preferences to access the service are constant across the quintiles) and that this disparity is increasing. This is because 20% of the population with a greater economic disadvantage within Australia are less likely to access palliative care. Inequities in relation to accessing specialist palliative care in Australia based on its geography have been previously described in a study that geocoded palliative care services nationally (using postcode) to one nationally standardized measure of socioeconomic deprivation and the location of the inpatient service and each person's home postcode. The earlier study



Scores that commence as absent (Score=0)

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
🟩 Got better	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
🟫 Stayed same	69%	72%	72%	72%	71%	71%	70%	71%	70%	68%	69%
🟦 Got worse	31%	28%	28%	28%	29%	29%	30%	29%	30%	32%	31%

Scores that commence as mild (Score = 1-3)

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
🟩 Got better	40%	41%	41%	42%	43%	44%	43%	43%	42%	43%	41%
🟫 Stayed same	30%	30%	31%	29%	29%	29%	29%	30%	30%	30%	31%
🟦 Got worse	30%	29%	29%	29%	28%	27%	27%	27%	27%	28%	28%

Scores that commence as moderate (Score = 4-7)

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
🟩 Got better	63%	63%	64%	65%	67%	68%	68%	68%	69%	71%	69%
🟫 Stayed same	21%	21%	21%	20%	20%	19%	20%	20%	19%	18%	19%
🟦 Got worse	16%	16%	15%	15%	13%	13%	12%	12%	12%	12%	11%

Scores that commence as severe (Score = 8-10)

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
🟩 Got better	80%	77%	77%	76%	78%	77%	77%	76%	79%	79%	81%
🟫 Stayed same	17%	19%	20%	21%	19%	20%	21%	22%	18%	18%	17%
🟦 Got worse	3%	4%	3%	3%	3%	3%	2%	2%	2%	2%	2%

FIGURE 2
Proportion of change in distress related to pain over a 10-year period by absent, mild, moderate, and severe scores.

showed that, on average, those that were least socioeconomically disadvantaged had to travel 14 km to their closest inpatient palliative care service, whilst those that were most disadvantaged had to travel three times the distance to be able to receive inpatient palliative care. This earlier study also analyzed PCOC data (29).

The intervention we examined in our study involved a close partnership between a community of practice that involves clinical services and a university (10). Our case study, therefore, adds valuable information to supplement a gap in the literature that places an emphasis on the involvement of groups outside of the professional healthcare system in relation to public health interventions (11). A relevant limitation for PCOC though is the lack of any description of how PCOC engages with patients, caregivers, and the public to help develop and inform the programme. This means that PCOC, similar to other initiatives, has an opportunity to engage more fully with members of the public as partners to help shape and inform the development of the programme. Involving the public in the ongoing development of this initiative may help derive ways to expand the coverage of the programme, develop measures of unmet needs, and help support population-based planning (30).

Strengths and limitations

Changes in population structures, diseases, and risk factors (e.g., lifestyle behaviors) have led to growing public health challenges. In response, policymakers are experimenting with different interventions that improve population health in a sustainable way. However, achieving public health objectives continues to be challenging. One of the strengths of our study is the use of the OECD's 5E Framework because the framework has provided a pragmatic approach to begin to identify and evaluate a public health intervention that may be transferrable to other countries and settings, and in doing so, we have addressed the dearth of population-level public health interventions that focus on those with life-limiting illnesses (2). A second strength is the use of a patient-reported measure to help evaluate health system performance. These types of measures are rarely implemented nationally, and therefore, they are rarely available to assist with health systems monitoring. However, limitations of our application of the framework include the lack of a more comprehensive evaluation of the effectiveness of the public health intervention, alongside an examination of its efficiency, and the evidence-based one used to inform the programme. These areas should be addressed. Our study also fails to account for growth in the development of palliative care services (and therefore improved availability) throughout Australia. Nevertheless, future evaluations regarding these dimensions are possible, especially as the PCOC programme is being implemented within a range of other countries. As discussed earlier, a key limitation of our study rests with its reliance on methods to derive estimates of needs that equate access to care with unmet needs and the lack of data regarding primary palliative care.

Conclusion

Public health and palliative care have much in common. Both disciplines include a commitment to optimal health for all and the use of data to achieve this aim. Population-level, patient-reported outcome data are useful and necessary in addressing public health objectives in populations with life-limiting illnesses. Our application of the OECD's Best-Practice Public Health Framework has helped identify a national intervention that may be transferred to other settings to address health promotion objectives, especially in relation to the effective targeting of treatments and issues related to equity.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical Human Research Ethics Committee (2021/ETH00988). Written informed consent from the participants' legal guardian/next of kin was not required to participate in this study in accordance with the national legislation and the institutional requirements.

Author contributions

BD conceived and led the drafting of the article. All other authors helped refine and develop the concept of the article, collect data, refine the material analyzed and presented and the methods used for this study and analysis, and they also developed an interpretation of the findings.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Strengthening of palliative care as a component of comprehensive care throughout the life course. Sixty-seventh World Health *Assem.* (2014) 24:9–14.

2. OECD. *Guidebook on Best Practices in Public Health.* Paris: OECD Publishing (2022). doi: 10.1787/4f4913dd-en

3. Dolley S. Big data's role in precision public health. *Front Public Health.* (2018) 6:68. doi: 10.3389/fpubh.2018.00068

4. Kane PM, Daveson BA, Ryan K, McQuillan R, Higginson IJ, Murtagh FE. The need for palliative care in Ireland: a population-based estimate of palliative care using

routine mortality data, inclusive of nonmalignant conditions. *J Pain Symptom Manage.* (2015) 49:726–33. doi: 10.1016/j.jpainsymman.2014.09.011

5. Henson LA, Gao W, Higginson IJ, Smith M, Davies JM, Ellis-Smith C, et al. Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis. *J Clin Oncol.* (2015) 33:370–6. doi: 10.1200/JCO.2014.57.3568

6. Lal A, McCaffrey N, Gold L, Roder D, Buckley E. Variations in utilisation of colorectal cancer services in South Australia indicated by MBS/PBS benefits: a benefit incidence analysis. *Aust N Z J Public Health.* (2022) 46:237–42. doi: 10.1111/1753-6405.13197

7. DiGiacomo M, Hatano Y, Phillips J, Lewis J, Abernethy AP, Currow DC. Caregiver characteristics and bereavement needs: findings from a population study. *Palliat Med.* (2017) 31:465–74. doi: 10.1177/0269216316663855

8. Abernethy A, Burns C, Wheeler J, Currow D. Defining distinct caregiver subpopulations by intensity of end-of-life care provided. *Palliat Med.* (2009) 23:66–79. doi: 10.1177/0269216308098793

9. Currow DC, Agar M, Sanderson C, Abernethy AP. Populations who die without specialist palliative care: does lower uptake equate with unmet need? *Palliat Med.* (2008) 22:43–50. doi: 10.1177/0269216307085182

10. D'Eer L, Quintiens B, Van den Block L, Dury S, Deliens L, Chambaere K, et al. Civic engagement in serious illness, death, and loss: a systematic mixed-methods review. *Palliat Med.* (2022) 36:625–51. doi: 10.1177/02692163221077850

11. Dumont K, Marcoux I, Warren É, Alem F, Alvar B, Ballu G, et al. How compassionate communities are implemented and evaluated in practice: a scoping review. *BMC Palliat Care.* (2022) 21:131. doi: 10.1186/s12904-022-01021-3

12. Currow DC, Eagar K, Aoun S, Fildes D, Yates P, Kristjanson LJ. Is it feasible and desirable to collect voluntarily quality and outcome data nationally in palliative oncology care? *J Clin Oncol.* (2008) 26:3853–9. doi: 10.1200/JCO.2008.16.5761

13. Daveson BA, Blanchard M, Davis WR, Connolly J, Clapham S, William L, et al. Considering community care in public health responses: A national study regarding palliative care during a prolonged coronavirus disease 2019 lockdown. *Aust N Z J Public Health.* (2023) 47:100019. doi: 10.1016/j.anzjph.2023.100019

14. Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine.* (2014) 28:49–58. doi: 10.1177/0269216313489367

15. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Espinosa J, Contel JC, Ledesma A. Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. *Curr Opin Support Palliat Care.* (2012) 6:371–8. doi: 10.1097/SPC.0b013e328356aaed

16. Rosenwax LK, McNamara B, Blackmore AM, Holman CD. Estimating the size of a potential palliative care population. *Palliat Med.* (2005) 19:556–62. doi: 10.1191/0269216305pm1067oa

17. Daveson BA, Allingham SF, Clapham S, Johnson CE, Currow DC, Yates P, et al. The PCOC symptom assessment scale (SAS): a valid measure for daily use at point of care and in palliative care programs. *PLoS ONE.* (2021) 16:e0247250. doi: 10.1371/journal.pone.0247250

18. Aoun S, McConigley R, Abernethy A, Currow DC. Caregivers of people with neurodegenerative diseases: profile and unmet needs from a population-based survey in South Australia. *J Palliat Med.* (2010) 13:653–61. doi: 10.1089/jpm.2009.0318

19. Kristjanson LJ, Nikoletti S, Porock D, Smith M, Lobchuk M, Pedler P. Congruence between patients' and family caregivers' perceptions of symptom distress in patients with terminal cancer. *J Palliat Care.* (1998) 14:24–32. doi: 10.1177/082585979801400306

20. Lobchuk MM, Kristjanson L, Degner L, Blood P, Sloan JA. Perceptions of symptom distress in lung cancer patients: I. Congruence between patients and primary family caregivers. *J Pain Symptom Manage.* (1997) 14:136–46. doi: 10.1016/S0885-3924(97)00022-5

21. Lobchuk MM, Kristjanson L, Degner L, Blood P, Sloan JA. [Perception of symptom distress in lung cancer patients: I. Agreement between patients and their caregiving relatives. *Pflege.* (1999) 12:352–61. doi: 10.1024/1012-5302.12.6.352

22. Statistics ABO. *Socio-Economic Indexes For Areas (SEIFA) 2016.* (2016). Available online at: https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2033.0.55.001~2016~Main%20Features~SOCIO-ECONOMIC%20INDEXES%20FOR%20AREAS%20(SEIFA)%202016~1 (accessed June 18, 2023).

23. Daveson BA, Alonso JP, Calanzani N, Ramsenthaler C, Gysels M, Antunes B, et al. Learning from the public: citizens describe the need to improve end-of-life care access, provision and recognition across Europe. *Eur J Public Health.* (2014) 24:521–7. doi: 10.1093/eurpub/ckt029

24. Life expectancy at birth. United Nations. (2023). Available online at: https://population.un.org/dataportal/data/indicators/61/locations/36/start/2010/end/2023/table/pivotbylocation (accessed May 31, 2023).

25. Welfare AIoH. *Deaths Web Report—Supplementary Tables.* Canberra: Australian Government (2022).

26. Razis E, Escudero MJ, Palmieri C, Mueller V, Bartsch R, Rossi G, et al. Assessment of the management of carcinomatous meningitis from breast cancer globally: a study by the breast international group brain metastasis task force. *ESMO Open.* (2022) 7:483. doi: 10.1016/j.esmoop.2022.100483

27. Rosa WE, Bhadelia A, Knaul FM, Travers JL, Metheny N, Fulmer T, et al. A longevity society requires integrated palliative care models for historically excluded older people. *The Lancet Healthy Longevity.* (2022) 3:e227–e8. doi: 10.1016/S2666-7568(22)00031-9

28. Currow DC, Abernethy AP, Fazekas BS. Specialist palliative care needs of whole populations: a feasibility study using a novel approach. *Palliat Med.* (2004) 18:239–47. doi: 10.1191/0269216304pm873oa

29. Currow DC, Allingham S, Bird S, Yates P, Lewis J, Dawber J, et al. Referral patterns and proximity to palliative care inpatient services by level of socio-economic disadvantage. A national study using spatial analysis. *BMC Health Serv Res.* (2012) 12:424. doi: 10.1186/1472-6963-12-424

30. Wright J, Williams R, Wilkinson JR. Development and importance of health needs assessment. *Bmj.* (1998) 316:1310–3. doi: 10.1136/bmj.316.7140.1310

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Prolonged grief during and beyond the pandemic: factors associated with levels of grief in a four time-point longitudinal survey of people bereaved in the first year of the COVID-19 pandemic

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Background: The COVID-19 pandemic has been a devastating and enduring mass-bereavement event, with uniquely difficult sets of circumstances experienced by people bereaved at this time. However, little is known about the long-term consequences of these experiences, including the prevalence of Prolonged Grief Disorder (PGD) and other conditions in pandemic-bereaved populations.

Methods: A longitudinal survey of people bereaved in the UK between 16 March 2020 and 2 January 2021, with data collected at baseline (*n* = 711), c. 8 (*n* = 383), 13 (*n* = 295), and 25 (*n* = 185) months post-bereavement. Using measures of Prolonged Grief Disorder (PGD) (Traumatic Grief Inventory), grief vulnerability (Adult Attitude to Grief Scale), and social support (Inventory of Social Support), this analysis examines how participant characteristics, characteristics of the deceased and pandemic-related circumstances (e.g., restricted visiting, social isolation, social support) are associated with grief outcomes, with a focus on symptoms of PGD.

Results: At baseline, 628 (88.6%) of participants were female, with a mean age of 49.5 (SD 12.9). 311 (43.8%) deaths were from confirmed/suspected COVID-19. Sample demographics were relatively stable across time points. 34.6% of participants met the cut-off for indicated PGD at c. 13 months bereaved and 28.6% at final follow-up. Social isolation and loneliness in early bereavement and lack of social support over time strongly contributed to higher levels of prolonged grief symptoms, while feeling well supported by healthcare professionals following the death was associated with reduced levels of prolonged grief symptoms. Characteristics of the deceased most strongly associated with lower levels of prolonged grief symptoms, were a more distant relationship (e.g., death of a grandparent), an expected death and death occurring in a care-home. Participant characteristics associated with higher levels of prolonged grief symptoms included low level of formal education and existence of medical conditions.

Conclusion: Results suggest higher than expected levels of PGD compared with pre-pandemic times, with important implications for bereavement policy, provision and practice now (e.g., strengthening of social and specialist support) and in preparedness for future pandemics and mass-bereavement events (e.g., guidance on infection control measures and rapid support responses).

KEYWORDS

bereavement, longitudinal, COVID-19, COVID-19 pandemic, grief, UK

1. Background

Millions of people were bereaved during the COVID-19 pandemic, with close to seven million reported deaths caused by the virus world-wide, and over 200,000 in the UK (1). This prolonged mass-bereavement event was characterized by high death-rates and unprecedented restrictions to usual end-of-life, death and mourning practices and social life in general. In the early months of the pandemic, observers predicted worsened grief and bereavement outcomes in response to the sudden and unexpected nature of COVID-19 deaths, the traumatic circumstances in which these deaths occurred and the likely diminished coping capacities of bereaved people (and the people and services supporting them) (2–4).

More than 3 years on from the start of the global pandemic, there is now a considerable body of evidence documenting the impacts of these devastating, unique sets of circumstances on those bereaved at this time. However, little is currently known about the longer-term consequences of pandemic bereavement, including which groups of people are most at risk of adverse outcomes over time and whether initial predictions of increased levels of Prolonged Grief Disorder (PGD) are substantiated (2–4). Although it is generally expected that most bereaved individuals will adequately cope with their grief and slowly readjust to life without the deceased, it is recognized that a significant minority of bereaved individuals will experience more complicated and problematic grieving processes, including development of PGD (5, 6). Essential characteristics of PGD include persistent and pervasive longing for, or preoccupation with, the deceased, associated with intense emotional pain (e.g., sadness, guilt, denial), functional impairment, and atypically prolonged symptoms relative to cultural norms (lasting a minimum of 6 months post-bereavement) (5–8). Although figures on PGD or complex grief vary between studies [e.g., between 6 and 20%; (5, 6, 9, 10)] in non-pandemic public health models, it is commonly accepted that around 10% of bereaved people will experience PGD, requiring specialist psychological intervention, while those with "moderate" level needs and risk (estimated at around 30%) may also need formal bereavement support such as peer-support groups or grief counseling (9, 11). Evidence on PGD levels during and following the pandemic is therefore needed to better understand the long-term grief and associated support-needs of people bereaved during this and future pandemics, with implications for bereavement service-planning and delivery. It is also critical for informing policy considerations relating to infection-control isolation measures in both the current COVID-19 recovery phase, and as part of our preparedness for future outbreaks of infectious diseases.

Most evidence to date on the grief and mental health consequences of pandemic bereavement is from studies conducted in China (12, 13), North America (14–18), Holland (4, 19, 20) and the earlier qualitative and quantitative results from this UK-based study (21–26). Several of these cross-sectional studies [including our baseline publication, (23)] indicate higher levels of grief and functional impairment among people bereaved during the pandemic, compared with pre-pandemic populations (14–20). Many of these studies have demonstrated the negative grief impacts of pandemic-specific or related circumstances. These have included restricted visiting at the end of life and opportunities to say goodbye (15, 17, 20, 24), sub-optimal communication and support from healthcare staff at the end of life (17, 22, 24), disrupted funerals (17, 23, 24), experiences of loneliness and isolation (8, 15, 17, 23, 24) and the role of disrupted meaning-making in mediating the effects of these sets of circumstances (15, 17). Another study, by contrast, found no differences in levels of PGD, attendance at, or evaluations of funerals and other mourning rituals, between pandemic and pre-pandemic bereaved populations (27).

Of particular interest early on in the pandemic was whether COVID-19 deaths would be associated with worse grief experiences than other types of death. Higher levels of grief and other psychological conditions have been identified among those bereaved by COVID-19 than would be expected in non-pandemic populations (12–14, 17), or compared with "natural" but not "unnatural" causes of deaths pre and during the pandemic (4, 18–20), with the "unexpected" nature of these deaths an explanatory factor (19, 20). However, other studies (including the baseline results from this study) have not found significant differences in grief and other psychological outcomes between COVID-19 and non-COVID-19 bereavement during the pandemic (15, 23). Several of these studies have also investigated the effects of demographic and other known risk factors for adverse grief and health outcomes. Consistent with pandemic (12–14, 28, 29) and non-pandemic research (9, 30), our baseline results identified relationship with the deceased as the strongest factor predicting grief vulnerability (23). Younger age of the deceased was also associated with worse baseline grief vulnerability (23), as in other studies (9, 29, 31). Age, gender, race/ethnicity of the bereaved person, and time since death were not significantly associated with level of grief in our baseline results (23) or functional impairment in one of the US studies (14). By contrast, lower levels of education were associated with poorer outcomes in our baseline results (23), reflecting the findings of previous non-pandemic research (32–34). Related associations with low income have also been identified, including a study involving pandemic and pre-pandemic bereaved participants (8).

However, to date no longitudinal results that we know of have been published on grief outcomes during the pandemic, and most of the above mentioned studies included pandemic-bereaved populations who were on average bereaved less than 6 months before [e.g., (4, 12, 14, 15, 17, 19, 20, 23)], thus limiting observations that can be made regarding levels of, and factors associated with, PGD symptoms in their respective populations. Addressing this knowledge gap, this paper reports longitudinal results regarding factors associated with PGD symptoms among a cohort of participants bereaved during the first two waves of the pandemic in the UK, using data collected at four time-point survey rounds, up to 25 months post-bereavement.

2. Methods

2.1. Study design and aim

A longitudinal survey of people bereaved during the pandemic in the UK. The web-based survey was conducted as part of a larger mixed methods study, which aimed to investigate the grief experiences, support needs and use of bereavement support by people bereaved during the pandemic (21–26). The current analysis examines how clinical and demographic factors, and pandemic-related challenges are associated with symptoms of PGD in a cohort of participants surveyed at baseline (T1) and c. 8, 13, and 25 months post-bereavement (T2–T4). The mediating role of perceived social support was also investigated in this analysis, reflecting its established importance for healthy grieving and adaptation [e.g., (10, 35–37)] and its likely association with other demographic factors potentially also predictive of grief severity (e.g., gender, ethnicity, age).

The Checklist for Reporting Results of Internet E-Surveys (38) was followed.

2.2. Survey development

An open web survey was designed by the research team, which includes a public representative (KS), with input from the study advisory group. Each survey was piloted, refined with public representatives with experience of bereavement, and tested by the study advisory group and colleagues. Non-randomized open and closed questions covered end of life experiences, grief experiences, and perceived needs for, access to and experiences of formal and informal bereavement support (21, 22).

2.3. Outcome measures

Prolonged Grief Disorder was assessed at surveys T2-T4 using the Traumatic Grief Inventory Self-Report version (TGI-SR) (39, 40). This widely used 18-item self-report measure assesses symptoms of Persistent Complex Bereavement Disorder (PCBD) and PGD, as defined by Prigerson et al. (6). The TGI-SR includes all 16 symptoms of PCBD, one additional symptom of PGD that is not part of the PCBD criteria (i.e., item 12: "feeling stunned/shocked") and one item tapping "functional impairment" (i.e., item 13), included in criteria-sets for both PCBD and PGD (40). Participants rated the frequency of symptoms (e.g., "I felt a strong longing or yearning for the deceased") during the previous month on 5-point scales (1 = never and 5 = always). Total scores ranged from 16 to 80. A cut-off score of ≥54 (i.e., mean item score of 3.0) is indicative of PCBD and PGD when using the total score (40). The measure was not used at baseline as PGD should be assessed at least 6 months after a death, and PCBD at least 12 months afterwards (39, 40).

Vulnerability in Grief was assessed in all survey time points using the validated 9-item Adult Attitude to Grief (AAG) scale (41), with our reasons for selecting this measure reported in baseline publications (21, 23). The scale is based on the Range of Response to Loss model (42), which identifies three distinct responses: being "overwhelmed," a state dominated by emotional/cognitive distress; being "controlled," needing to avoid emotional expression and focus on day-to-day life; and being balanced or "resilient," feeling supported and able to cope. AAG subscale scores indicate levels of feeling overwhelmed, controlled, and reversed resilience on a scale of 0 (none) to 12 (very high). An overall index of vulnerability (IoV) is calculated by summing subscale scores [IoV: 0–20 = low vulnerability, 21–23 = high vulnerability, and 24–36 = severe vulnerability (41)]. Although this analysis and publication is focused on symptoms of PGD, we included this measure to enable comparisons to be made with our analysis of baseline survey data, which did not include the TGI measure (23).

Social support was assessed using the Inventory of Social Support (ISS) (43). The ISS is a 5-item measure that assesses how far a bereaved person can talk with other people about their loss in a way which supports adaptive coping. The measure includes such statements as "I can express my feelings about my grief openly and honestly" "There is at least one person I can talk to about my grief." Participants respond to such statements on a 5-point Likert scale that ranges from 1 (Does not describe me very well) to 5 (Describes me very well). Higher scores on the ISS indicate higher levels of social support. Social support was investigated both as a dependent variable and as an independent variable in the PGD/TGI model.

2.4. Associated factors

We assessed whether participant characteristics and characteristics of the deceased, experiences of end-of-life care and pandemic-related problems independently predicted levels of PGD symptoms and grief vulnerability and whether perceived social support mediated the relationships of these variables and symptoms of PGD. Factors included in the analysis are recognized risk factors for poor bereavement outcomes (age of deceased and bereaved, gender, time since death, relationship to deceased, expectedness of the death, ability to say goodbye to the deceased, support from healthcare professionals at the end of life, perceived social support) (10, 23, 44–46) or are known to be indirectly associated with such outcomes (qualifications, health status, place of death, cause of death) (47, 48).

Six items at baseline assessed pandemic-related challenges prior to and after the death, e.g., being unable to visit the person who died prior to their death, restricted funeral arrangements, social isolation and loneliness. All items were answered yes/no. Respondents were asked to tick all experiences that applied to them.

See Supplementary Files 1, 2 for baseline and final questionnaires, including all measures used in this analysis.

2.5. Study procedure

The baseline survey was administered via JISC[1] and was open from 28th August 2020 to 5th January 2021 (21–24). It was disseminated to a convenience sample from social and mainstream media and via voluntary sector associations and bereavement support organizations, including those working with ethnic minority communities. Organizations helped disseminate the voluntary (non-incentivized) survey by sharing on social media, web-pages, newsletters, on-line forums and via direct invitations to potential participants. For ease of access, the survey was posted onto a bespoke study-specific website with a memorable URL.[2] Hard-copy postal surveys were available on request. The second, third and fourth follow up surveys were sent to baseline participants who consented to receive follow up surveys around seven, 13 and 25 months post date of death. These were personalized for each participant using individual survey links, labeled with their participant study IDs. Where baseline surveys were completed at least 5 months post-death (or the date of death was not given), the second survey was sent out 2 months after the first survey was received. All second-round surveys were completed between 20/11/20 and 24/08/2021 and on average 242 days (median = 234 days or 8 months) after the date of death (range 145 to 345 days). All third-round surveys were completed between 04/05/2021 and 09/01/22 and on average 408 days (median = 404 or 13 months) after the date of death (range 396–481 days). All fourth round surveys were completed between 17/05/2022 and 12/01/2023, on average 776 days (median = 774 or 25 months) after the date of death (range 762–812 days).

Inclusion criteria for study enrolment: aged 18+; family member or close friend bereaved since social-distancing requirements were introduced in the UK (16/03/2020); death occurred in the UK; ability to consent. The initial section of the survey requested informed consent and details data protection.

2.6. Data analysis

All analysis was performed using R (version 4.1.1), implemented in R-Studio[3] (49). Descriptive statistics were used to describe all variables. The main outcome variable of interest in this study was levels of PGD symptoms, assessed through the TGI questionnaire. ISS scores were used both as a predictor of levels of PGD symptoms and as an outcome variable, indirectly exploring the potential mediation effect of ISS between some of the independent variables and PGD levels. Since TGI and ISS scores were not collected at baseline, IoV scores for the AAG questionnaire were also used as an outcome variable to allow for comparisons between baseline and the other time points. Mean imputation was used to replace missing values in the AAG questionnaire for each sub-category if two of the three scores were available; IoV scores were used only if data were available for all three sub-categories. Mean imputation was also used to replace missing values for ISS and TGI scores. No more than 2% of data points were mean imputed for AAG and ISS at each round of surveys (including zero imputations for AAG at T4) and less than 5% of data points were mean imputed for TGI at each round of surveys. Most participants only had one missing value imputed and the maximum number of imputations for the same participant was three for TGI and ISS and two for AAG. The thresholds used for IoV categories followed Sim et al. (41) and the threshold used for PCBD and PGD was TGI score ≥ 54 (40).

Independent variables were classified into three categories: characteristics of the participant/bereaved, characteristics of the deceased, and characteristics of the experience of bereavement. The latter included the six items assessing the pandemic-related challenges prior to and after the death as well as whether participants felt well supported by healthcare professionals immediately after the death. For the analysis of levels of PGD symptoms, ISS was also included in this category.

Independent variables with more than 5% missing data at any of the four time points were not considered for analysis. A summary analysis of missing data was carried out for the remaining variables to check if there were any obvious patterns of missingness and none were identified. In order to maximize the sample, results presented are from analysis carried on all data available for each variable or combination of variables used in each analysis, but all the analyses were also carried out using complete cases (i.e., excluding any participants with at least one missing data for any of the variables of interest) as a control to ensure that the missing data were not causing a great influence in the results.

Days since bereavement was scaled into z-scores due to the wide range of values. This variable was initially tested both as a linear and as a quadratic term, but the latter showed very small effects and did not improve the fit of the statistical models significantly and hence the scaled linear effect was used instead. Other genders besides male or female were not included in the analysis due to the very small sample sizes. For relationship with the deceased, the categories "other family member" and "colleague or friend" were merged into one category in the analysis. Likewise, for place of death, the categories "other" and "do not know" were also merged. The existence of any medical conditions, whether the bereaved respondent was unemployed during the pandemic and whether they had suffered any further bereavements throughout the study were considered cumulatively, i.e., if a participant had reported a medical condition, becoming unemployed or suffering a further bereavement in one round of the survey, that was carried through even though they might not have reported it again in a subsequent round.

The first step of the analysis consisted of fitting Linear Mixed Models (LMMs) to assess the single effects of each independent variable on each of the outcome variables (IoV, ISS, and TGI scores). The second step consisted of fitting LMMs for each group of variables in combination to assess which group of variables (characteristics of the participant/bereaved, characteristics of the deceased, or characteristics of the experience of bereavement) were better at explaining each of the outcome variables.

The third step consisted of fitting LMMs that included all groups of variables in combination to assess the effect of the experience of

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[1] https://www.onlinesurveys.ac.uk/

[2] www.covidbereavement.com

[3] www.r-studio.com

bereavement in each of the outcome variables, while controlling for the characteristics of the participant/bereaved and the characteristics of the deceased. These models failed to converge and, hence, a Principal Component Analysis (PCA) was carried out on the six items assessing the pandemic-related challenges prior to and after the death, to assess if these could be reduced to a smaller number of factors. The models were initially run with the factors from the PCA, instead of the six different items. Variables with negligible effect sizes were then removed and the factors were replaced by the six items in the reduced model. The final models were used to compute and plot predictions showing the change of IoV, ISS, and TGI scores across time for the different levels of the independent variables that showed medium or strong effect sizes. For the TGI (symptoms of PGD), two different models were fit, one with ISS as predictor and one without, to assess the role of ISS as a potential mediator of other predictors.

All models included participant ID as random term and days since bereavement as a covariate. Interactions between days since bereavement and all other variables were tested at this stage. Statistically significant interactions ($p < 0.05$) found in the single models were also tested in the final models. Model estimates and standardized effect sizes were used to evaluate the effect of each variable independently on IoV, ISS, and TGI scores; Cohen's d were used for categorical predictors: $d = 0.3$: small effect, $d = 0.5$: medium effect, $d = 0.8$: large effect, $d = 1.2$: very large; and partial R for continuous predictors: <0.10: trivial effect, 0.1–0.3: small to medium effect, 0.3–0.5: medium to large effect, >0.50: large to very large effect (50). Where categorical predictors contained more than one group, we chose a reference category that allowed us to show the maximum difference in means between any two groups and the average standard deviation across all groups (i.e., maximum effect size of the difference). By using a standardized measure of effect size, the effects of factors on outcomes could be compared directly and patterns across multiple outcomes ascertained. Marginal R^2 (51) were used to assess the overall fit of the models in terms of their explanatory power and to explore which variables were the greatest contributors to explaining variability in IoV, ISS, and TGI scores.

The fit of the models was assessed visually. Residuals were checked for normality and homoscedasticity and all the models showed a good enough fit. Correlation matrices showed no problems with multicollinearity.

The full list of R packages and functions used in the analysis is presented in Supplementary File S3.

2.7. Ethical approval

The study was approved by Cardiff University School of Medicine Research Ethics Committee (SMREC 20/59) and conducted in accordance with the Declaration of Helsinki. All respondents provided informed consent.

3. Results

A total of 711 participants answered the survey at baseline (T1), 383 answered it in the second round (T2) and 295 answered it in the third round (T3), including 35 who had not completed T2. A total of 185 answered it on the fourth round (T4), two of whom had only completed T1 (but not T2 or T3) and 19 who had completed either T2 or T3. A total of 165 participants completed the survey at all time points.

3.1. Characteristics of the participants

Table 1 shows the characteristics of the participants for each round of surveys. The average age of participants was around 50 and most participants were women, heterosexual and white. Across the four rounds of the study there was a tendency of the youngest and oldest participants to stop engaging, as well as those from minoritized ethnic backgrounds and those with lowest qualification levels. Over three quarters of the participants had not suffered unemployment or further bereavements at baseline, but toward the end of the study approximately 40% had experienced either at some point since the start of the pandemic. Similarly, approximately 40% of participants reported having medical conditions at baseline, but toward the end of the study, this increased to approximately 60% of participants. Overall, there was no strong change in participants' demographic characteristics throughout the study. Spiritual/religious beliefs, sexual orientation and region were not considered for analyses due to high levels (over 5%) of missing data for these items.

3.2. Characteristics of the deceased

Table 2 shows the characteristics of the deceased person for each round of surveys. Across the study, days since bereavement ranged from 1 to 812 days. The mean age of the deceased across the four timelines was either 72 or 73 and the median was 74, with a range of less than 1 year (during pregnancy) to 102 years. Over 70% of participants lost either their parent (56%) or their partner (21%); 2.1% experienced the death of their child and 3.2% of their sibling. There was an increase in the percentage of those who lost a partner across the four time-points in the study and a decrease in the percentage of those who lost a grandparent or a family member in the "other" category, suggesting lower retention in the latter. A slight majority of deaths were not due to COVID-19 and over 70% were unexpected by the bereaved respondent. Most deaths occurred in the hospital, followed by at home and in a care home. These trends were very similar across the whole study period.

3.3. Characteristics of the experience of bereavement

Table 3 summarizes the characteristics of the experience of bereavement in terms of pandemic-related challenges before or after the death of a loved one and the support received by healthcare professionals immediately following the death. Most participants reported having had restricted funeral arrangements and limited contact with close relatives or friends (over 90% and over 80% across all time points, respectively), while a smaller majority reported a sense of isolation and loneliness (66.7% at baseline, varying by a maximum of 5.7 percentual points across all time points). Smaller majorities also reported being unable to say goodbye as they liked (63.9% at baseline, varying by a maximum of 2.9 percentual points across time points)

TABLE 1 Characteristics of the bereaved person.

	T1 (n = 711)			T2 (n = 383)			T3 (n = 295)			T4 (n = 185)		
Age	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max
	8	50 ± 13 [50]	18–90	3	51 ± 13 [53]	21–90	4	51 ± 13 [52]	22–86	3	53 ± 12 [55]	22–84
Gender identity	n	%		n	%		n	%		n	%	
Man	74	10.0%		45	12.0%		32	11.0%		25	14.0%	
Woman	628	89.0%		336	88.0%		261	89.0%		159	86.0%	
Non-binary/Other	5	0.7%		1	0.3%		1	0.3%		0	0.0%	
Didn't respond/ Missing data	2			1			1			1		
Sexual orientation	n	%		n	%		n	%		n	%	
Asexual	1	0.2%		0	0.0%		0	0.0%		0	0.0%	
Bisexual/ Bicurious/ Pansexual	19	3.1%		6	1.8%		5	1.9%		3	1.8%	
Gay/Lesbian/ Queer	28	4.6%		22	6.5%		17	6.4%		9	5.4%	
Straight	564	92.0%		313	92.0%		242	91.3%		154	93.0%	
Unsure	1	0.2%		0	0.0%		1	0.4%		0	0.0%	
Didn't respond/ Missing data	98			42			30			19		
Ethnicity	n	%		n	%		n	%		n	%	
White (total)	676	95.3%		368	96.3%		287	97.6%		180	97.8%	
White British	438	64.8%		241	66.5%		179	62.4%		114	63.3%	
White English	111	16.4%		68	18.5%		51	17.8%		31	17.2%	
White Welsh	41	6.1%		21	5.7%		17	5.9%		13	7.2%	
White Scottish	40	5.9%		19	5.2%		20	7.0%		10	5.6%	
White Northern Irish	22	3.3%		10	2.7%		9	3.1%		5	2.8%	
White Irish	7	1.0%		2	0.5%		3	1.0%		3	1.7%	
Any other white background	17	2.5%		7	1.9%		8	2.8%		4	2.2%	
Minoritized ethnic (total)	33	4.7%		14	3.7%		7	2.4%		4	2.2%	

(Continued)

TABLE 1 (Continued)

	T1 (*n* = 711)			T2 (*n* = 383)			T3 (*n* = 295)			T4 (*n* = 185)		
Age	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max
	8	50 ± 13 [50]	18–90	3	51 ± 13 [53]	21–90	4	51 ± 13 [52]	22–86	3	53 ± 12 [55]	22–84
White and Black Caribbean	11	33.3%		3	21.4%		1	14.3%		1	25.0%	
Black Caribbean	4	12.1%		2	14.3%		1	14.3%		0	0.0%	
White and Black African	2	6.1%		0	0.0%		0	0.0%		0	0.0%	
Arab	1	3.0%		1	7.1%		1	14.3%		0	0.0%	
Bangladeshi	2	6.1%		1	7.1%		1	14.3%		1	25.0%	
Pakistani	1	3.0%		0	0.0%		0	0.0%		0	0.0%	
Indian	4	12.1%		3	21.4%		0	0.0%		0	0.0%	
White and Asian	4	12.1%		3	21.4%		2	28.6%		2	50.0%	
Any other Asian background	1	3.0%		0	0.0%		0	0.0%		0	0.0%	
Any other mixed background	3	9.1%		1	7.1%		1	14.3%		0	0.0%	
Didn't respond/ Missing data	2			1			1			1		
Spiritual/Religious beliefs	n	%		n	%		n	%		n	%	
Buddhism	8	1.2%		4	1.1%		2	0.7%		1	0.6%	
Christianity	244	37.7%		144	40.1%		111	39.6%		76	43.4%	
Hinduism	3	0.5%		1	0.3%		0	0.0%		0	0.0%	
Islamism	5	0.8%		2	0.6%		2	0.7%		2	1.1%	
Judaism	6	0.9%		2	0.6%		3	1.1%		2	1.1%	
Sikhism	2	0.3%		1	0.3%		0	0.0%		0	0.0%	
Other	5	0.8%		3	0.8%		3	1.1%		2	1.1%	
Spiritual but not religious	68	10.5%		43	12.0%		31	11.1%		18	10.3%	
Agnostic*	25	3.9%		9	2.5%		8	2.9%		4	2.3%	
Spiritual or religious (total)	349	53.9%		203	56.5%		155	55.4%		103	58.9%	

(Continued)

TABLE 1 (Continued)

	T1 (*n* = 711)			T2 (*n* = 383)			T3 (*n* = 295)			T4 (*n* = 185)		
Age	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max
	8	50 ± 13 [50]	18–90	3	51 ± 13 [53]	21–90	4	51 ± 13 [52]	22–86	3	53 ± 12 [55]	22–84
No religious beliefs	298	46.1%		150	41.8%		125	44.6%		72	41.1%	
Didn't respond/ Missing data	64			24			15			10		
Highest qualification	n	%		n	%		n	%		n	%	
None/GCSEs	108	15.0%		49	13.0%		35	12.0%		25	14.0%	
A-level/ apprenticeship/ ONC	132	19.0%		68	18.0%		48	16.0%		24	13.0%	
HND/University degree	468	66.0%		266	69.0%		212	72.0%		136	74.0%	
Didn't respond/ Missing data	3			0			0			0		
Region/Country	n	%		n	%		n	%		n	%	
England (total)	517	72.4%		291	75.9%		216	73.7%		132	71.4%	
East Midlands	39	5.5%		22	5.7%		19	6.4%		12	6.5%	
West Midlands	52	7.3%		27	7.0%		20	6.8%		12	6.5%	
East of England	39	5.5%		25	6.5%		19	6.4%		13	7.0%	
Greater London	68	9.6%		43	11.0%		37	13.0%		24	13.0%	
Yorkshire and the Humber	55	7.7%		31	8.1%		25	8.5%		12	6.5%	
North East	40	5.6%		20	5.2%		12	4.1%		6	3.2%	
North West	95	13.0%		45	12.0%		28	9.5%		15	8.1%	
South East	78	11.0%		46	12.0%		29	9.8%		21	11.4%	
South West	51	7.2%		32	8.4%		27	9.2%		17	9.2%	
Northern Ireland	26	3.7%		12	3.1%		10	3.4%		5	2.7%	
Scotland	53	7.5%		28	7.3%		28	9.5%		17	9.2%	
Wales	63	8.9%		37	9.7%		26	8.8%		20	10.8%	
Didn't respond/ Missing data	52			15			15			11		

(Continued)

TABLE 1 (Continued)

	T1 (*n* = 711)			T2 (*n* = 383)			T3 (*n* = 295)			T4 (*n* = 185)		
Age	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max
	8	50 ± 13 [50]	18–90	3	51 ± 13 [53]	21–90	4	51 ± 13 [52]	22–86	3	53 ± 12 [55]	22–84
Medical conditions	n	%		n	%		n	%		n	%	
Yes (at baseline/ cumulative)	279	39.8%		162/192	42.7%/50.7%		113/147	38.7%/50.3%		75/111	41%/60.3%	
No (at baseline/ cumulative)	422	60.2%		217/187	57.3%/49.3%		179/145	61.3%/49.7%		108/73	59%/39.7%	
Didn't respond/ Missing data	10			5			3			2/1		
Unemployed during the pandemic?	n	%		n	%		n	%		n	%	
Yes (at baseline/ cumulative)	55	7.9%		39/56	10.3%/14.8%		24/75	8.3%/25.8%		14/68	7.7%/37.2%	
No (at baseline/ cumulative)	645	92.1%		339/322	89.7%/85.2%		267/216	91.7%/74.2%		169/115	92.3%/62.8%	
Didn't respond/ Missing data	11			6			4			2		
Further bereavements during the study?	n	%		n	%		n		%	n	%	
Yes (at baseline/ cumulative)	158	22.5%		80/116	21.2%/30.3%		64/103		22.2%/34.9%	38/81	21.0%/43.8%	
No (at baseline/ cumulative)	543	77.5%		297/267	78.8%/69.7%		224/192		77.8%/65.1%	143/104	79%/56.2%	
Didn't respond/ Missing data	10			7/1			7/0			4/0		

All variables were taken at baseline only, except for medical conditions, becoming unemployed and other recent bereavements. *Some participants who reported being agnostic were classified as spiritual/religious while others were classified as having no spiritual beliefs or religion, depending on the answers they provided in the long text box.

TABLE 2 Characteristics of the deceased.

	T1 (*n* = 711)			T2 (*n* = 383)			T3 (*n* = 295)			T4 (*n* = 185)		
	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max
Days since death	4	137 ± 65 [152]	1–279	0	242 ± 28 [234]	145–345	0	408 ± 12 [404]	396–481	0	775 ± 11 [774]	762–812
Age	7	72 ± 16 [74]	<1–102	3	72 ± 17 [74]	<1–102	2	73 ± 16 [74]	<1–100	0	72 ± 16 [74]	<1–100
Relationship of the deceased person to the bereaved	n	%		n	%		n	%		n	%	
Partner	152	21.0%		97	25.0%		78	26.0%		57	31.0%	
Parent	395	56.0%		216	56.0%		169	57.0%		102	55.0%	
Grandparent	54	7.6%		15	3.9%		13	4.4%		2	1.1%	
Sibling	23	3.2%		14	3.7%		8	2.7%		5	2.7%	
Child	15	2.1%		10	2.6%		7	2.4%		6	3.2%	
Other family member	46	6.5%		18	4.7%		12	4.1%		5	2.7%	
Colleague or friend	26	3.7%		13	3.4%		8	2.7%		8	4.3%	
Didn't respond/ Missing data	0			0			0			0		
Cause of death	n	%		n	%		n	%		n	%	
COVID (confirmed or suspected)	311	44.0%		164	43.0%		122	41.0%		79	43.0%	
Non-COVID (total)	399	56.0%		219	57.0%		173	59.0%		106	57.0%	
Cancer	156	39.1%		92	42.0%		75	43.4%		49	46.2%	
Other LLC*	118	29.6%		64	29.2%		51	29.5%		31	29.2%	
Non LLC**	112	28.1%		57	26.0%		45	26.0%		25	23.6%	
Do not know	12	3.0%		6	2.7%		2	1.2%		1	0.9%	
Not specified	1	0.3%		0	0.0%		0	0.0%		0	0.0%	
Didn't respond/ Missing data	1			0			0			0		

(Continued)

TABLE 2 (Continued)

	T1 (*n* = 711)			T2 (*n* = 383)			T3 (*n* = 295)			T4 (*n* = 185)		
	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max
Days since death	4	137 ± 65 [152]	1–279	0	242 ± 28 [234]	145–345	0	408 ± 12 [404]	396–481	0	775 ± 11 [774]	762–812
Was the death expected?	n	%		n	%		n	%		n	%	
Yes	113	16.0%		65	17.0%		58	20.0%		37	20.0%	
No	552	78.0%		293	77.0%		215	73.0%		137	74.0%	
Do not know	43	6.1%		24	6.3%		21	7.1%		10	5.4%	
Didn't respond/ Missing data	3			1			1					
Place of death	n	%		n	%		n	%		n	%	
In hospital	410	58.0%		208	54.0%		160	54.0%		94	51.0%	
In their home	158	22.0%		92	24.0%		74	25.0%		45	24.0%	
In a hospice	37	5.2%		24	6.3%		15	5.1%		11	5.9%	
In a care home	91	13.0%		53	14.0%		42	14.0%		32	17.0%	
Other	11	1.6%		6	1.6%		4	1.4%		3	1.6%	
Do not know	2	0.3%		0	0.0%		0	0.0%		0	0.0%	
Didn't respond/ Missing data	2			0			0			0		

*LLC, Life-limiting condition, for example, heart disease, COPD, dementia. **Examples of non-LLC are stroke, heart attack, accident, suicide.

TABLE 3 Characteristics of the experience of bereavement regarding COVID-19 restrictions and perceived level of support offered by healthcare professionals.

	T1 (*n* = 711)		T2 (*n* = 383)		T3 (*n* = 295)		T4 (*n* = 185)	
Contact prior to death	n (yes)	%	n (yes)	%	n (yes)	%	n (yes)	%
Unable to visit them prior to their death	386	54.3%	188	49.0%	136	46.1%	87	47.0%
Unable to say goodbye as I would have liked	454	63.9%	238	62.1%	180	61.0%	114	61.6%
Limited contact with them in last days of their life	411	57.8%	222	58.0%	174	59.0%	107	57.8%
Social isolation	n (yes)	%	n (yes)	%	n (yes)	%	n (yes)	%
Restricted funeral arrangements	664	93.4%	363	94.8%	280	94.9%	176	95.1%
Limited contact with other close relatives or friends	574	80.7%	318	83.0%	253	85.8%	157	84.9%
Sense isolation and loneliness	474	66.7%	267	69.7%	200	67.8%	134	72.4%
Number of negative experiences related to contact prior to death	n	%	n	%	n	%	n	%
0	147	21.0%	88	23.0%	74	25.0%	44	23.8%
1	128	18.0%	69	18.0%	50	17.0%	34	18.4%
2	185	26.0%	99	26.0%	73	25.0%	47	25.4%
3	251	35.0%	127	33.0%	98	33.0%	60	32.4%
Number of negative experiences related to social isolation	n	%	n	%	n	%	n (yes)	%
0	26	3.7%	11	2.9%	7	2.4%	3	1.6%
1	87	12.0%	44	11.0%	33	11.0%	21	11.4%
2	169	24.0%	80	21.0%	65	22.0%	37	20.0%
3	429	60.0%	248	65.0%	190	64.0%	124	67.0%
Total number of negative experiences	n	%	n	%	n	%	n	%
0	9	1.3%	5	1.3%	4	1.4%	1	0.5%
1	38	5.3%	17	4.4%	12	4.1%	7	3.8%
2	68	9.6%	40	10.0%	32	11.0%	18	9.7%
3	127	18.0%	68	18.0%	56	19.0%	38	20.5%
4	127	18.0%	68	18.0%	49	17.0%	32	17.3%
5	152	21.0%	87	23.0%	69	23.0%	44	23.8%
6	190	27.0%	98	26.0%	73	25.0%	45	24.3%
Felt supported by healthcare professionals	n	%	n	%	n	%	n	%
Not at all supported	252	35.0%	138	36.0%	101	34.0%	68	36.8%
A little bit supported	139	20.0%	70	18.0%	62	21.0%	44	23.8%
Fairly well supported	105	15.0%	61	16.0%	44	15.0%	23	12.4%
Very well supported	95	13.0%	61	16.0%	50	17.0%	30	16.2%
Not relevant (not next of kin)	120	17.0%	53	14.0%	38	13.0%	20	10.8%
Didn't respond/Missing data	0		0		0		0	

and having limited contact with the deceased in the last days of their lives (57.8% at baseline, varying by a maximum of 1.2 percentual points across time points), while approximately half of respondents reported being unable to visit the deceased in the last days of their lives (54.3% at baseline, varying by a maximum of 8.2 percentual points across time points). Accordingly, a greater proportion of people reported facing all three challenges related to social isolation (60%, at baseline, varying by a maximum of 7 percentual points across time points) compared to the proportion of people who reported facing all three challenges related to contact prior to death (35%, at baseline, varying by a maximum of 2.6 percentual points across time points). Less than 2% of people reported not facing any of the COVID-19 related challenges and around a quarter of respondents reported facing all six challenges. Approximately 20% reported facing three, four or five of the challenges. Over half of the participants felt little or no support by healthcare professionals and only 20% reported feeling very well supported. Changes in these proportions across time points do not suggest major bias in sample retention regarding experience of bereavement.

3.4. Grief and social support outcomes

Table 4 summarizes the participants' outcome measures across the study.

TGI: Mean TGI (PGD) score at T2 was 51.5. This decreased steadily across survey time points, dropping to 48.5 at T3 and 44.7 at T4. At T2 43.7% met the threshold for indicated PGD (≥54), dropping to 34.6% at T3 (c.13 months post-bereavement) and 28.6% at final follow up, c. 25 months post-bereavement.

AAG: Mean IoV (grief vulnerability) score at baseline was 20.4, decreasing slightly but steadily to 18.7 at T3 and 18.3 at 24. At baseline 48.4% exhibited low levels of vulnerability (i.e., $0 \leq \text{IoV} \leq 20$); 23.4% exhibited high levels (i.e., $21 \leq \text{IoV} \leq 23$), and 28.2% exhibited severe levels (i.e., $\text{IoV} \geq 24$). By T4 67% exhibited low levels of vulnerability, 18.9% exhibited high levels and 13.5% demonstrated severe levels.

ISS: Social support scores were stable and did not change across survey time points. Mean ISS score at T2,T3,T4 was 3.3 (see Table 4). This could be interpreted as feeling "fairly well supported," with a score of 5 meaning "very well" and a score of 1 meaning "not at all."

3.5. Factors associated with levels of prolonged grief symptoms, social support and vulnerability in grief

Table 5 shows the effect sizes for each individual variable from the single models on TGI (PGD symptoms), ISS and IoV and the marginal R^2 values for the models containing each set of variables. Table 6 shows the model outputs for the full models containing all groups of variables in combination to assess the effect of the experience of bereavement in each of the outcome variables, while controlling for the characteristics of the participant/bereaved and the characteristics of the deceased; Figures 1–4 show the model predictions for TGI (PGD symptoms), ISS and IoV for variables that had the largest effect sizes.

Across all the analyses, characteristics of the deceased were generally and consistently the best predictors of all three indices: TGI (PGD symptoms), ISS and IoV. For TGI and IoV, relationship with deceased, followed by place of death, showed the largest effect sizes across all variables, while for ISS, the largest effects were from feeling supported by health care professionals following the death and ethnicity, only then followed by place of death and relationship with deceased. Ethnicity also showed a large effect on TGI, with white respondents showing worse grief outcomes compared to minoritized ethnic respondents, but not on IoV. Qualifications showed large effects for TGI and IoV, with those from lower education levels showing worse grief outcomes, but not for ISS. All items related to contact prior to death showed small effects for all three indices, while items for social isolation showed large and very large effects for TGI and IoV; specifically sense of isolation and loneliness had a very large effect on TGI and a large effect on IoV, while restricted funeral arrangements had a large effect on TGI but a medium effect on IoV. Days since death had a larger effect on TGI than IoV or ISS; although the effect of the slope is not very large even for TGI, it represents a considerable change in TGI scores over an extended period of time (e.g., an approximate reduction of 4 scale points in TGI for each 5 months).

3.6. Effect of time

Figure 1 shows trends of TGI, ISS, and IoV in relation to time since bereavement. There was a general tendency for TGI and IoV to improve with time, which was more noticeable for TGI than for IoV. Furthermore, there was an interaction between days since bereavement and age of participant for IoV, with younger participants improving more through time compared to older participants. The relationship between days since bereavement and ISS is less strong with a slight tendency for ISS to improve with time, although this is mainly driven by those from minoritized ethnic groups, with white participants showing no change in ISS through time. Although only the linear trend was fitted for simplicity, visual analysis showed that the sharpest decline in grief scores seem to occur between 6 months to a year since bereavement.

These were general patterns averaged across participants, but it was noticeable that for all indices of bereavement different participants would show different patterns, with some improving through time, some worsening through time, some showing oscillations but no real trend and some showing no change (Figure 5).

3.7. Effect of experience of bereavement

The results from the full models examining the effects of the experiences of bereavement while controlling for characteristics of the participant and the bereaved, showed that sense of isolation and feeling supported by healthcare professionals were the most important experiences in predicting TGI and IoV scores, while only the latter was an important predictor of ISS. Those who felt very well supported by healthcare professionals showed better grief and support outcomes compared to all other groups. ISS score was also an important predictor of TGI; in the same model but without ISS, feeling supported by healthcare professionals showed a much larger effect on TGI than when ISS was included, which suggests that ISS has a mediating effect

TABLE 4 Summary of participants' grief and support outcomes across the study.

	T1 (n = 711)			T2 (n = 383)			T3 (n = 295)			T4 (n = 185)		
				Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max
ISS (1–5)				2	3.3 ± 0.9 [3.2]	1–5	0	3.3 ± 0.9 [3.2]	1–5	0	3.3 ± 0.9 [3.2]	1–5
TGI (PGD score) (18–90)				1	51.5 ± 14.6 [52]	22–90	0	48.5 ± 14.7 [48]	18–89	0	44.7 ± 15.1 [43]	20–90
PGD Diagnosis (≥54)				n	%		n	%		n	%	
Yes				167	43.7%		102	34.6%		53	28.6%	
No				215	56.3%		193	65.4%		132	71.4%	
Didn't respond/ Missing data				1			0			0		
	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max	Missing	Mean ± SD [Median]	Min-Max
AAG (IoV score) (0–34)	13	20.4 ± 4.8 [21]	4–34	5	19.6 ± 4.9 [20]	6–31	0	18.7 ± 4.4 [19]	5–33	0	18.3 ± 4.7 [18]	6–29
IoV risk	n	%		n	%		n	%		n	%	
Low (0–20)	338	48.4%		218	57.7%		200	67.8%		125	67.6%	
High (21–23)	163	23.4%		71	18.8%		58	19.7%		35	18.9%	
Extreme (≥ 24)	197	28.2%		89	23.5%		37	12.5%		25	13.5%	
Didn't respond/ Missing data	13			5			0			0		

TABLE 5 Results of the mixed models with participant ID as random term, days since bereavement as co-variate and each of the predictors individually.

	TGI (PGD score) (18–90)				ISS (1–5)				AAG (IoV score) (0–34)			
	Coeff.	SE	DF	Partial R	Coeff.	SE	DF	Partial R	Coeff.	SE	DF	Partial R
Age of participant	0.038	0.056	408	0.03	0.0008	0.003	406	−0.02	0.011	0.013	680	0.03
	Diff	SE	DF	Cohen's *d*	Diff	SE	DF	Cohen's *d*	Diff	SE	DF	Cohen's *d*
Gender identity												
Man—Woman	−4.34	2.24	408	−0.648	0.19	0.13	401	0.351	−0.27	0.55	657	−0.096
Ethnicity												
White—Minoritized ethnic	7.80	3.94	432	1.160	−0.53	0.23	441	−0.977	0.71	0.80	753	0.249
Highest qualification												
A-level/apprenticeship/ONC—None/GCSEs	−3.16	2.55	419	−0.478	0.15	0.15	421	0.286	−0.55	0.58	703	−0.195
HND/University degree/Postgraduate (etc.)—None/GCSEs	−8.62	2.12	414	−1.307	0.13	0.13	412	0.249	−2.33	0.48	699	−0.823
HND/University Degree/Postgraduate (etc.)—A-level/apprenticeship/ONC	−5.45	1.84	423	−0.829	−0.02	0.11	428	−0.037	−1.78	0.43	692	−0.628
Medical conditions												
Yes—No	2.53	1.09	829	0.375	−0.12	0.07	714	−0.216	0.71	0.24	1,531	0.150
Unemployed during the pandemic												
Yes—No	−0.72	1.09	786	−0.107	0.06	0.08	845	0.110	−0.61	0.33	1,496	−0.215
Further bereavements during the study												
Yes—No	−0.64	1.08	858	−0.095	<−0.0001	0.07	790	−0.0001	−0.24	0.28	1,527	−0.0854
Marginal R2 (95%CI)	0.086 (0.061–0.134)				0.023 (0.019–0.064)				0.063 (0.047–0.094)			
	Coeff.	SE	DF	Partial R	Coeff.	SE	DF	Partial R	Coeff.	SE	DF	Partial R
Days since death (scaled)	−2.538	0.262	471	−0.41	−0.001	0.021	499	−0.02	−0.601	0.082	1,009	−0.23
Age of deceased	−0.171	0.043	408	−0.2	−0.005	0.003	405	−0.1	−0.047	0.01	668	−0.17
	Diff	SE	DF	Cohen's *d*	Diff	SE	DF	Cohen's *d*	Diff	SE	DF	Cohen's *d*
Relationship of the deceased person to the bereaved (reference = Partner)												
Parent	−6.79	1.61	405	−1.011	−0.31	0.10	398	−0.581	−1.92	0.40	646	−0.676
Grandparent	−17.60	3.54	428	−2.623	−0.30	0.22	438	−0.561	−2.86	0.69	759	−1.010
Sibling	−4.23	4.05	415	−0.630	−0.42	0.24	420	−0.771	−1.30	0.97	678	−0.459
Child	−4.29	4.52	401	−0.639	−0.18	0.27	390	−0.337	0.35	1.13	640	0.123
Other family member or a colleague or friend	−15.70	2.75	415	−2.339	0.12	0.17	413	0.220	−4.42	0.63	699	−1.560
Cause of death												
Non-COVID—COVID	−6.01	1.40	416	−0.897	0.18	0.08	414	0.332	−1.66	0.33	683	−0.587

(Continued)

TABLE 5 (Continued)

	TGI (PGD score) (18–90)				ISS (1–5)				AAG (IoV score) (0–34)			
	Coeff.	SE	DF	Partial R	Coeff.	SE	DF	Partial R	Coeff.	SE	DF	Partial R
Was the death expected?												
Yes—No	−9.05	1.79	412	−1.350	0.21	0.11	407	0.391	−2.06	0.44	659	−0.728
Place of death (reference = in a care home)												
In hospital	9.12	2.10	404	1.359	−0.09	0.13	395	−0.170	2.30	0.51	663	0.811
In their home	2.87	2.34	405	0.429	0.10	0.14	397	0.194	1.54	0.57	657	0.542
In a hospice	6.58	3.43	409	0.982	−0.15	0.21	402	−0.284	2.67	0.85	663	0.942
Other	9.54	6.03	408	1.423	0.47	0.36	400	0.868	1.56	1.39	685	0.551
Marginal R2 (95%CI)	0.210 (0.174–0.266)				0.056 (0.042–0.103)				0.145 (0.120–0.183)			
	Diff	SE	DF	Cohen's *d*	Diff	SE	DF	Cohen's *d*	Diff	SE	DF	Cohen's *d*
Contact prior to death (Yes—No)												
Unable to visit them prior to their death	−0.52	1.41	417	−0.078	−0.18	0.08	414	−0.335	0.13	0.33	678	0.045
Unable to say goodbye as I would have liked	1.23	1.45	416	0.183	−0.10	0.09	414	−0.194	0.55	0.35	682	0.194
Limited contact with them in last days of their life	1.57	1.43	417	0.234	−0.01	0.08	414	−0.026	0.08	0.34	682	0.029
Social isolation (Yes—No)												
Restricted funeral arrangements	3.66	3.23	413	0.545	−0.32	0.19	408	−0.590	1.52	0.69	719	0.537
Limited contact with other close relatives or friends	5.60	1.91	419	0.834	−0.24	0.11	420	−0.452	0.98	0.43	709	0.346
Sense isolation and loneliness	9.42	1.48	411	1.400	−0.16	0.09	406	−0.305	2.30	0.35	691	0.812
Feel supported (reference = Not at all supported)												
A little bit supported	−1.55	1.95	408	−0.231	0.29	0.11	400	0.534	−0.92	0.46	675	−0.326
Fairly well supported	−0.71	2.07	421	−0.107	0.35	0.12	424	0.645	−0.91	0.50	675	−0.322
Very well supported	−7.31	2.08	410	−1.091	0.64	0.12	404	1.183	−2.82	0.51	651	−0.999
Not relevant (not next of kin)	−8.72	2.23	416	−1.301	0.32	0.13	417	0.594	−2.54	0.49	711	−0.898
	Coeff.	SE	DF	Partial R	Coeff.	SE	DF	Partial R	Coeff.	SE	DF	Partial R
Total number of negative experiences	1.439	0.453	411	0.15	−0.065	0.027	404	−0.12	0.363	0.106	691	0.13
ISS	−3.194	0.473	790	−0.23								
Marginal R2 (95%CI)*	0.171 (0.138–0.225)				0.070 (0.051–0.117)				0.101 (0.08–0.135)			

The table is split by groups of variables: characteristics of the participants in yellow; characteristics of the deceased in salmon and characteristics of the experience of the bereavement in blue. Marginal R-squared are presented for the models containing each group of variables. Partial R and the Cohen's *d*, the intensity of the shading reflects the strength of the effect.
*Model do not converge with all variables so ran it without number of negative experiences, as the variable with smallest effect.

TABLE 6 Outcomes of the General Linear Mixed models for TGI score, ISS, and AAG score with participant ID as random term, days since bereavement as covariate and all the predictors in combination (excluding those with very small effects for each given model that were necessary to remove for the model to fit appropriately—further bereavements during the study and total number of negative experiences were included in the starting models but were removed from all the models due to small effects).

	TGI (PGD score)			ISS			AAG (IoV score)		
Predictors [Reference category]	Estimates	95% CI	*p*	Estimates	95% CI	*p*	Estimates	95% CI	*p*
(Intercept)	68.31	54.26 to 82.37	**<0.001**	3.91	2.95 to 4.87	**<0.001**	22.97	20.07 to 25.87	**<0.001**
Days (scaled)	−2.69	−3.21 to −2.17	**<0.001**	0.35	0.08 to 0.63	**0.011**	−1.88	−2.57 to −1.19	**<0.001**
Gender—Male [Female]	−1.86	−5.84 to 2.13	0.361	0.14	−0.13 to 0.42	0.298	*	*	*
Ethnicity—White [Minoritized Ethnic]	4.9	−2.40 to 12.21	0.188	−0.18	−0.70 to 0.33	0.487	*	*	*
Medical conditions—Yes [No]	2.17	0.21 to 4.13	**0.03**	−0.12	−0.26 to 0.02	0.102	*	*	*
Unemployed during the pandemic—Yes [No]	*	*	*	0.01	−0.14 to 0.17	0.854	*	*	*
Highest qualification—A-level/ apprenticeship/ ONC [No qualifications]	−1.79	−6.25 to 2.67	0.432	0.07	−0.24 to 0.37	0.663	−0.08	−1.14 to 0.98	0.886
Highest qualification—HND/University Degree/ Postgraduate (etc.) [No qualifications]	−5.19	−9.01 to −1.38	**0.008**	0.03	−0.24 to 0.29	0.851	−1.27	−2.19 to −0.35	0.007
Age of participant				−0.01	−0.02 to 0.01	0.372	0.02	−0.02 to 0.06	0.27
Relationship—Parent [Partner]	−4.18	−7.49 to −0.87	**0.013**	−0.38	−0.72 to −0.03	**0.031**	−0.57	−1.75 to 0.60	0.34
Relationship—Sibling [Partner]	−3.58	−10.87 to 3.70	0.335	−0.17	−0.66 to 0.32	0.499	−1.73	−3.62 to 0.16	0.072
Relationship—Child [Partner]	−11.42	−20.58 to −2.25	**0.015**	−0.29	−0.93 to 0.36	0.383	−1.32	−3.66 to 1.01	0.267
Relationship—Grandparent [Partner]	−10.03	−17.84 to −2.22	**0.012**	−0.44	−1.19 to 0.31	0.252	−0.47	−2.74 to 1.80	0.683
Relationship—Other [Partner]	−10.52	−16.37 to −4.68	**<0.001**	0.16	−0.26 to 0.58	0.465	−2.84	−4.26 to −1.42	**<0.001**
Death expected—Yes [No]	−6.39	−9.96 to −2.81	**<0.001**	0.04	−0.20 to 0.28	0.737	−1.42	−2.32 to −0.51	**0.002**
Place of death—In a hospice [Care home]	5.5	−1.02 to 12.02	0.098	−0.44	−0.88 to −0.00	**0.047**	3.24	1.58 to 4.89	**<0.001**
Place of death—In hospital [Care home]	4.77	0.91 to 8.64	**0.016**	−0.16	−0.42 to 0.10	0.241	1.42	0.45 to 2.39	**0.004**

(Continued)

TABLE 6 (Continued)

	TGI (PGD score)			ISS			AAG (IoV score)		
Predictors [Reference category]	Estimates	95% CI	*p*	Estimates	95% CI	*p*	Estimates	95% CI	*p*
Place of death—In their home [Care home]	3.45	−1.23 to 8.14	0.148	0	−0.31 to 0.32	0.991	2	0.82 to 3.18	**0.001**
Place of death—Other [Care home]	8.46	−3.11 to 20.04	0.152	0.48	−0.29 to 1.26	0.221	0.95	−1.73 to 3.62	0.487
Cause of death—Non-Covid [Covid]	−1.32	−4.42 to 1.78	0.405	0	−0.21 to 0.21	0.978	−0.93	−1.70 to −0.17	**0.016**
Age of deceased person	−0.11	−0.21 to −0.00	**0.043**	0	−0.01 to 0.01	0.769	−0.05	−0.08 to −0.01	**0.011**
Limited contact last days—Yes [No]	1.44	−1.36 to 4.25	0.313	0.14	−0.06 to 0.33	0.17	−0.24	−0.95 to 0.47	0.506
Restricted funeral—Yes [No]	−1.7	−7.54 to 4.14	0.567	−0.18	−0.57 to 0.22	0.385	−0.02	−1.37 to 1.33	0.974
Sense of Isolation—Yes [No]	5.86	2.75 to 8.97	**<0.001**	−0.05	−0.26 to 0.17	0.664	1.4	0.64 to 2.16	**<0.001**
Limited contact relatives—Yes [No]	0.46	−3.26 to 4.17	0.809	−0.11	−0.36 to 0.14	0.372	−0.18	−1.06 to 0.69	0.681
Unable to visit—Yes [No]	2.29	−0.58 to 5.17	0.118	0.13	−0.06 to 0.33	0.181	0.23	−0.49 to 0.95	0.528
Unable to say goodbye—Yes [No]	1.43	−1.84 to 4.71	0.39	−0.14	−0.36 to 0.08	0.221	−0.03	−0.84 to 0.78	0.944
Feel supported—A little bit supported [Not at all supported]	−0.55	−3.92 to 2.82	0.749	0.27	0.04 to 0.50	**0.02**	−0.8	−1.64 to 0.03	0.06
Feel supported—Fairly well supported [Not at all supported]	0.54	−3.14 to 4.22	0.774	0.32	0.07 to 0.57	**0.011**	−0.37	−1.33 to 0.58	0.443
Feel supported—Very well supported [Not at all supported]	−4.23	−8.15 to −0.31	**0.034**	0.6	0.33 to 0.86	**<0.001**	−2.46	−3.46 to −1.47	**<0.001**
Feel supported—Not relevant to my situation [Not at all supported]	−2.06	−6.80 to 2.67	0.392	0.12	−0.19 to 0.44	0.446	−1.04	−2.12 to 0.05	0.062
ISS	−3.12	−4.04 to −2.21	**<0.001**						
Days (scaled) × Ethnicity grouped [White]				−0.37	−0.64 to −0.10	**0.008**			
Days (scaled) × Age of participant							0.02	0.01 to 0.04	**<0.001**
Random effects									
σ^2	43.31			0.28			7.91		

(Continued)

TABLE 6 (Continued)

	TGI (PGD score)			ISS			AAG (IoV score)		
Predictors [Reference category]	Estimates	95% CI	*p*	Estimates	95% CI	*p*	Estimates	95% CI	*p*
$\tau_{00\,\text{respondents}}$	119.58			0.48			10.7		
ICC	0.73			0.63			0.57		
$N_{\text{respondents}}$	411			402			672		
Sample size	842			821			1,510		
Marginal R^2/ Conditional R^2	0.311/0.817			0.119/0.674			0.206/0.662		

*Variables with very small effect sizes that were removed from the final model.
The *p* values highlighted in bold are less than 0.05 (i.e. statistically significant).

between feeling supported and TGI levels, while sense of isolation has both a direct and indirect effect on TGI. These patterns are depicted in Figure 2.

Despite representing a relatively modest effect, being unable to visit a loved one prior to death had an increased effect on TGI once all other factors were accounted for (an estimated average difference of 2.3 scale points in TGI level). Restricted funeral arrangements showed a much smaller effect for IoV when other variables were controlled for than in the single model. Number of negative experiences during bereavement showed very low effect sizes across all three indices, once other variables were accounted for.

3.8. Effect of the characteristics of the participant and the deceased

Place of death and relationship with the deceased remained the strongest predictors of grief and support outcomes, although the effect of relationship with the deceased was generally smaller when other factors were accounted for, most noticeably for IoV. Specifically, the estimated differences in IoV between losing a partner or a parent or grandparent were much smaller than when the variable was considered in the single model. Those bereaved of a partner showed higher TGI scores and slightly higher IoV scores compared to other groups. Losing a child showed small differences in TGI and IoV scores compared to losing a partner when looked at in isolation, but when other factors were accounted for, those bereaved of a child showed smaller TGI and IoV scores than all other groups. However, confidence intervals for these differences are wide (Figure 3) and these contradictory results seem more likely to be due to the small sample size for those bereaved of a child. Those bereaved of a partner and those bereaved of a distant relative or friend showed greater ISS scores compared to all other groups.

There were generally worse outcomes for those who had a loved one dying in a hospice and best for those who had a loved one dying in a care home, with TGI scores also high for those on the "other" category. ISS scores were lowest for deaths in hospices and highest for the "other" category.

An unexpected death had a negative effect on both TGI and IoV, while cause of death only had a meaningful influence on IoV—those who lost someone to COVID-19 had slightly worse outcomes, while age of deceased only had a meaningful influence on TGI, with worse outcomes for bereavements of younger people. Although only the linear trend was fitted for simplicity, visual analysis of the relationship between age of deceased and TGI showed a sharper decrease from the age of 70 years (this was also the case for IoV and ISS scores also showed a slightly more pronounced decrease from this point). These patterns are shown in Figure 3.

Qualifications also showed important effects for TGI and IoV, with those with higher education levels showing better outcomes. Having medical conditions showed a negative effect for TGI. Ethnicity showed an estimated average difference of around 5 scale points in TGI level (with higher TGI scores for white group), but due to the small sample size and large variability in the minoritized ethnic group and potentially its relatively high association with ISS, this variable has an overall small effect size on TGI when controlling for other variables. These patterns are shown in Figure 4.

Age of participant, further bereavements during the study, and whether people were unemployed during the pandemic showed the lowest effect sizes across all three indices, once other variables were accounted for.

4. Discussion

This analysis represents the only published longitudinal examination of COVID-19 pandemic grief outcomes that we are aware of, with a focus on symptoms of PGD as our primary outcome. In a sample of people bereaved during the first 9 months of the COVID-19 pandemic in the UK, we found decreasing but relatively high levels of indicated PGD at c. 8 (44%), 13 (35%), and 25 (29%) months post-bereavement. Factors most strongly associated with levels of PGD symptoms were those relating to the person who died, in terms of their relationship to the participant, where they died and whether the death was expected. Large effects relating to support were also observed, specifically isolation and loneliness around the time of bereavement and perceived social support over time, with support from healthcare professionals immediately following the death also a factor. Level of education and existence of medical conditions were the main participant characteristics found to have an effect. These findings have important implications for bereavement policy, provision and practice in the current COVID-recovery and post-pandemic period (e.g., strengthening of specialist and social support) and in preparedness for future pandemics and mass bereavement events (e.g., infection control measures and rapid support responses).

4.1. Grief levels and the effects of time

We found relatively high levels of indicated PGD and grief vulnerability (IoV) overall, and across time. As in other studies, time since death was negatively associated with overall levels of PGD symptoms (8, 34), and to a lesser extent levels of grief vulnerability (IoV), with a pattern of improvement and "normal" grief trajectories for many (5, 6). However, there were also patterns of worsening grief and grief which remained relatively static over time (52) and the proportions of people meeting the threshold for indicative PGD remained higher than would be expected in non-pandemic times, with around 36% at c. 13 months bereaved and around 29% at c. 25 months. Public health models of bereavement (9, 11) suggest that in non-pandemic times, around 10% of bereaved people are at high risk of PGD and may need professional mental health support, and a further 30% are at moderate risk and may need some additional support, e.g., via peer support groups. These estimates were confirmed in a 2015 Australian survey, which in a sample of people on average 14 months bereaved, identified 6.4% at high-risk of PGD, 35.2% at moderate risk and the remaining 58.4% at low risk (9). Although our sample is limited by its self-selecting design and is not representative, our findings would nonetheless appear to support predictions that grief disorder prevalence would rise because of the pandemic (2–4), providing longer-term evidence that is consistent with the results of earlier cross-sectional studies with more recently bereaved populations (14–20).

We now summarize the factors associated with poorer grief outcomes and consider which of these factors might explain the apparently higher levels of indicated PGD that we observed in this pandemic-bereaved cohort.

4.2. The person who died

We found that, over time, relationship to the deceased continued to be strongly associated with symptoms of PGD and grief vulnerability, as in our baseline analysis (23). People whose partner, child or sibling died showed higher levels of grief compared with bereavements of more distant relatives/friends, although group sizes for child and sibling loss were very small. These effects became relatively less important once other factors were controlled for, especially in relation to grief vulnerability (IoV), and were influenced by perceived social support in the PGD symptoms (TGI) model. Specifically, our results suggest that people who lost parents and siblings experienced poorer social support, which might have contributed to their relatively worse levels of PGD symptoms, while the better support experienced by bereaved spouses/partners could have buffered the effects of their loss, despite their overall higher grief levels. These varying levels of support also demonstrate greater perceived lack of understanding and empathy within social networks in relation to deaths of siblings, parents and grandparents, or greater reluctance to seek or ask for help among those experiencing these types of bereavement, as also indicated in our qualitative findings (21).

Age of the deceased had a small but significant effect on symptoms of PGD [although not grief vulnerability, unlike our baseline analysis, (23)], with younger age associated with higher levels of PGD symptoms. These associations between relationship with and age of the deceased are consistent with pre-pandemic studies (9, 10, 30, 53) and some studies of pandemic bereavement (8, 12–14, 29). Although our sample is not directly comparable to Aoun et al. (9) study, which provided empirical data for the proportions of low, moderate and high-risk groups reported above, comparisons of these participant characteristics (relationship with/age of deceased) would suggest that these two factors, albeit important predictors of grief severity, cannot explain the higher grief levels observed in our pandemic study. Mean age of deceased was very similar (72 vs. 75), while the Australian study included higher proportions of people who had lost spouses and children, and a similar proportion of people whose siblings had died.

4.3. Cause, expectedness, and place of death

While worse outcomes have been identified for people bereaved by COVID-19 compared with pre- pandemic general bereaved populations (12–14, 17), or "natural" causes of death before and during the pandemic (18–20), our analysis found no effect on PGD symptoms for cause of death (COVID-19 vs. non COVID-19) when other factors were controlled for (15), but a small and significant effect on vulnerability scores [unlike our baseline analysis, (23)]. However, it should also be noted that several of these factors/co-variates were associated with both COVID-19 deaths (22) and worse grief outcomes (discussed below, e.g., reduced support from healthcare professionals, loneliness and isolation). As in other studies, unexpected deaths were found to have a significant negative effect on PGD symptoms and grief vulnerability (19, 20, 50). The fact that a much larger group of participants reported that the death was not expected (78%) than those bereaved by COVID-19 (45%), would suggest that that this aspect of a death, which likely increased in relation to both COVID and non-COVID deaths during the pandemic [e.g., due to cancer treatment delays, disruption to services, (54, 55)] may be an explanatory factor for elevated PGD levels during the pandemic.

As in our baseline analysis (23), place of death was also found to be strongly associated with levels of grief. Despite care-home deaths being associated with worse experiences of end-of-life care and visiting restrictions (22), with the troubling consequences of prolonged periods of separation also described qualitatively (24), grief outcomes (IoV and PGD symptoms) were better when a death occurred in a care home compared with other settings (controlling for aspects of end-of-life experience, e.g., support from healthcare professionals after the death, being able to visit). This relationship may be due to anticipatory grief work, e.g., in the context of dementia diagnoses, and reflect the more "expected" nature of some of these deaths. A US study similarly found that deaths from dementia during the pandemic were negatively associated with probable PGD compared with deaths from other causes (18). The finding that those reporting "Other" places of death had worst PGD symptoms (although a very small group-size), followed by hospice and hospital deaths might reflect the

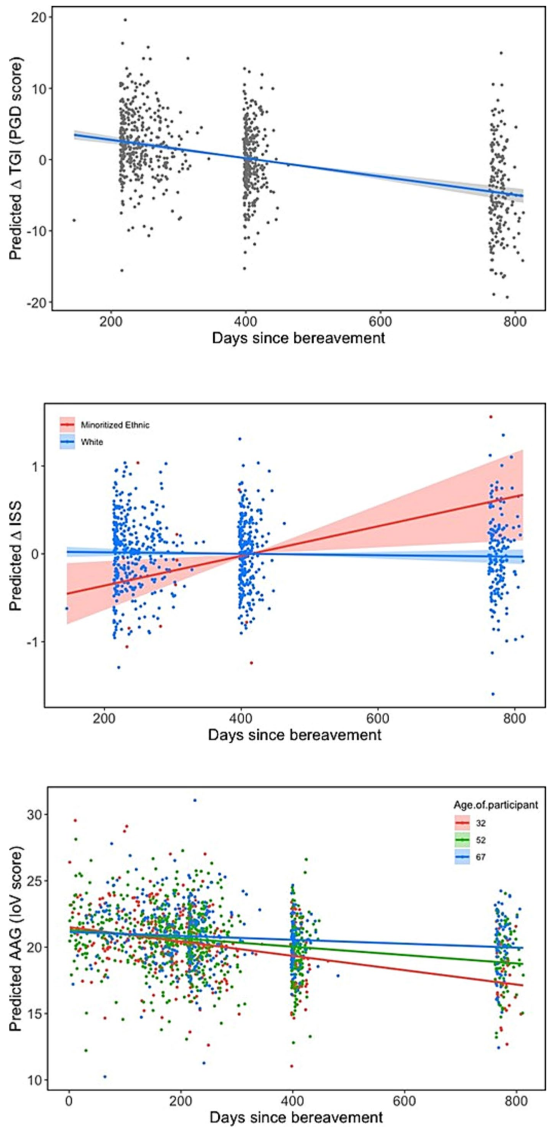

FIGURE 1
Predicted temporal patterns of TGI, ISS, and IoV scores regarding days since bereavement. ISS and Iov score showed significant interactions between days since bereavement and, respectively, ethnicity and age of participant, which are depicted here. Note that TGI scores and ISS are plotted as contrasts, showing the predicted average change in TGI score and ISS across all groups of participants, while IoV is depicted as predicted scores for the first, second and third quartiles of participants' ages while keeping all other variables constant (set for the group with larger sample size); predicted scores were plotted instead of contrasts because the interaction was more visually easily interpreted this way.

consequences of especially traumatic, sudden deaths (e.g., accidents) (7, 19, 20), the more difficult end-of-life experiences identified in hospital settings, beyond those factors which we controlled for (22, 24), or distress and anger among relatives whose loved ones died of terminal illness, without the expected levels of treatment or care (24). The slightly better levels of social support perceived among those who experienced care home deaths, compared with hospital and hospice deaths, might also help to explain this relationship (35–37).

4.4. Circumstances of the death

There are a number of factors relating to the circumstances of the death that might be expected to have impacted upon grief levels. In previous quantitative and qualitative publications we identified experiences of sub-optimal end-of-life care, as healthcare systems and settings navigated the incredible strain and restrictions placed upon them (22, 24). As in our baseline analysis (23), we again found that feeling supported by healthcare professionals immediately following the death had a significant and lasting positive effect on PGD symptoms and grief vulnerability. Interestingly, we also found that this relationship with PGD symptoms was mediated by perceived social support at later time-points. This mediating effect might be explained by improved access to bereavement services as a result of supportive post-death care (and associated benefits relating to expressing feelings and receiving help with grieving, as captured in the ISS measure). It may also reflect the possibility that people with more negatives experiences (including problematic end-of-life care and related unanswered questions) may be more likely to feel poorly understood or unable to talk openly with others about how they are feeling, as also described in our qualitative findings (21, 24). Alongside other pandemic (17, 56, 57) and non-pandemic studies (44, 46) these findings demonstrate the importance of compassionate and effective communication around the time of death, and the likely significance of supportive post-death conversations and signposting for accessing further support and coming to terms with the circumstances of the death.

We found only small effects on PGD symptoms and grief vulnerability for factors relating to restricted contact at the end of life (e.g., visiting and saying goodbye), although being able to visit the patient at the end of life increased in importance once other factors were controlled in the PGD model, suggesting the "real" impact of this experience may be somewhat masked by other factors. These relatively small effects are nonetheless surprising given the devastating impacts of these experiences that were described in our qualitative data, including lasting feelings of guilt, anger, regret (24), and the effects of these circumstances identified in other studies (14, 15, 17, 20). "Dealing with my feelings around how my loved one died" was also the top-ranking need for support that we identified at baseline, with 60% of people experiencing high-level needs for help in this domain (21). These findings, the greater observed impact of feeling supported after the death, and examples in our interview data of some participants coming to terms with difficult end of life experiences (58), might therefore suggest that it is not just the circumstances of the death that are of importance, but also one's ability to make sense of what happened (15, 58–60). This again points to the importance of good communication and support from healthcare providers for mitigating the effects of stressful and traumatic experiences (60).

4.5. Disruption to grieving, coping, and support processes

We found that loneliness and social isolation in early bereavement was strongly predictive of worse levels of PGD symptoms and grief vulnerability, as in our baseline analysis (23). Lower levels of social support, measured at later time points with the ISS, were also strongly predictive of poorer PGD symptoms. These findings are consistent

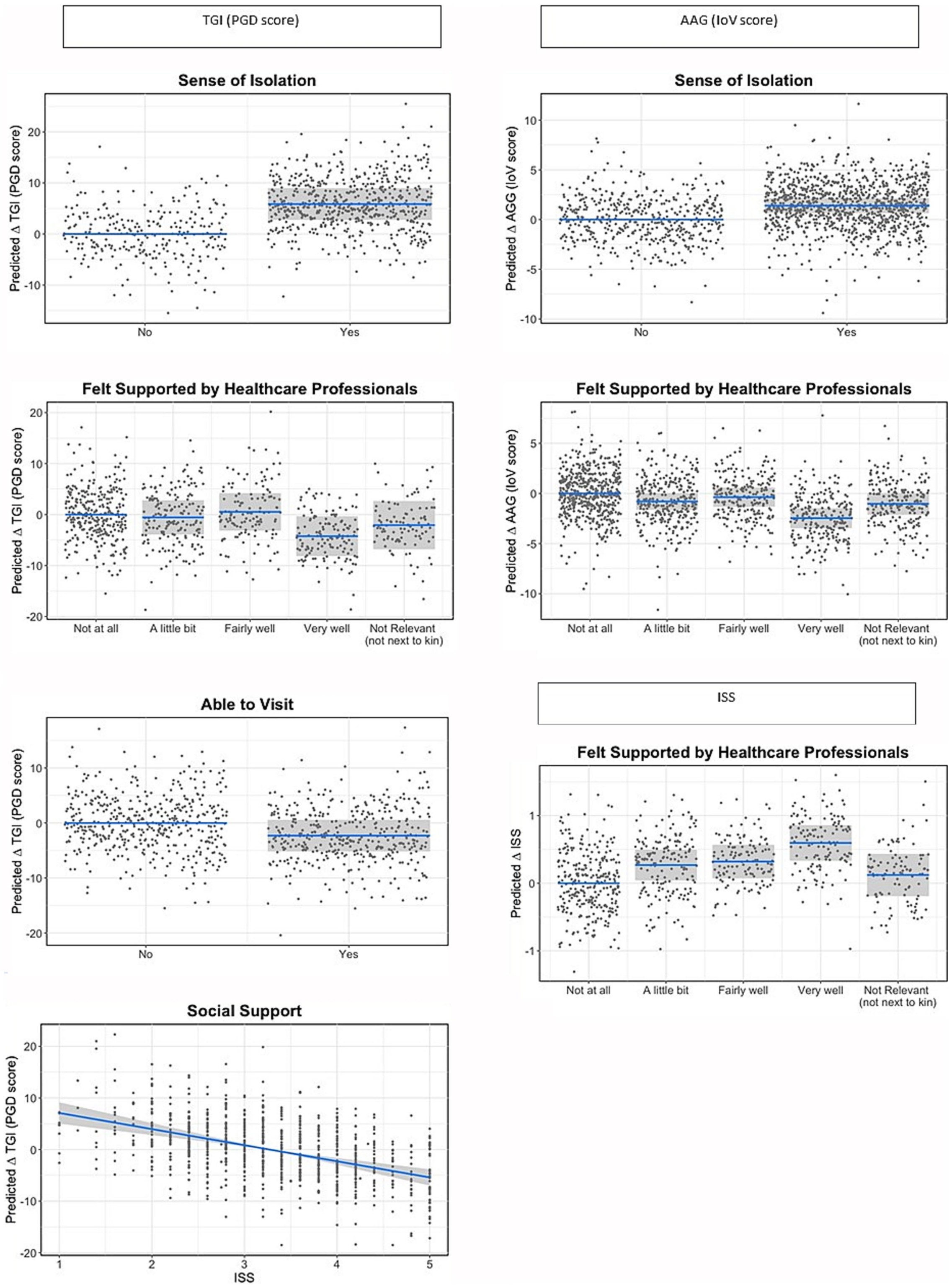

FIGURE 2
Predicted changes (statistical contrasts) in TGI, ISS, and loV scores across different experiences of bereavement identified in the statistical models as having the strongest effect sizes for each outcome. Shaded areas represent 95% confidence intervals for the change in TGI, ISS, or lov score in relation to the reference category. Note that TGI scores range from 18 to 90, lov from 0 to 34 and ISS from 1 to 5, and hence the same change in TGI and lov represents an approximate twofold change in magnitude for lov compared to TGI, while a change in ISS represents an approximate sevenfold change in magnitude compared to lov and 14-fold change in magnitude compared to TGI.

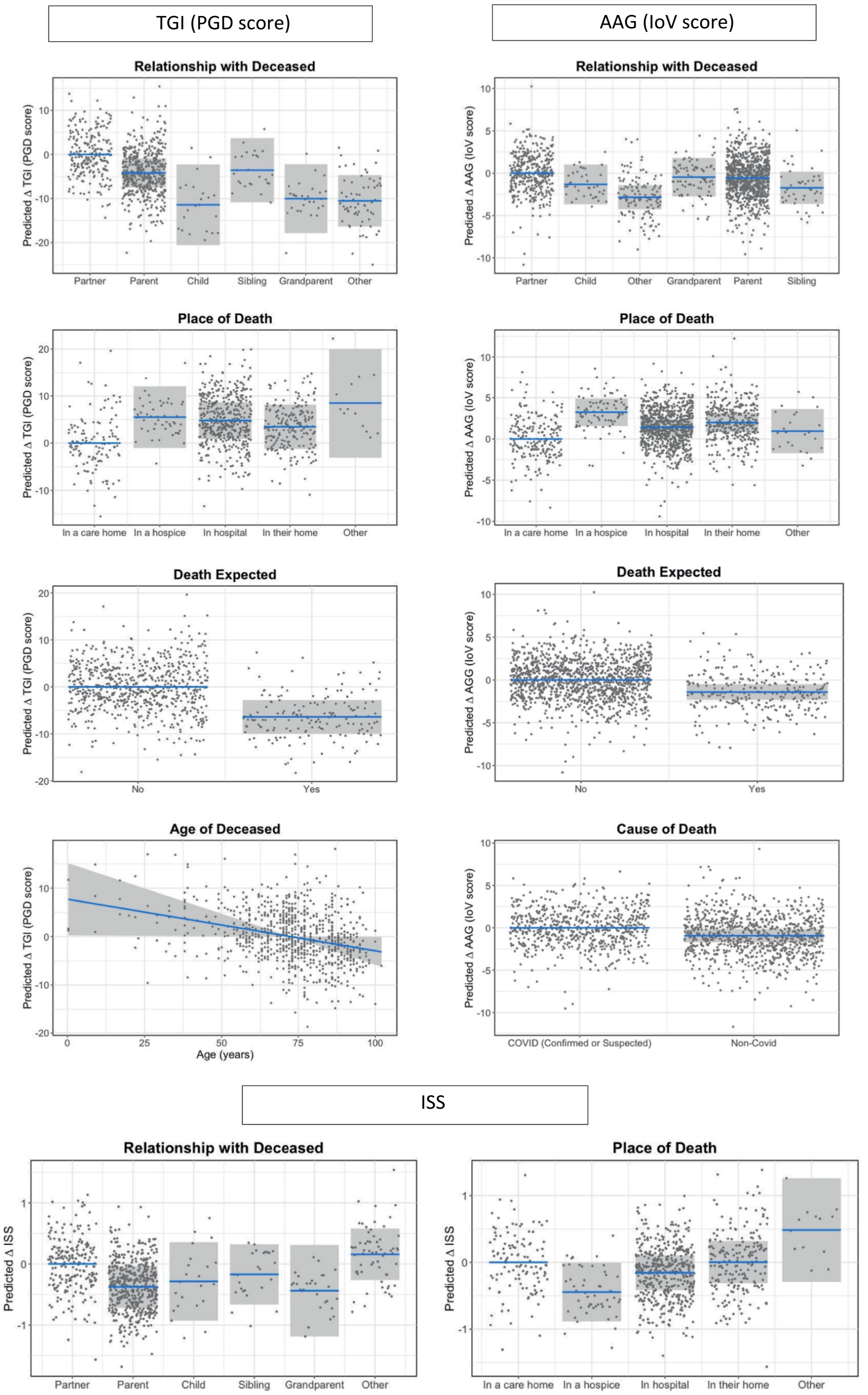

FIGURE 3
Predicted changes (statistical contrasts) in TGI, ISS, and IoV scores in relation to characteristics of the deceased and circumstances of death identified in the statistical models as having the strongest effect sizes for each outcome. Shaded areas represent 95% confidence intervals for the change in TGI, ISS or IoV score in relation to the reference category. Note that TGI scores range from 18 to 90, IoV from 0 to 34 and ISS from 1 to 5, and hence the same change in TGI and IoV represents an approximate twofold change in magnitude for IoV compared to TGI, while a change in ISS represents an approximate sevenfold change in magnitude compared to IoV and 14-fold change in magnitude compared to TGI.

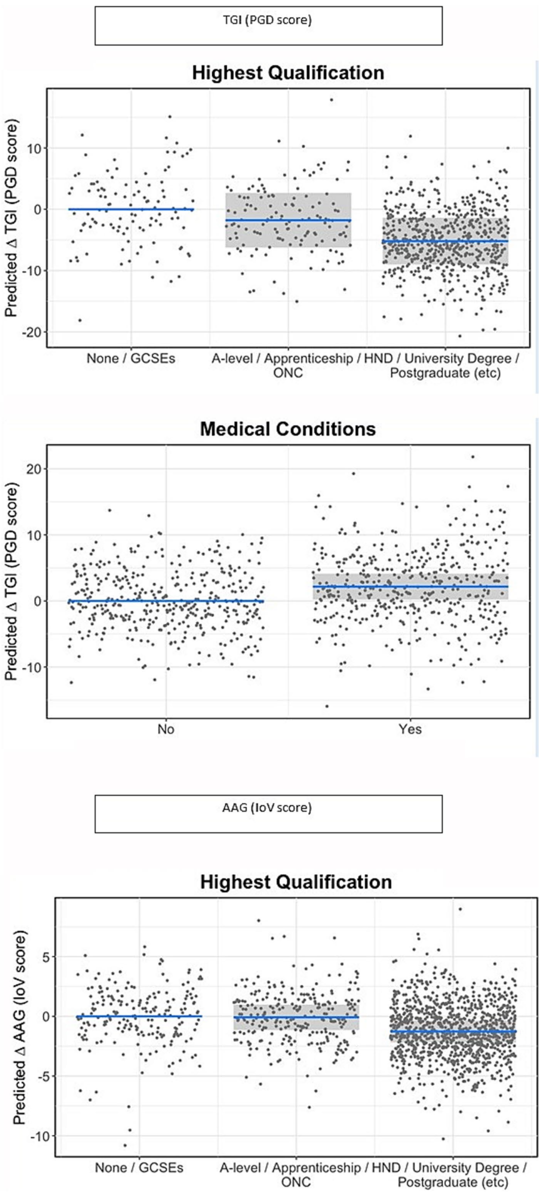

FIGURE 4
Predicted changes (statistical contrasts) in TGI and loV scores in relation to characteristics of the participants identified in the statistical models as having the strongest effect sizes for each outcome. Shaded areas represent 95% confidence intervals for the change in TGI or lov score in relation to the reference category. Note that TGI scores range from 18 to 90 and lov from 0 to 34, hence the same change in TGI and loV represents an approximate twofold change in magnitude for lov compared to TGI.

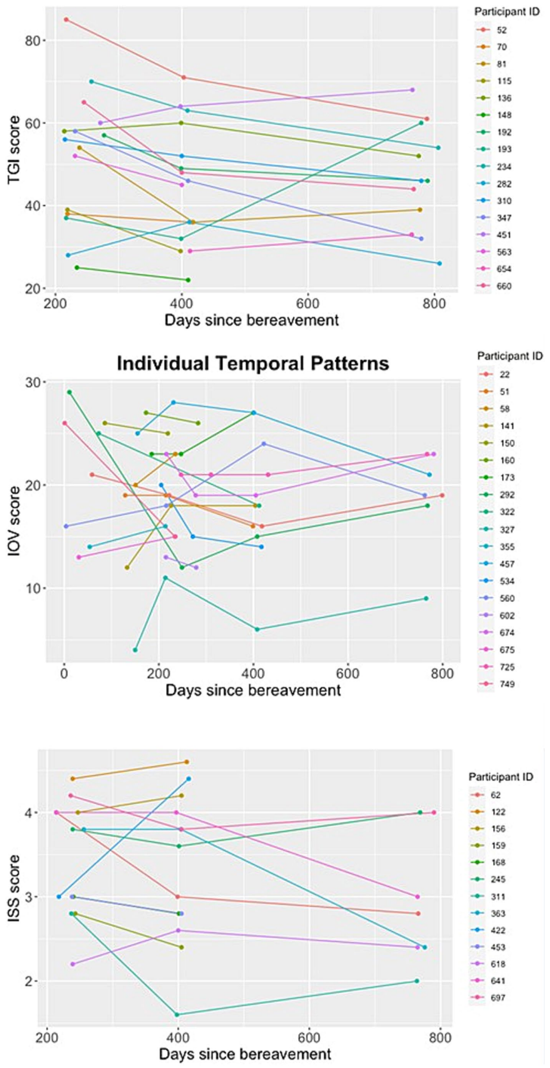

FIGURE 5
Temporal patterns of TGI, ISS and IoV scores regarding days since bereavement for different randomly generated selections of study participants.

with pandemic and pre-pandemic evidence on the negative impacts of social isolation, loneliness and lack of social support on bereavement outcomes (8, 29, 35–37). Our qualitative findings provide detailed accounts of how lockdown restrictions and shielding not only limited the emotional support and comfort available to people, but also prevented the collective rituals and acts of remembrance needed to begin processing their grief (21, 24). While the negative impacts of poor social support on grief is not unique to the pandemic, this is a factor clearly exacerbated by the pandemic-context, as people suffered not only from physical separation but also emotional "distance" and perceived lack of understanding and sensitivity to the realities of pandemic bereavement within social networks (15, 17, 21, 23, 24). Increased isolation and problematic social support during COVID-19 therefore seems likely to help explain elevated pandemic grief levels, while also reaffirming the important protective role of social support around the time of death and throughout bereavement generally [e.g., (10, 35–37)]. Positive support from friends and family described in our qualitative data included help with practical tasks, expressing feelings and sharing grief, remembering the person who died and feeling cared for and less isolated (61); benefits which are highly consistent with items in the social support measure that we used (43). Participants also commonly received emotional support from fellow bereaved people through online peer support communities and more formally from counselors, with both sources of support similarly valued for helping people to feel listened to and understood (61), further demonstrating how informal and formal emotional support can benefit people who are bereaved (62). Although restricted funerals had a large effect on PGD symptoms (and medium effect on grief vulnerability), this experience was not predictive once other factors were controlled for. This may be explained by the lessening effects of this experience over time and/or the greater relevance of other factors such as social support, along with the fact that almost all (93%) of respondents experienced these restrictions. Although most participants described the upsetting and distressing effects of restricted funerals in the qualitative data, a small minority described positive experiences and many described plans for future commemorative activities (24), which may have helped to mitigate the early effects of funeral restrictions. This uncertainty regarding the impact of funerals on bereavement outcomes is also reflected in the wider literature, which has been inconclusive (63) or found no effect (27), but also pointed to the important role of funeral providers and celebrants in providing alternative meaningful services in the contexts of restrictions.

4.6. Demographic influences and participant characteristics

Several demographic or participant factors were found to have an effect on support and grief outcomes. Existence of medical conditions was associated with higher levels of PGD symptoms (but not grief vulnerability), and a small negative (but non-significant) effect on perceived social support. This points toward the detrimental impact of poorer health status on a person's ability to cope and adjust, in particular at a time where clinically vulnerable populations were required to "shield," and opportunities for usual social and recreational activities and access to services were heavily restricted (24, 64). This is consistent with evidence from prior studies that existing mental-health conditions are associated with more complex grief (30, 65) or poorer mental health outcomes (66). There is of course also the possibility that the bereavement itself may have led to new or worsened medical conditions among some participants, indicated in the increased numbers of people reporting new conditions across time. This would be consistent with studies reporting increased rates of morbidity and mortality among surviving spouses compared with general populations [e.g., the "widowhood" effect, (67, 68)] and worse mental health among people bereaved during the pandemic compared with those not bereaved (66). Future analysis will investigate changes in health status and other associated factors over time (e.g., primary care and medication use) to explore these relationships further, along with other health economic outcomes, such as unemployment and time-off work.

As in previous research, and our baseline analysis (23), lower levels of education were associated with worse grief outcomes (PGD symptoms and grief vulnerability) (6, 30, 32–34). Although this factor became less important in the mixed-models, it underlines the importance of addressing structural disadvantage and inequity in healthcare and bereavement support (28, 69), particularly given the association that we previously identified between lower education-level and lower perceived healthcare professional support at the end of life (22). This association might reflect a poorer quality of healthcare in socially disadvantaged areas generally, e.g., due to higher demand and/or fewer resources [the "inverse care" law, (70, 71)], or the "cultural capital" and greater ability to engage and effectively communicate with healthcare providers among people from middle class backgrounds and with higher levels of formal education (72–74). This effect might also relate to the unequal impacts of the pandemic on poorer communities across the UK, potentially affecting community-level mental health and resilience, and in turn a more limited capacity for healthy grieving and adaptation among people living in the worst affected localities. The overall negative mental health impact of living through the pandemic at general population-level has been documented (66, 75, 76), including worse outcomes associated with lower socio-economic status (8, 76), economic stressors (77), and bereavement (66, 77).

Despite the disproportionate impacts of the pandemic on minoritized ethnic communities, in terms of death-rates, and disruption to grieving practices and community networks (28, 78), this group of participants actually had better levels of PGD symptoms (but not grief vulnerability), although the difference was not statistically significant in the mixed-model. Further, the small size of this group (particularly at later time points) and the lessened effect of ethnicity once other factors were controlled, means that this finding should be treated cautiously. Of note though, is the observed potential mediating role of social support, and possibility that the better social support reported by our minority ethnic participants may have mitigated the effects of some of the general and culturally-specific challenges of pandemic bereavement faced by minoritized communities [e.g., see (21, 28, 75)], although again these differences should be treated with caution.

4.7. The bigger picture

This analysis has identified several pandemic-related factors which, in influencing grief outcomes, might at least partially explain the apparently higher levels of indicated PGD that we observed, compared with similar non-pandemic studies (9). When considered alongside our qualitative findings, however, what is also apparent is the intensity of feelings surrounding these and other factors; experiences which clearly had compounding and far-reaching effects on the lives of our participants, but which were not fully captured in our quantitative measures and analyses. Pandemic-related factors not fully measured or included in this analysis, but which we know to be highly consequential for grieving include: death-trauma (e.g., perceived suffering, poor treatment, shock), inability to collectively mourn or remember loved ones, the isolating and disenfranchising effects of being bereaved during a prolonged period of mass-bereavement (including lasting anger at political and societal responses to the pandemic and continuing fear of the virus), limited opportunities to engage in recreational and other coping activities, stressful death-administration and financial/work-based challenges, and reduced access to critical support-services (21, 24).

Within our qualitative findings, as in other studies (15), the significance of meaning-making in mediating the effects of many of these circumstantial factors is also evident (21, 24, 58). Examples of pandemic-related difficulties finding meaning included anger and unanswered questions surrounding and preventing acceptance of the death, descriptions of grief feeling "unreal" without recourse to collective ritual, and lack of appropriate support and help with processing feelings (21, 24). Pandemic-related disruption to meaning-making processes might therefore also explain the higher levels of pathological grief that we observed, as well as the small or insignificant effects of factors where only the occurrence of the "event" rather than responses to it was captured (e.g., restricted funerals, being unable to say goodbye). This underlines the importance not only of considering how any infection-control restrictions that may be needed are managed and implemented (with meaningful alternatives available where possible), but equally that there is appropriate and effective communication with bereaved people and support surrounding any restrictions, coupled with opportunities to formally revisit and reflect upon what happened.

4.8. Strengths and weaknesses

This longitudinal study benefits from a large initial sample-size, with quantitative and qualitative data collected across four time points up to approximately 2 years post-bereavement. Although participant numbers decreased over this time-period, we retained sufficient numbers to enable robust analysis, albeit with reducing proportions of younger and older participants, and people from minoritized ethnic backgrounds or with lowest qualifications levels. The sample was reasonably well represented across geographical areas, education and deprivation, but was self-selecting and biased toward female and white respondents, despite targeting men and people from minoritized ethnic communities in our recruitment approaches. Due to missing data on religious/spiritual beliefs and sexual orientation we were also unable to consider the effects of these other aspects of participant identity and subjectivity that may have influenced their coping and grief experiences (27, 32, 79, 80). By recruiting mostly online, we were less likely to reach the very old or other digitally marginalized groups. Convenience sampling might have resulted in more people with negative experiences participating, as well as those accessing support. Despite these limitations, group sizes were sufficient to enable comparisons (although not to the level of specific ethnic groups) and, while not providing population-level prevalence data, the sample does enable comparisons to be made with data from similar pre-pandemic studies [e.g., (9)], and the identification of potential risk factors which can inform future practice and policy. However, as argued elsewhere, there is a risk of pathologizing "normal" grief when attempting to determine PGD using fixed time-frames (81), especially in a pandemic context when "delayed grief" has been hypothesized (82, 83), further underlining the importance of collecting longitudinal and long-term follow-up data.

4.9. Implications for further research

Through subsequent qualitative interviews, we have explored in depth the experiences of people with characteristics less well represented in the survey, including men, people identifying with a sexual or ethnic minority background, with publication forthcoming. However, further research is required exploring the needs of bereaved people from minoritized ethnic and socially disadvantaged backgrounds, same-sex couples, men, children and young people, and people with pre-existing mental health conditions, as we navigate the COVID-recovery phase and beyond. Research exploring the impact of religious and spiritual beliefs would also help to address current gaps in the evidence (27). Given the importance of our qualitative data for establishing the "bigger picture" and the meaning of pandemic circumstances for bereaved individuals, the use of qualitative or mixed-methods approaches when investigating novel and unpredictable future mass-bereavement events is essential. The development or further refinement of tools for measuring identified event-specific risk factors, and the meaning and significance of such factors for individuals, e.g., the Inventory of Pandemic Grief Risk Factors (17), would also be helpful.

5. Conclusions and implications for policy and practice

We found relatively high-levels of indicated PGD at c. 8, 13, and 25 months post-bereavement when compared with similar non-pandemic studies of bereaved populations [e.g., (9)]. Several pandemic-related factors were identified which, in influencing grief outcomes, seem likely to at least partially explain this phenomenon. The strongest of these predictors were social isolation and problems accessing social support during bereavement, which while not unique to the pandemic was almost certainly exacerbated by it (21). Other likely explanatory factors included higher rates of unexpected deaths, and the disproportionately higher numbers of deaths occurring within socially deprived/less formally "educated" communities during the pandemic (given the poorer grief outcomes of these groups). In their relationships with grief-levels, and the unique pandemic-context, poorer care-experiences at the end of life (including visiting restrictions) and the existence of other medical conditions, might also help to explain higher grief levels among people bereaved during the pandemic.

However, effect sizes for many of these factors were in absolute terms "small," and our qualitative insights paint a much fuller and more intricate picture than we could capture in our quantitative measures and analyses. Taken together, our mixed-methods findings suggest that is likely the combined and compounding effects of the many different challenging experiences of people bereaved during the pandemic that contributed to higher-levels of complex and prolonged grief.

Based on these findings we make the following recommendations to inform bereavement support and policy at the present time and in future pandemics, many of which resonate with the recent report by the UK Commission on Bereavement (78).

Implications for the current COVID-recovery phase and beyond:

1. In view of the higher proportions of people experiencing or at risk of PGD following the pandemic, bereavement support services require increased investment to ensure adequate levels of specialist provision which can effectively cater for those with more complex needs, as well as robust methods of identifying and reaching people most in need of more intensive support. Bereaved people more likely to require such support include

those grieving children, partners and siblings and following unexpected deaths, as well as people who are isolated and have limited social support, health conditions and low levels of formal education.

2. Opportunities for informal emotional and social support should be strengthened through provision of peer-support groups, as well as compassionate community initiatives and educational programs which seek to improve grief literacy and the support available to people within existing social and community networks (84). Communities worst affected by COVID-19 and structural inequalities should be prioritized for such initiatives.
3. Policies and training should be implemented to ensure compassionate and supportive communication and behaviors from healthcare professionals at the end of life, especially in acute and care-home settings. "Follow-up" contact should be consistently delivered by care providers following the death and enable meaningful discussion and reflection on difficult and troubling experiences, with signposting to locally and nationally available bereavement support services.

To ensure preparedness for future pandemics and other mass-bereavement events, best practice-guidance and related policies should be developed for:

4. Health-care settings, with specific regard to managing and balancing infection-risk with the need to facilitate patient-family contact, including use of Personal Protective Equipment and remote communication-methods, and ensuring effective and compassionate communication with family members during times of crises.
5. Funeral-providers and crematoria, including identifying different options for meaningful and alternative funeral and mourning practices when restrictions are needed. The role of funeral directors in providing compassionate and supportive responses should be recognized, including their roles in sign-posting to further support-services (27, 62).
6. Managing social contact, recognizing the need to restrict social interaction in times of high-infection rates, while making allowances for those living alone and with particular vulnerabilities, including the recently bereaved. Greater understanding of permissible levels of "safe" contact relative to infection levels, and the best means of enabling this (e.g., outdoor socialization) would also be helpful.
7. Rapid mobilization of locally and nationally coordinated bereavement support provision, including existing providers and other community organizations. Any such responses should involve proactive sign-posting to and advertising of such support, mechanisms for identifying those requiring more intensive specialist support, and crisis-specific training and practice- sharing to ensure that the support offered is crisis- as well as culturally-competent (21, 85).

Data availability statement

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found at: UK Data Service via https://reshare.ukdataservice.ac.uk/855751.

Ethics statement

The studies involving humans were approved by the Cardiff University School of Medicine Research Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

EH and LS designed the study, led the application for funding, and were co-principal investigators. EH drafted the manuscript. RM conducted the statistical analyses, with data management assistance from SG. RM wrote the statistical analysis and results sections of the manuscript. SG, ML, AB, DF, LM, KS, AP, and SS were members of the research team or the study advisory group and contributed to the design of the study and survey. All authors contributed to drafting the manuscript and read and approved the final manuscript.

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Conflict of interest

AP declared a potential financial interest relating to lobbying by the Childhood Bereavement Network and National Bereavement Alliance for additional financial support for the bereavement sector.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1215881/full#supplementary-material

References

1. WHO Coronavirus (COVID-19) Dashboard. *WHO coronavirus (COVID-19) dashboard with vaccination data*. Available at: https://covid19.who.int/.

2. Menzies RE, Neimeyer RA, Menzies RG. Death anxiety, loss, and grief in the time of COVID-19. *Behav Chang*. (2020) 37:111–5. doi: 10.1017/bec.2020.10

3. Palliative Care Australia. *Palliative care and COVID19: grief, bereavement and mental health* Palliative Care Australia (2020). Available at: https://www.palliativecare.org.au

4. Eisma MC, Tamminga A. Grief before and during the COVID-19 pandemic: multiple group comparisons. *J Pain Symptom Manag*. (2020) 60:e1–4. doi: 10.1016/j.jpainsymman.2020.10.004

5. Lundorff M, Holmgren H, Zachariae R, Farver-Vestergaard I, O'Connor M. Prevalence of prolonged grief disorder in adult bereavement: a system review and meta-analysis. *J Affect Disord*. (2017) 212:138–49. doi: 10.1016/j.jad.2017.01.030

6. Prigerson HG, Horowitz MJ, Jacobs SC, Parkes CM, Aslan M, Goodkin K, et al. Prolonged grief disorder: psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Med*. (2009) 6:e1000121. 7. doi: 10.1371/journal.pmed.1000121

7. World Health Organization. *International classification of diseases for mortality and morbidity statistics*. 11th ed (2018) Available at: https://icd.who.int/browse11/l-m/en.

8. Shevlin M, Redican E, Hyland P, Murphy J, Karatzias T, McBride O, et al. Symptoms and levels of ICD-11 Prolonged Grief Disorder in a representative community sample of UK adults. *Soc Psychiatry Psychiatr Epidemiol*. (2023):1–13. doi: 10.1007/s00127-023-02469-1

9. Aoun SM, Breen LJ, Howting DA, Rumbold B, McNamara B, Hegney D. Who needs bereavement support? A population based survey of bereavement risk and support need. *PLoS One*. (2015) 10:e0121101. doi: 10.1371/journal.pone.0121101

10. Lobb EA, Kristjanson L, Aoun S, et al. Predictors of complicated grief: a systematic review of empirical studies. *Death Stud*. (2010) 34:673–98. doi: 10.1080/07481187.2010.496686

11. Aoun SM, Breen LJ, O'Connor M, Rumbold B, Nordstrom C. A public health approach to bereavement support services in palliative care. *Aust N Z J Public Health*. (2012) 36:14–6. doi: 10.1111/j.1753-6405.2012.00825.x

12. Tang S, Xiang Z. Who suffered most after deaths due to COVID-19? Prevalence and correlates of prolonged grief disorder in COVID-19 related bereaved adults. *Glob Health*. (2021) 17:1–9. doi: 10.1186/s12992-021-00669-5

13. Tang S, Yu Y, Chen Q, Fan M, Eisma MC. Correlates of mental health after COVID-19 bereavement in Mainland China. *J Pain Symptom Manag*. (2021) 61:e1–4. doi: 10.1016/j.jpainsymman.2021.02.016

14. Breen LJ, Lee SA, Neimeyer RA. Psychological risk factors of functional impairment after COVID-19 deaths. *J Pain Symptom Manag*. (2021) 61:e1–4. doi: 10.1016/j.jpainsymman.2021.01.006

15. Breen LJ, Mancini VO, Lee SA, Pappalardo EA, Neimeyer RA. Risk factors for dysfunctional grief and functional impairment for all causes of death during the COVID-19 pandemic: the mediating role of meaning. *Death Stud*. (2022) 46:43–52. doi: 10.1080/07481187.2021.1974666

16. Downar J, Parsons HA, Cohen L, Besserer E, Adeli S, Gratton V, et al. Bereavement outcomes in family members of those who died in acute care hospitals before and during the first wave of COVID-19: a cohort study. *Palliat Med*. (2022) 36:1305–12. doi: 10.1177/02692163221109711

17. Neimeyer RA, Lee SA. Circumstances of the death and associated risk factors for severity and impairment of COVID-19 grief. *Death Stud*. (2022) 46:34–42. doi: 10.1080/07481187.2021.1896459

18. Gang J, Falzarano F, She WJ, Winoker H, Prigerson HG. Are deaths from COVID-19 associated with higher rates of prolonged grief disorder (PGD) than deaths from other causes? *Death Stud*. (2022) 46:1287–96. doi: 10.1080/07481187.2022.2039326

19. Eisma MC, Tamminga A, Smid GE, Boelen PA. Acute grief after deaths due to COVID-19, natural causes and unnatural causes: an empirical comparison. *J Affect Disord*. (2021) 278:54–6. doi: 10.1016/j.jad.2020.09.049

20. Eisma MC, Tamminga A. COVID-19, natural, and unnatural bereavement: comprehensive comparisons of loss circumstances and grief severity. *Eur J Psychotraumatol*. (2022) 13:2062998. doi: 10.1080/20008198.2022.2062998

21. Harrop E, Goss S, Farnell D, Longo M, Byrne A, Barawi K, et al. Support needs and barriers to accessing support: baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic. *Palliat Med*. (2021) 35:1985–97. doi: 10.1177/02692163211043372

22. Selman LE, Farnell DJ, Longo M, Goss S, Seddon K, Torrens-Burton A, et al. Risk factors associated with poorer experiences of end-of-life care and challenges in early bereavement: results of a national online survey of people bereaved during the COVID-19 pandemic. *Palliat Med*. (2022) 36:717–29. doi: 10.1177/02692163221074876

23. Selman LE, Farnell DJ, Longo M, Goss S, Torrens-Burton A, Seddon K, et al. Factors associated with higher levels of grief and support needs among people bereaved during the pandemic: results from a national online survey. *Omega*. (2022). doi: 10.1177/00302228221144925

24. Torrens-Burton A, Goss S, Sutton E, Barawi K, Longo M, Seddon K, et al. 'It was brutal. It still is': a qualitative analysis of the challenges of bereavement during the COVID-19 pandemic reported in two national surveys. *Palliat Care Soc Pract*. (2022) 16:263235242210924. doi: 10.1177/26323524221092456

25. Harrop E, Selman LE. Bereavement during the Covid-19 pandemic in the UK: what do we know so far? *Bereav J Grief Resp Death*. (2022) 1:1. doi: 10.54210/bj.2022.18

26. Harrop E, Goss S, Longo M, Seddon K, Torrens-Burton A, Sutton E, et al. Parental perspectives on the grief and support needs of children and young people bereaved during the COVID-19 pandemic: qualitative findings from a national survey. *BMC Palliat Care*. (2022) 21:177. doi: 10.1186/s12904-022-01066-4

27. Mitima-Verloop HB, Mooren T, Kritikou ME, Boelen PA. Restricted mourning: impact of the COVID-19 pandemic on funeral services, grief rituals, and prolonged grief symptoms. *Front Psych*. (2022) 13:1103. doi: 10.3389/fpsyt.2022.878818

28. Selman LE, Sutton E, Medeiros Mirra R, Stone T, Gilbert E, Rolston Y, et al. 'Sadly I think we are sort of still quite white, middle-class really'–Inequities in access to bereavement support: findings from a mixed methods study. *Palliat Med*. (2023) 37:586–601. doi: 10.1177/02692163221133665

29. Chen C, Tang S. Profiles of grief, post-traumatic stress, and post-traumatic growth among people bereaved due to COVID-19. *Eur J Psychotraumatol*. (2021) 12:1947563. doi: 10.1080/20008198.2021.1947563

30. Newson RS, Boelen PA, Hek K, Hofman A, Tiemeier H. The prevalence and characteristics of complicated grief in older adults. *J Affect Disord*. (2011) 132:231–8. doi: 10.1016/j.jad.2011.02.021

31. Ringdal GI, Jordhøy MS, Ringdal K, Kaasa S. Factors affecting grief reactions in close family members to individuals who have died of cancer. *J Pain Symptom Manag*. (2001) 22:1016–26. doi: 10.1016/S0885-3924(01)00363-3

32. Mason TM, Tofthagen CS, Buck HG. Complicated grief: risk factors, protective factors, and interventions. *J Soc Work End Life Palliat Care*. (2020) 16:151–74. doi: 10.1080/15524256.2020.1745726

33. Milic J, Muka T, Ikram MA, Franco OH, Tiemeier H. Determinants and predictors of grief severity and persistence: the Rotterdam study. *J Aging Health*. (2017) 29:1288–307. doi: 10.1177/0898264317720715

34. Nielsen MK, Carlsen AH, Neergaard MA, Bidstrup PE, Guldin MB. Looking beyond the mean in grief trajectorieS: A prospective, population-based cohort study. *Soc Sci Med*. (2019) 232:460–9. doi: 10.1016/j.socscimed.2018.10.007

35. Cacciatore J, Thieleman K, Fretts R, Jackson LB. What is good grief support? Exploring the actors and actions in social support after traumatic grief. *PLoS One*. (2021) 16:e0252324. doi: 10.1371/journal.pone.0252324

36. Stroebe W, Zech E, Stroebe MS, Abakoumkin G. Does social support help in bereavement? *J Soc Clin Psychol*. (2005) 24:1030–50. doi: 10.1521/jscp.2005.24.7.1030

37. Smith KV, Wild J, Ehlers A. The masking of mourning: social disconnection after bereavement and its role in psychological distress. *Clin Psychol Sci*. (2020) 8:464–76. doi: 10.1177/2167702620902748

38. Eysenbach G. Correction: improving the quality of web surveys: the checklist for reporting results of internet E-surveys (CHERRIES). *J Med Internet Res*. (2012) 14:e2042. doi: 10.2196/jmir.2042

39. Boelen PA, Smid GE. The traumatic grief inventory self-report version (TGI-SR): introduction and preliminary psychometric evaluation. *J Loss Trauma*. (2017) 22:196–212. doi: 10.1080/15325024.2017.1284488

40. Boelen PA, Djelantik AM, de Keijser J, Lenferink LI, Smid GE. Further validation of the Traumatic Grief Inventory-Self Report (TGI-SR): a measure of persistent complex bereavement disorder and prolonged grief disorder. *Death Stud*. (2019) 43:351–64. doi: 10.1080/07481187.2018.1480546

41. Sim J, Machin L, Bartlam B. Identifying vulnerability in grief: psychometric properties of the Adult Attitude to Grief Scale. *Qual Life Res*. (2014) 23:1211–20. doi: 10.1007/s11136-013-0551-1

42. Machin L. *Exploring a framework for understanding the range of response to loss; a study of clients receiving bereavement counselling*. (Unpublished PhD thesis). Keele University (2001).

43. Hogan NS, Schmidt LA. Inventory of social support (ISS) In: *Techniques of grief therapy*. ed. Neimeyer R. New York: Routledge. (2015). 99–102.

44. Kentish-Barnes N, Chaize M, Seegers V, Legriel S, Cariou A, Jaber S, et al. Complicated grief after death of a relative in the intensive care unit. *Eur Respir J*. (2015) 45:1341–52. doi: 10.1183/09031936.00160014

45. Selman LE, Chao D, Sowden R, Marshall S, Chamberlain C, Koffman J. Bereavement support on the frontline of COVID-19: recommendations for hospital clinicians. *J Pain Symptom Manag*. (2020) 60:e81–6. doi: 10.1016/j.jpainsymman.2020.04.024

46. Yamaguchi T, Maeda I, Hatano Y, Mori M, Shima Y, Tsuneto S, et al. Effects of end-of-life discussions on the mental health of bereaved family members and quality of patient death and care. *J Pain Symptom Manag*. (2017) 54:17–26.e1. doi: 10.1016/j.jpainsymman.2017.03.008

47. Haugen DF, Hufthammer KO, Gerlach C, Sigurdardottir K, Hansen MI, Ting G, et al. Good quality care for cancer patients dying in hospitals, but information needs unmet: bereaved relatives' survey within seven countries. *Oncologist*. (2021) 26:e1273–84. doi: 10.1002/onco.13837

48. Miyashita M, Morita T, Sato K, Hirai K, Shima Y, Uchitomi Y. Factors contributing to evaluation of a good death from the bereaved family member's perspective. *Psychooncology*. (2008) 17:612–20. doi: 10.1002/pon.1283

49. R Core Team. (2021). *R-Studio. R (version 4.1.1)*. Available at: www.r-studio.com.

50. Cohen J. A power primer. *Psychol Bull*. (1992) 112:155–9. doi: 10.1037/0033-2909.112.1.155

51. Nakagawa S, Schielzeth H. A general and simple method for obtaining R2 from generalized linear mixed effects models. *Methods Ecol Evol*. (2013) 4:133–42. doi: 10.1111/j.2041-210x.2012.00261.x

52. Titlestad KB, Schmid MT, Dyregrov K. Prevalence and predictors of prolonged grief symptoms among those bereaved from a drug-related death in a convenience sample of Norwegian parents: a cross-sectional study. *Death Stud*. (2022) 46:1354–63. doi: 10.1080/07481187.2020.1867255

53. Boelen PA, Smid GE, Mitima-Verloop HB, de Keijser J, Lenferink LI. Patterns, predictors, and prognostic validity of persistent complex bereavement disorder symptoms in recently bereaved adults: a latent class analysis. *J Nerv Ment Dis*. (2019) 207:913–20. doi: 10.1097/NMD.0000000000001053

54. Dhada S, Stewart D, Cheema EA-O, Hadi MA-O, Paudyal VA-O. Cancer services during the COVID-19 pandemic: systematic review of patient's and caregiver's experiences. *Cancer Manag Res*. (2021) 13:5875–87. doi: 10.2147/CMAR.S318115

55. Lai AG, Pasea L, Banerjee A, Hall G, Denaxas S, Chang WH, et al. Estimated impact of the COVID-19 pandemic on cancer services and excess 1-year mortality in people with cancer and multimorbidity: near real-time data on cancer care, cancer deaths and a population-based cohort study. *BMJ Open*. (2020) 10:e043828. doi: 10.1136/bmjopen-2020-043828

56. Mayland CR, Hughes R, Lane S, McGlinchey T, Donnellan W, Bennett K, et al. Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic. *Palliat Med*. (2021) 35:1480–91. doi: 10.1177/02692163211019885

57. Hanna JR, Rapa E, Dalton LJ, Hughes R, McGlinchey T, Bennett KM, et al. A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. *Palliat Med*. (2021) 35:843–51. doi: 10.1177/02692163211004210

58. Mazzaschi F, Barawi K, Torren-Burton A, Sutton E, Wakefield D, Gilbert E, et al. 12 Grieving during COVID-19: exploring the lived experiences of people bereaved during the first two waves of the pandemic. *BMJ Support Palliat Care*. (2023) 13:A5. doi: 10.1136/spcare-2023-MCRC.11

59. Neimeyer RA. *Meaning reconstruction and the experience of loss* American Psychological Association (2001). doi: 10.1037/10397-000

60. Harrop E, Morgan F, Byrne A, Nelson A. "It still haunts me whether we did the right thing": a qualitative analysis of free text survey data on the bereavement experiences and support needs of family caregivers. *BMC Palliat Care*. (2016) 15:1–8. doi: 10.1186/s12904-016-0165-9

61. Goss S, Mirra RM, Longo M, et al. 15 Bereavement during COVID-19: findings from a UK-wide online survey on the use and perceived helpfulness of informal and formal support during the pandemic. *BMJ Support Palliat Care*. (2023) 13:A6. doi: 10.1136/spcare-2023-MCRC.14

62. Harrop E, Morgan F, Longo M, Semedo L, Fitzgibbon J, Pickett S, et al. The impacts and effectiveness of support for people bereaved through advanced illness: a systematic review and thematic synthesis. *Palliat Med*. (2020) 34:871–88. doi: 10.1177/0269216320920533

63. Burrell A, Selman LE. How do funeral practices impact bereaved relatives' mental health, grief and bereavement? A mixed methods review with implications for COVID-19. *Omega*. (2022) 85:345–83. doi: 10.1177/0030222820941296

64. Dos Santos CF, Picó-Pérez M, Morgado P. COVID-19 and mental health—what do we know so far? *Front Psych*. (2020) 11:565698. doi: 10.3389/fpsyt.2020.565698

65. Chiu YW, Huang CT, Yin SM, Huang YC, Chien CH, Chuang HY. Determinants of complicated grief in caregivers who cared for terminal cancer patients. *Support Care Cancer*. (2010) 18:1321–7. doi: 10.1007/s00520-009-0756-6

66. Joaquim RM, Pinto AL, Guatimosim RF, de Paula JJ, Costa DS, Diaz AP, et al. Bereavement and psychological distress during COVID-19 pandemics: the impact of death experience on mental health. *Curr Res Behav Sci*. (2021) 2:100019. doi: 10.1016/j.crbeha.2021.100019

67. Sullivan AR, Fenelon A. Patterns of widowhood mortality. *J Gerontol*. (2014) 69B:53–62. doi: 10.1093/geronb/gbt079

68. Elwert F, Christakis NA. The effect of widowhood on mortality by the causes of death of both spouses. *Am J Public Health*. (2008) 98:2092–8. doi: 10.2105/AJPH.2007.114348

69. Bindley K, Lewis J, Travaglia J, DiGiacomo M. Disadvantaged and disenfranchised in bereavement: a scoping review of social and structural inequity following expected death. *Soc Sci Med*. (2019) 242:112599. doi: 10.1016/j.socscimed.2019.112599

70. Hart JT. The inverse care law. *Lancet*. (1971) 297:405–12. doi: 10.1016/S0140-6736(71)92410-X

71. Rowley J, Richards N, Carduff E, Gott M. The impact of poverty and deprivation at the end of life: a critical review. *Palliat Care Soc Pract*. (2021) 15:26323524211033873. doi: 10.1177/26323524211033873

72. Bourdieu P. The forms of capital In: JG Richardson, editor. *Handbook of theory and research for the sociology of education*. New York, NY: Greenwood Press ([1983] 1986). 241–58.

73. Pinxten W, Lievens J. The importance of economic, social and cultural capital in understanding health inequalities: using a Bourdieu-based approach in research on physical and mental health perceptions. *Sociol Health Illn*. (2014) 36:1095–110. doi: 10.1111/1467-9566.12154

74. Shim JK. Cultural health capital: a theoretical approach to understanding health care interactions and the dynamics of unequal treatment. *J Health Soc Behav*. (2010) 51:1–5. doi: 10.1177/0022146509361185

75. Kira IA, Shuwiekh HA, Ashby JS, Elwakeel SA, Alhuwailah A, Sous MS, et al. The impact of COVID-19 traumatic stressors on mental health: is COVID-19 a new trauma type. *Int J Ment Heal Addict*. (2021) 21:51–70. doi: 10.1007/s11469-021-00577-0

76. Maffly-Kipp J, Eisenbeck N, Carreno DF, Hicks J. Mental health inequalities increase as a function of COVID-19 pandemic severity levels. *Soc Sci Med*. (2021) 285:114275. doi: 10.1016/j.socscimed.2021.114275

77. Zacher M, Raker EJ, Meadows MC, Ramírez S, Woods T, Lowe SR. Mental health during the COVID-19 pandemic in a longitudinal study of Hurricane Katrina survivors. *SSM Ment Health*. (2023) 3:100198. doi: 10.1016/j.ssmmh.2023.100198

78. UK Commission on Bereavement (2022) *Bereavement is everybody's business*. Available at: https://bereavementcommission.org.uk/ukcb-findings/UKCB findings

79. Bristowe K, Marshall S, Harding R. The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: a systematic review, thematic synthesis and modelling of the literature. *Palliat Med*. (2016) 30:730–44. doi: 10.1177/0269216316634601

80. Walsh K, King M, Jones L, Tookman A, Blizard R. Spiritual beliefs may affect outcome of bereavement: prospective study. *BMJ*. (2002) 324:1551. doi: 10.1136/bmj.324.7353.1551

81. Poxon L. 'Doing the same puzzle over and over again': a qualitative analysis of feeling stuck in grief. *Bereavement*. (2023) 2:2. doi: 10.54210/bj.2023.1095

82. Ahmadi K, Ramezani MA. Iranian emotional experience and expression during the COVID-19 crisis. *Asia Pacif J Public Health*. (2020) 32:285–6. doi: 10.1177/1010539520937097

83. Albuquerque S, Santos AR. "In the same Storm, but not on the same Boat": children grief during the COVID-19 pandemic. *Front Psych*. (2021) 12:638866. doi: 10.3389/fpsyt.2021.638866

84. Breen LJ, Kawashima D, Joy K, et al. Grief literacy: a call to action for compassionate communities. *Death Stud*. (2020) 18:1–9. doi: 10.1080/07481187.2020.1739780

85. Harrop E, Mann M, Semedo L, Chao D, Selman LE, Byrne A. What elements of a systems' approach to bereavement are most effective in times of mass bereavement? A narrative systematic review with lessons for COVID-19. *Palliat Med*. (2020) 34:1165–81. doi: 10.1177/0269216320946273

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Temporal trends and barriers for inpatient palliative care referral in metastatic gynecologic cancer patients receiving specific critical care therapies

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Objective: Existing evidence suggests that palliative care (PC) is highly underutilized in metastatic gynecologic cancer (mGCa). This study aims to explore temporal trends and predictors for inpatient PC referral in mGCa patients who received specific critical care therapies (CCT).

Methods: The National Inpatient Sample from 2003 to 2015 was used to identify mGCa patients receiving CCT. Basic characteristics were compared between patients with and without PC. Annual percentage change (APC) was estimated to reflect the temporal trend in the entire cohort and subgroups. Multivariable logistic regression was employed to explore potential predictors of inpatient PC referral.

Results: In total, 122,981 mGCa patients were identified, of whom 10,380 received CCT. Among these, 1,208 (11.64%) received inpatient PC. Overall, the rate of PC referral increased from 1.81% in 2003 to 26.30% in 2015 (APC: 29.08%). A higher increase in PC usage was found in white patients (APC: 30.81%), medium-sized hospitals (APC: 31.43%), the Midwest region (APC: 33.84%), and among patients with ovarian cancer (APC: 31.35%). Multivariable analysis suggested that medium bedsize, large bedsize, Midwest region, West region, uterine cancer and cervical cancer were related to increased PC use, while metastatic sites from lymph nodes and genital organs were related to lower PC referral.

Conclusion: Further studies are warranted to better illustrate the barriers for PC and finally improve the delivery of optimal end-of-life care for mGCa patients who receive inpatient CCT, especially for those diagnosed with ovarian cancer or admitted to small scale and Northeast hospitals.

KEYWORDS

trends, barriers, palliative care, metastatic gynecologic cancer, critical care therapies

1 Introduction

Gynecologic cancer is the most common malignancy in women, encompassing ovarian cancer, uterine cancer, and cervical cancer. According to the Cancer Statistics for 2022, it is estimated that there will be approximately 19,880 new cases of ovarian cancer, 65,950 new cases of uterine cancer, and 14,100 new cases of cervical cancer in the United States (US). Meanwhile, the estimated deaths for gynecologic cancer are also less than encouraging (1). Early diagnosis and treatment could improve cancer survival, while a significant number of cases progress rapidly and are diagnosed with metastasis (1). For those admitted to intensive care units, patients are frequently administrated with critical care therapies (CCT) to provide respiratory and nutritional support for life-saving measures (2–4). These patients are usually experience severe physical, psychological and social suffering (5, 6).

Palliative care (PC) is a structured system that provides care to patients with end-stage diseases. It has been reported to improve symptom management, alleviate psychological suffering, and reduce cancer-related mortality (7). The American Society of Clinical Oncology (ASCO) and the Society of Gynecologic Oncology (SGO) have formally endorsed early palliative care for gynecologic cancer patients (8–10). Multiple studies have demonstrated the beneficial role of early PC in addressing symptoms and managing psychological concerns in patients with gynecologic oncology (11, 12). However, studies have reported that PC is highly underutilized in metastatic gynecologic cancer (mGCa) patients, with utilization rates ranging from 5% to 24% (13–17). mGCa patients receiving CCT have increased cancer-related complications and long-term morbidity, and thus are strong indications for PC referral (18). Increasing awareness and accessibility of PC in this population is clinically significant. Although several publications have examined the utilization pattern of inpatient PC across different cancers in patients receiving life-sustaining treatments (19–21), there is a dearth of data focusing specifically on PC referral in mGCa patients receiving CCT while hospitalized.

The present study aims to investigate the temporal trends, predictors and barriers for inpatient PC referral in mGCa patients who specific CCT from a national perspective using the National Inpatient Sample (NIS) database.

2 Patients and methods

2.1 Data source

Data in the study is de-identified and thus exempt from approval by an institutional review board. The NIS database is the largest publically available all-payer healthcare database in the US (22), developed by the Agency for Healthcare Research and Quality (AHRQ), as part of the Healthcare Cost and Utilization project (HCUP), which collected a stratified sample from nearly 1000 hospitals. Each hospitalization contains up to 30 inpatient diagnoses and 15 procedures that could be identified through the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes.

2.2 Study design and patient selection

NIS database from 2003 to 2015 was used in this cross-sectional study. Gynecologic cancers were obtained by retrieving the following diagnostic codes: 1830, 1832, 1838, 1839 (ovarian cancer), 179, 1820, 1821, 1828 (uterine cancer), 1800, 1801, 1808, 1809 (cervical cancer) (16). Cases were considered metastatic gynecologic cancer (mGCa) with the presence of bone & bone marrow, brain & spinal cord, lymph nodes, liver, respiratory organs, urinary organs, adrenal glands, gastrointestinal organs, genital organs or other organs in the field of the secondary codes (Supplementary Table 1) (23). Among the selected mGCa cases, specific CCT including invasive mechanic ventilation (IMV), total parenteral nutrition (TPN), percutaneous endoscopic gastrostomy (PEG) tube, tracheostomy and dialysis for acute kidney failure (AKF) were considered (19–21). These procedures are aggressive and commonly used during the end-of-life period to provide necessary respiratory and nutritional support.

2.3 Patient and hospital characteristics

Patient-related, cancer-related and hospital-related characteristics were collected. Patient-related characteristics included age, year of admission, race, insurance type, income category, discharge destination, primary diagnosis and Elixhauser comorbidity score. The last consisted of 29 common comorbidities that could represent the disease burdens (excluded cancer in this study) (24). Cancer-related characteristics encompassed cancer type, metastatic sites, number of metastatic sites and chemotherapy. Lastly, hospital-related characteristics were hospital type, hospital bedsize and hospital region.

2.4 Definition of principal diagnosis and inpatient PC use

The principal diagnosis was categorized using the Clinical Classifications Software codes, which collapsed diagnoses and procedures into clinically meaningful categories (22).The primary outcome was temporal trend of inpatient PC referral in mGCa patients who received specific CCT. The secondary outcome included predictors of PC referral in the overall patients and in the subgroup undergoing IMV treatment. PC referral was defined using ICD-9-CM diagnostic code V66.7, which has been validated in metastatic disease with moderate sensitivity and high specificity (25, 26). Cases involving patients under 18 years old or admitted to hospitals that did not provide PC service during the study period were excluded from the analysis.

2.5 Statistical analysis and covariates

Continuous characteristics between patients with and without PC referral were expressed as mean and compared using t-test, while categorical variables were reported as proportions and compared using chi-square tests. We calculated annual percentage change (APC) in the entire cohort and subgroups by race, hospital region, hospital bedsize, teaching status, cancer type and discharge destination. Sampling stratas, clusters and weights were considered to derive estimates from the national perspective using complex survey methods. Additionally, we preformed multivariable logistic regression analysis to explore the predictors of PC referral in mGCa patients receiving CCT, taking into account patient-related, cancer-related and hospital-related characteristics. Confidence intervals for the ORs were calculated using the Taylor series method.

A P value ≤ 0.05 was considered statistically significant. All statistical analyses were performed using SAS version 9.4 and R version 3.6.2.

3 Results

3.1 Study population

In total, 122,981 hospitalizations diagnosed with mGCa were identified from 2003 to 2015, among which 10,737 have received inpatient CCT. We further excluded 357 patents who were under 18 years old or admitted to hospitals where PC was not available. Consequently, 10,380 (weighted 51,008) mGCa patients receiving CCT were identified in the further analysis. Among these patients, 7,254 (69.88%) were diagnosed with metastatic ovarian cancer (mOCa), 1,931 (18.60%) were diagnosed with metastatic uterine cancer (mUCa) and 1,195 (11.51%) were diagnosed with metastatic cervical cancer (mCCa). Regarding specific CCT, 3,641 (35.08%) patients received IMV, 1,207 (11.63%) received PEG, 5,918 (57.01%) received TPN, 265 (2.55%) received tracheostomy and 695 (6.70%) received dialysis for AKF. Characteristics between patients with and without PC in the IMV subgroup were summarized in Supplementary Table 2.

3.2 Trends of IPC use

Among the included patients, 1208 (11.64%) received inpatient PC. There were 743(10.24%), 288 (14.91%) and 177(14.81%) patients who received PC in mOCa, mUCa and mCCa patients, respectively. As showed in Figure 1, the rates of PC referral varied across different types of CCT and cancer. Patients who received PC were younger (61.74 vs. 62.92), less likely to be diagnosed with mOCa (61.51% vs. 70.99%), more likely to be admitted for infections (14.32% vs. 8.18%) and admitted in Midwest (22.60% vs. 19.41%) or urban teaching hospitals (69.62% vs. 62.91%) (Table 1).

Overall, the rate of PC referral increased from 1.81% in 2003 to 26.30% in 2015 (APC: 29.08%%; p < 0.0001). Stratified by race, the PC rate increased from 0.78% to 24.93% in White (APC: 30.81%%; p < 0.0001), from 3.33% to 30.43% in Black (APC: 24.92%%; p < 0.0001) and from 7.47% to 28.07% (APC: 16.48%%; p=0.0005) in the Hispanic population (Figure 2). Stratified by bedsize, the PC rate increased from 4.46% to 20.90% in small bedsize hospitals (APC: 23.99%; p=0.0001), from 1.60% to 27.97% in medium bedsize hospitals (APC: 31.43%%; p < 0.0001) and from 1.53% to 26.63% in large bedsize hospitals (APC: 30.55%%; p < 0.0001). Stratified by hospital region, the PC rate increased from 2.29% to 23.48% in the Northeast (APC: 24.92%; p < 0.0001), from 0.87% to 25.62% in the Midwest (APC: 33.84%; p < 0.0001), from 1.40% to 28.72% in the South (APC: 31.88%; p < 0.0001)

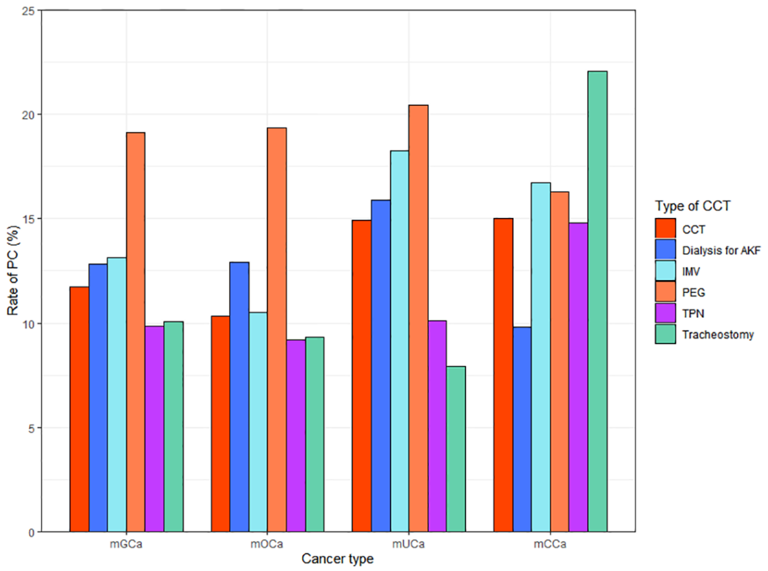

FIGURE 1
Rate of palliative care referral by CCT and cancer type.

TABLE 1 Basic characteristics of mGCa patients receiving CCT stratified according to use of inpatient PC.

Variables	No PC (N=9172, %)	PC (N=1208, %)	*P*-value
Age	62.92 (12.65)	061.74 (13.14)	0.0024
Year interval			<0.0001
2003-2009	5046 (55.02)	228 (18.87)	
2010-2014	4126 (44.98)	980 (81.13)	
Race			<0.0001
White	5775 (62.97)	741 (61.34)	
Black	1013 (11.04)	205 (16.97)	
Hispanic	651 (7.10)	102 (8.44)	
Other	544 (5.93)	81 (6.71)	
Unknown	1189 (12.96)	79 (6.54)	
Type of insurance			
Medicare	4288 (46.75)	534 (44.21)	0.0004
Medicaid	1018 (11.10)	177 (14.65)	
Private	3452 (37.64)	427 (35.35)	
Self-pay/other	414 (4.51)	70 (5.79)	
Income quartile			0.2463
0-25th Percentile	1985 (21.64)	282 (23.34)	
25th-50th Percentile	2043 (22.27)	277 (22.93)	
50th-75th Percentile	2406 (26.23)	287 (23.76)	
75th-100th Percentile	2738 (29.86)	362 (29.97)	
Hospital bedsize			0.0008
Small	951 (10.36)	86 (7.12)	
Medium	1945 (21.21)	285 (23.59)	
Large	6276 (68.43)	837 (69.29)	
Hospital type			<0.0001
Rural	358 (3.90)	55 (4.55)	
Urban non-teaching	3044 (33.19)	312 (25.83)	
Urban teaching	5770 (62.91)	841 (69.62)	
Hospital region			0.0124
Northeast	2063 (22.49)	232 (19.21)	
Midwest	1780 (19.41)	273 (22.60)	
South	3012 (32.84)	403 (33.36)	
West	2317 (25.26)	300 (24.83)	
Elixhauser comorbidity score	2.71 (1.78)	3.11 (1.73)	<0.0001
Primary diagnosis			<0.0001
Cancer-related disorders	5080 (55.39)	550 (45.53)	
Infections	750 (8.18)	173 (14.32)	
Genitourinary disorders	394 (4.30)	47 (3.89)	
Cardiovascular disorders	294 (3.21)	51 (4.22)	
Pulmonary disorders	436 (4.75)	74 (6.13)	
Gastrointestinal disorders	1390 (15.15)	188 (15.56)	
Fractures	*	*	
Fluid/Electrolyte disorders	121 (1.32)	23 (1.90)	
Neurologic disorders	75 (0.82)	14 (1.16)	
Complications of surgery	346 (3.77)	53 (4.39)	
Other disorders	278 (3.03)	31 (2.57)	
Cancer type			<0.0001
Ovarian cancer	6511 (70.99)	743 (61.51)	
Uterine cancer	1643 (17.91)	288 (23.84)	
Cervical cancer	1018 (11.10)	177 (14.65)	
Metastatic sites			
Bone & bone marrow	423 (4.61)	99 (8.20)	<0.0001
Brain & spinal cord	256 (2.79)	65 (5.38)	<0.0001
Lymph nodes	1499 (16.34)	155 (12.83)	0.0017
Liver	1747 (19.05)	336 (27.81)	<0.0001
Respiratory organs	2211 (24.11)	342 (28.31)	0.0014
Adrenal glands	64 (0.70)	13 (1.08)	0.1497
Gastrointestinal organs	5637 (61.46)	659 (54.55)	<0.0001
Urinary organs	529 (5.77)	66 (5.46)	0.6692
Genital organs	1088 (11.86)	61 (5.05)	<0.0001
Other organs	1881 (20.51)	195 (16.14)	0.0004
Number of metastatic sites (≥2)	3988 (43.48)	515 (42.63)	0.5763
Type of CCT			
IMV	3166 (34.52)	475 (39.32)	0.0010
PEG tube	977 (10.65)	230 (19.04)	<0.0001
TPN	5342 (58.24)	576 (47.68)	<0.0001
Tracheostomy	239 (2.61)	26 (2.15)	0.3476
AKI requiring dialysis	606 (6.61)	89 (7.37)	0.3202
Do Not Resuscitate	442 (4.82)	442 (36.59)	<0.0001

(Continued)

TABLE 1 Continued

Variables	No PC (N=9172, %)	PC (N=1208, %)	*P*-value
Chemotherapy	1041 (11.35)	122 (10.10)	0.1953
In-hospital mortality	1821 (19.85)	523 (43.29)	<0.0001
Discharge disposition (alive)			<0.0001
Home or home healthcare	5131 (69.80)	410 (59.85)	
Short term hospitals	268 (3.65)	17 (2.48)	
Intermediate facilities	1925 (26.19)	250 (36.50)	
Other	27 (0.36)	*	

CCT, critical care therapies; mGCa, metastatic gynecologic cancer; PC, palliative care; SD, standard deviation; IMV, invasive mechanic ventilation; PEG, percutaneous endoscopic gastrostomy; TPN, total parenteral nutrition; AKF, acute kidney failure.

*Small numbers of observations (<10) are at risk of identification of persons according to the HUCP and we replaced the number with an asterisk.

and from 2.71% to 26.15% in the West (APC: 24.35%; p=0.0004). In addition, stratified by cancer type, the rate of PC referral increased from 1.06% to 23.32% in mOCa (APC: 31.35%; p < 0.0001), from 3.06% to 33.58% in mUCa (APC: 27.68%; p < 0.0001), and from 4.81% to 28.17% in mCCa (APC: 25.80%; p < 0.0001; Figure 3). Stratified by discharge destination, the PC rate increased from 1.79% to 21.63% in patients who died during hospitalization (APC: 32.00%; p < 0.0001) and from 1.88% to 43.20% among the survivors (APC: 27.78%; p < 0.0001; Supplementary Figure 1).

3.3 Predictors of PC use

According to the multivariable analysis, year interval (odds ratio[OR]: 2.87, 95% confidence interval [CI]: 2.33-3.55), medium bedsize (OR: 1.59, 95% CI: 1.17-2.17), large bedsize (OR: 1.59, 95% CI: 1.20-2.12), Midwest region (OR: 1.37, 95% CI: 1.06-1.78), West region (OR: 1.30, 95% CI: 1.01-1.66), higher Elixhauser comorbidity score (OR: 1.04, 95% CI: 1.00-1.08), uterine cancer (OR: 1.28, 95% CI: 1.09-1.51), cervical cancer (OR: 1.38, 95% CI: 1.10-1.74), Do Not Resuscitate (OR: 6.20, 95% CI: 5.22-7.37), patients receiving PEG tube (OR: 1.98, 95% CI: 1.57-2.51), metastatic sites from brain & spinal cord (OR: 1.58, 95% CI: 1.10-2.28) and liver (OR: 1.34, 95% CI: 1.07-1.67) were associated with increased PC referral, while urban non-teaching hospitals, metastatic sites from lymph nodes and genital organs were related to lower PC referral. Additionally, predictors of PC referral in patients receiving IMV could be found in Table 2, which were similar to results in the main analysis.

4 Discussion

Although ASCO and SGO have long recommended early integration of PC to improve end-of-life care, practical evidence shows high underutilization of PC referral in mGCa patients (8, 10, 13, 16). Intensive care therapies are often provided to mGCa patients when severe treatment-related complications occurred or cancer progressed, highlighting the clinical importance and necessity of PC referral in this vulnerable population (2, 18). Our analysis suggested that approximately 11.64% of patients received inpatient PC, and the rate of PC referral increased from 1.81% in 2003 to 26.30% in 2015, with an average annual increase of 29.08%. Multivariable analysis suggested that medium bedsize, large bedsize, Midwest region, West region, higher Elixhauser comorbidity score, uterine cancer and cervical cancer were related to increased PC use, while urban non-teaching hospitals, metastatic sites from lymph nodes and genital organs were related to lower PC referral.

Overall, approximately 11.64% of mGCa patients with CCT received inpatient PC, which is more than two times higher than the reported PC rate of 5% in the entire population regardless of CCT,

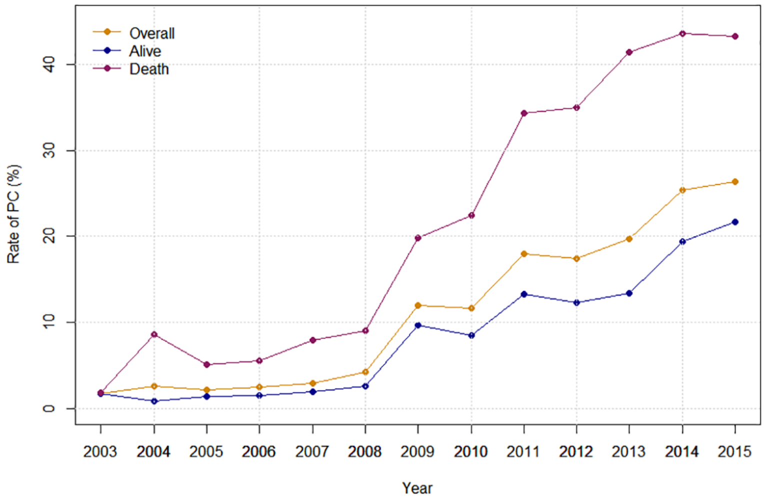

FIGURE 2
Inpatient palliative care referral over time, stratified by hospital region, race, hospital bedsize and hospital teaching status.

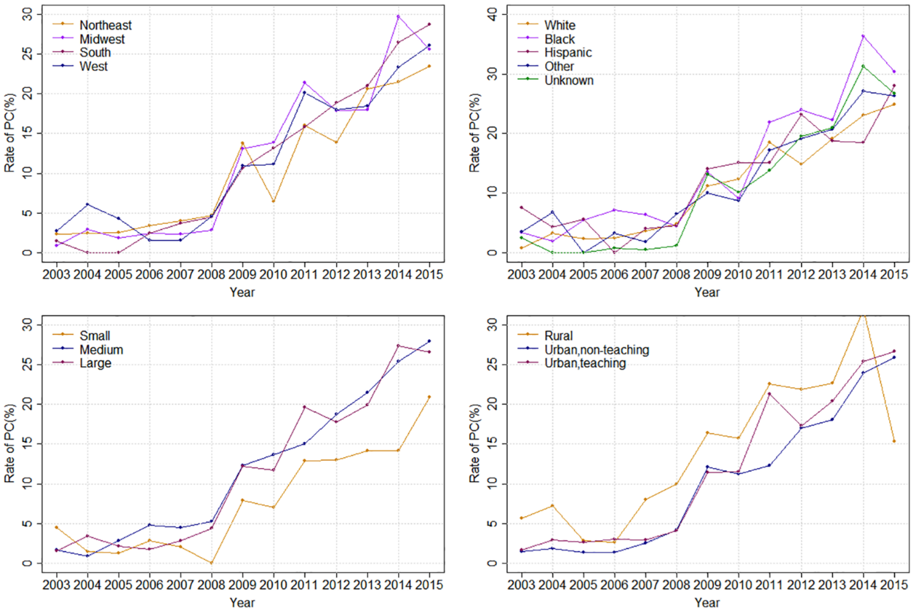

FIGURE 3
Inpatient palliative care referral over time, stratified by cancer type.

TABLE 2 Predictors of PC use in mGCa patients receiving CCT and IMV.

Variables	CCT		IMV	
	OR (95%CI)	*P*-value	OR (95%CI)	*P*-value
Age	1.00 (0.99,1.00)	0.2391	1.00 (0.98,1.01)	0.4806
Year interval				
2003-2009	1.00		1.00	
2010-2015	2.87 (2.33,3.55)	<0.0001	3.25 (2.33,4.54)	<0.0001
Race				
White	1.00		1.00	
Black	1.23 (0.99,1.51)	0.0587	1.20 (0.88,1.62)	0.2479
Hispanic	0.95 (0.72,1.25)	0.7184	0.84 (0.55,1.29)	0.4363
Other	1.07 (0.83,1.39)	0.6080	0.96 (0.63,1.47)	0.8508
Unknown	0.68 (0.50,0.93)	0.0156	0.68 (0.43,1.08)	0.0989
Type of insurance				
Medicare	1.00		1.00	
Medicaid	1.05 (0.82,1.35)	0.7069	0.96 (0.66,1.41)	0.8417
Private	0.98 (0.81,1.19)	0.8607	1.02 (0.75,1.39)	0.8773
Self-pay/other	1.21 (0.86,1.72)	0.2778	0.79 (0.44,1.42)	0.4280
Income quartile				
0-25th Percentile	1.00		1.00	
25th-50th Percentile	1.12 (0.91,1.37)	0.2928	1.21 (0.88,1.68)	0.2442
50th-75th Percentile	1.00 (0.81,1.22)	0.9771	1.09 (0.79,1.50)	0.6176

(Continued)

TABLE 2 Continued

Variables	CCT		IMV	
	OR (95%CI)	*P*-value	OR (95%CI)	*P*-value
75th-100th Percentile	1.23 (1.00,1.52)	0.0529	1.36 (0.98,1.89)	0.0646
Hospital bedsize				
Small	1.00		1.00	
Medium	1.59 (1.17,2.17)	0.0033	1.74 (1.05,2.88)	0.0331
Large	1.59 (1.20,2.12)	0.0014	1.83 (1.15,2.92)	0.0108
Hospital type				
Rural	1.00		1.00	
Urban non-teaching	0.65 (0.45,0.93)	0.0201	0.56 (0.33,0.98)	0.0415
Urban teaching	0.87 (0.61,1.23)	0.4332	0.86 (0.51,1.45)	0.5604
Hospital region				
Northeast	1.00		1.00	
Midwest	1.37 (1.06,1.78)	0.0181	1.23 (0.83,1.83)	0.3015
South	1.13 (0.89,1.43)	0.3072	1.04 (0.73,1.46)	0.8390
West	1.30 (1.01,1.66)	0.0399	1.24 (0.85,1.80)	0.2664
Elixhauser comorbidity score	1.04 (1.00,1.08)	0.0486	1.00 (0.93,1.06)	0.9017
Primary diagnosis				
Cancer-related disorders	1.00		1.00	
Infections	1.11 (0.88,1.41)	0.3882	1.37 (0.99,1.89)	0.0546
Genitourinary disorders	0.86 (0.60,1.25)	0.4358	1.34 (0.59,3.04)	0.4853
Cardiovascular disorders	1.01 (0.72,1.43)	0.9373	1.58 (1.03,2.41)	0.0355
Pulmonary disorders	1.11 (0.82,1.51)	0.4833	1.41 (0.96,2.07)	0.0778
Gastrointestinal disorders	0.93 (0.75,1.14)	0.4728	1.65 (1.03,2.63)	0.0369
Fractures	3.47 (0.69,17.37)	0.1306	5.01 (1.02,24.59)	0.0469
Fluid/Electrolyte disorders	1.71 (1.06,2.77)	0.0293	5.01 (1.31,19.19)	0.0189
Neurologic disorders	1.15 (0.60,2.21)	0.6751	0.74 (0.20,2.82)	0.6639
Complications of surgery	1.35 (0.99,1.84)	0.0551	1.97 (1.09,3.57)	0.0255
Other disorders	0.78 (0.50,1.20)	0.2572	1.22 (0.63,2.34)	0.5541
Cancer type				
Ovarian cancer	1.00		1.00	
Uterine cancer	1.28 (1.09,1.51)	0.0033	1.80 (1.37,2.35)	<0.0001
Cervical cancer	1.38 (1.10,1.74)	0.0051	1.61 (1.12,2.32)	0.0102
Metastatic sites				
Bone & bone marrow	1.14 (0.85,1.54)	0.3759	0.96 (0.63,1.46)	0.8561
Brain & spinal cord	1.58 (1.10,2.28)	0.0130	0.96 (0.57,1.62)	0.8731
Lymph nodes	0.78 (0.63,0.98)	0.0290	0.70 (0.50,0.98)	0.0402
Liver	1.34 (1.07,1.67)	0.0103	0.93 (0.66,1.30)	0.6549
Respiratory organs	1.00 (0.83,1.21)	0.9845	0.86 (0.62,1.17)	0.3366

(Continued)

TABLE 2 Continued

Variables	CCT		IMV	
	OR (95%CI)	*P*-value	OR (95%CI)	*P*-value
Adrenal glands	0.78 (0.39,1.58)	0.4936	0.63 (0.25,1.63)	0.3427
Gastrointestinal organs	0.98 (0.80,1.19)	0.8305	1.05 (0.77,1.42)	0.7660
Urinary organs	1.03 (0.75,1.40)	0.8718	0.74 (0.43,1.26)	0.2662
Genital organs	0.58 (0.42,0.78)	0.0004	0.55 (0.34,0.91)	0.0187
Other organs	0.88 (0.71,1.09)	0.2369	0.89 (0.63,1.27)	0.5298
Number of metastatic sites (≥2)	0.98 (0.77,1.25)	0.8951	1.29 (0.88,1.89)	0.1855
Type of CCT				
IMV	1.14 (0.90,1.43)	0.2807	—	—
PEG tube	1.98 (1.57,2.51)	<0.0001	1.38 (0.63,2.98)	0.4201
TPN	1.05 (0.84,1.32)	0.6639	1.04 (0.74,1.47)	0.8216
Tracheostomy	0.76 (0.46,1.25)	0.2801	0.84 (0.49,1.43)	0.5193
AKI requiring dialysis	0.99 (0.72,1.36)	0.9513	1.01 (0.61,1.66)	0.9700
Chemotherapy	1.05 (0.84,1.31)	0.6697	1.41 (0.89,2.22)	0.1445
Do Not Resuscitate	6.20 (5.22,7.37)	<0.0001	6.90 (5.27,9.03)	<0.0001

CCT, critical care therapies; mGCa, metastatic gynecologic cancer; PC, palliative care; IMV, invasive mechanic ventilation; PEG, percutaneous endoscopic gastrostomy; TPN, total parenteral nutrition; AKF, acute kidney failure; OR, odds ratio; CI, confidence interval.

as reported by Rosenfeld et al. (13). However, this proportion is still far from satisfactory considering that all mGCa patients with CCT are candidates for PC referral. It is worth noting that PC referral consistently increased by 29.08% from 2003 to 2015. This phenomenon might reflect improved adherence of oncological guideline by both physicians and patients. Subgroup analysis indicated that increasing trend of PC referral was more pronounced in White and patients admitted to medium bedsize, urban non-teaching and Midwest hospitals, suggesting a wider acceptance of PC use in these patients. From the trend charts, it is evident that PC rate experienced a sharp increase since 2009, which aligns with the findings of previous publications (13, 16). As aggressive measures such as CCT can reduce quality of life in mGCa patients, this unexpected increase may be partly attributed to the landmark ENABLE II trial in 2009 that revealed the effectiveness of PC interventions in improving the quality of life for patients with advanced cancer (27).

When considering hospital region, patients hospitalized in Midwest hospitals had the highest PC rate (13.30%), followed by South (11.80%), West (11.46%) and Northeast (10.11%), accompanied by the highest APC (33.84%). Multivariable analysis accounting for potential confounders suggested that Midwest region (OR: 1.37) and West region (OR: 1.30) were associated with increased probability of PC referral compared to the Northeast region. This regional disparities in PC use has been previously reported. Milki et al. enrolled mGCa patients who subsequently died during hospitalization and found that patients in Midwest region (OR: 1.37) and West region (OR: 1.30) had increased PC use (16). Another study focusing on metastatic bladder cancer receiving CCT also described a higher PC rate in the West region (21). Further studies are warranted to understand the undelaying mechanisms for this geographic disparities and to relieve barriers for lower PC utilization in the Northeast region.

When considering hospital size, we observed that both medium bedsize (OR: 1.59) and large bedsize (OR: 1.59) were associated with increased PC use compared to small bedsize. One possible explanation for this finding might be that larger hospitals have more dedicated end-of-life specialists to provide PC services. However, research on this topic has produced conflicting results. For instance, Rosenfeld et al. conducted a study using data from the 2005 to 2011 NIS database, including all mGCa cases, and concluded that bedsize was not a predictor for PC referral (13). Another study by Milki et al. found that large bedsize was a positive predictor of PC referral (OR: 1.36) in mGCa cases who died in hospital (16). We hypothesized that the severity of dying status might result this disparity, as mGCa patients receiving CCT or died in hospital represented more severe conditions with significant symptom burden. Large bedsize hospitals are likely to form well-organized PC team and well-established relationship between physicians and mGCa patients with more severe conditions.

There has been controversy surrounding the emerging evidence on racial disparities in PC use among mGCa patients (2, 13–16).

Understanding the racial and cultural differences among various racial groups can help personalize palliative care for mGCa patients receiving CCT and improve the delivery of comprehensive cancer care. Studies have reported Studies have reported that racial minority groups, such as Black or Hispanic gynecologic cancer patients, have expressed a desire for more intensive and invasive end-of-life care (2, 28), making them the potential candidates for PC delivery from the perspective of end-of-life decision-making. Consistent with previous publications (13, 29), our findings showed that Hispanic patients had the highest rate of PC use (16.83%), followed by Black patients (13.55%) and White patients (11.37%). However, this significant finding disappeared after adjustment for patient-related, cancer-related and hospital-related characteristics. Notably, Islam et al. analyzed data from the 2016 National Cancer Database and found that Hispanic and Black patients were less likely to utilize PC in metastatic ovarian cancer patients (14). In our subgroup analysis focusing exclusively on metastatic ovarian cancer patients, we did not observe such racial disparities. These discrepancies may be attributed to different population groups and data sources, especially considering that our study specifically involved patients receiving CCT during hospitalization. Therefore, further studies are needed to provide sufficient evidence to better understand the underlying racial differences and to improve equitable provision of PC among mGCa patients, irrespective of race.

For cancer types, uterine cancer ranked first in the rate of PC use (14.91%), followed by cervical cancer (14.81%) and ovarian cancer (10.24%). Although ovarian cancer patients has the lowest rate of PC use, the use of PC has dramatically increased over the study period, with the highest APC (31.35%). Previous studies have also reported lower PC use in ovarian cancer (13, 14). As we know, ovarian cancer has a higher degree of malignancy and worse survival compared to uterine cancer and cervical cancer (30). Therefore, future efforts are needed to improve and optimize PC referral in metastatic ovarian patients receiving CCT.

The present study utilized a national-level hospitalized database covering long time spans to investigate the temporal trends and predictors for inpatient PC referral in mGCa patients who frequently received CCT, including IMV, TPN, PEG tube, tracheostomy and dialysis for AKF. However, several limitations should also be considered for an accurate interpretation of our results. Firstly, PC use in the NIS database was defined based on the ICD-9-CM diagnostic code V66.7. Being an administrative database, the NIS may not capture all instances of PC discussions, and only those that are documented by physicians are recorded. Therefore, there may be a bias towards underestimating the actual number of PC use cases. However, the code was initially introduced in 1996 and has since been used in several publications, demonstrating moderate sensitivity (66.3% to 83%) and high specificity (95% to 99.1%) (25, 26). Secondly, this study focused only on specific CCTs that were frequently used in routine clinical practice. Any external extrapolation (eg, to all critically ill mGCa patients) should be interpreted with adequate caution. Thirdly, race information was unknown for nearly 12.22% of the included patients. Despite these limitations, the present study provides new evidence and insights into the understanding of PC referral in mGCa patients receiving CCT.

This analysis suggests that approximately 11.64% of patients received inpatient PC, which is still considerably below an ideal level. Further studies are necessary to elucidate the barriers to PC and ultimately enhance the provision of optimal end-of-life care for mGCa patients who receive inpatient CCT. This is particularly important for patients with ovarian cancer or those admitted to small-scale and northeast hospitals.

5 Conclusions

Despite the increase in PC referral over time, the absolute rate has remained low. The rates of PC referral in mGCa patients receiving CCT differ based on various sociodemographic and clinical factors. Thus, further studies are necessary to better understand the barriers to PC in mGCa patients undergoing inpatient CCT.

Data availability statement

The datasets presented in this article are not readily available because data are available in the NIS website: www.hcup-us.ahrq.go. Requests to access the datasets should be directed to www.hcup-us.ahrq.gov.

Ethics statement

The studies involving humans were approved by The NIS database is publically available and de-identified and thus is exempt from approval by an institutional review board in Aoyang Hospital of Jiangsu University. The studies were conducted in accordance with the local legislation and institutional requirements. The ethics committee/institutional review board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because The NIS database is publically available and de-identified and thus is exempt from approval by an institutional review board in Aoyang Hospital of Jiangsu University.

Author contributions

LS, LC, YZ, HH, ZL designed the study and drafted the manuscript. TC, QX edited the manuscript. In addition, each author has read and approved the final version of the manuscript. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fonc.2023.1173438/full#supplementary-material

References

1. Siegel RL, Miller KD, Fuchs HE and Jemal A. Cancer statistics, 2022. *CA Cancer J Clin* (2022) 72:7–33. doi: 10.3322/caac.21708

2. Taylor J, Rajan S, Zhang N, Meyer L, Ramondetta L, Bodurka D, et al. End-of-life racial and ethnic disparities among patients with ovarian cancer. *J Clin Oncol Off J Am Soc Clin Oncol* (2017) 35:1829–35. doi: 10.1200/jco.2016.70.2894

3. Nevadunsky NS, Spoozak L, Gordon S, Rivera E, Harris K and Goldberg GL. End-of-life care of women with gynecologic Malignancies: a pilot study. *Int J Gynecol Cancer* (2013) 23:546–52. doi: 10.1097/IGC.0b013e3182842efa

4. Fauci J, Schneider K, Walters C, Boone J, Whitworth J, Killian E and Straughn JM Jr. The utilization of palliative care in gynecologic oncology patients near the end of life. *Gynecol Oncol* (2012) 127:175–9. doi: 10.1016/j.ygyno.2012.06.025

5. Krakauer EL, Kwete X, Kane K, Afshan G, Bazzett-Matabele L, Bien-Aime DDR, et al. Cervical cancer-associated suffering: estimating the palliative care needs of a highly vulnerable population. *JCO Glob Oncol* (2021) 7:862–72. doi: 10.1200/GO.21.00025

6. Taylor JS, Brown AJ, Prescott LS, Sun CC, Ramondetta LM, Bodurka DC. Dying well: How equal is end of life care among gynecologic oncology patients? *Gynecol Oncol* (2016) 140:295–300. doi: 10.1016/j.ygyno.2015.12.012

7. Swetz KM, Kamal AH. Palliative care. *Ann Intern Med* (2018) 168:ITC33–48. doi: 10.7326/AITC201803060

8. Ferrell BR, Temel JS, Temin S, Alesi ER, Balboni TA, Basch EM, et al. Integration of palliative care into standard oncology care: American Society of clinical oncology clinical practice guideline update. *J Clin Oncol* (2017) 35:96–112. doi: 10.1200/JCO.2016.70.1474

9. Bauman JR, Temel JS. The integration of early palliative care with oncology care: the time has come for a new tradition. *J Natl Compr Canc Netw* (2014) 12:1763–71. doi: 10.6004/jnccn.2014.0177

10. *Choosing wisely campaign: Society of Gynecologic Oncology* (2013). Available at: http://www.choosingwisely.org/societies/society-of-gynecologic-oncology/.

11. Lefkowits C, Teuteberg W, Courtney-Brooks M, Sukumvanich P, Ruskin R and Kelley JL. Improvement in symptom burden within one day after palliative care consultation in a cohort of gynecologic oncology inpatients. *Gynecol Oncol* (2015) 136:424–8. doi: 10.1016/j.ygyno.2014.12.030

12. Lopez-Acevedo M, Lowery WJ, Lowery AW, Lee PS and Havrilesky LJ. Palliative and hospice care in gynecologic cancer: a review. *Gynecol Oncol* (2013) 131:215–21. doi: 10.1016/j.ygyno.2013.06.012

13. Rosenfeld EB, Chan JK, Gardner AB, Curry N, Delic L and Kapp DS. Disparities associated with inpatient palliative care utilization by patients with metastatic gynecologic cancers: A study of 3337 women. *Am J Hosp Palliat Care* (2018) 35:697–703. doi: 10.1177/1049909117736750

14. Islam JY, Saraiya V, Previs RA and Akinyemiju T. Health care access measures and palliative care use by race/ethnicity among metastatic gynecological cancer patients in the United States. *Int J Environ Res Public Health* (2021) 18:6040. doi: 10.3390/ijerph18116040

15. Islam JY, Deveaux A, Previs RA and Akinyemiju T. Racial disparities in palliative care utilization among metastatic gynecological cancer patients living at last follow-up: An analysis of the National Cancer Data Base. *Data Brief* (2021) 34:106705. doi: 10.1016/j.dib.2020.106705

16. Milki A, Mann AK, Gardner A, Kapp DS, English D and Chan JK. Trends in the utilization of palliative care in patients with gynecologic cancer who subsequently died during hospitalization. *Am J Hosp Palliat Care* (2021) 38:138–46. doi: 10.1177/1049909120935038

17. Uppal S, Rice LW, Beniwal A and Spencer RJ. Trends in hospice discharge, documented inpatient palliative care services and inpatient mortality in ovarian carcinoma. *Gynecol Oncol* (2016) 143:371–8. doi: 10.1016/j.ygyno.2016.08.238

18. Azoulay E, Schellongowski P, Darmon M, Bauer PR, Benoit D, Depuydt P, et al. The Intensive Care Medicine research agenda on critically ill oncology and hematology patients. *Intensive Care Med* (2017) 43:1366–82. doi: 10.1007/s00134-017-4884-z

19. Loh KP, Abdallah M, Shieh MS, Stefan MS, Pekow PS, Lindenauer PK, et al. Use of inpatient palliative care services in patients with advanced cancer receiving critical care therapies. *J Natl Compr Canc Netw* (2018) 16:1055–64. doi: 10.6004/jnccn.2018.7039

20. Chen Y, Lin S, Zhu Y, Xu R, Lan X, Xiang F, et al. Prevalence, trend and disparities of palliative care utilization among hospitalized metastatic breast cancer patients who received critical care therapies. *Breast* (2020) 54:264–71. doi: 10.1016/j.breast.2020.11.001

21. Mazzone E, Knipper S, Mistretta FA, Palumbo C, Tian Z, Gallina A, et al. Trends and social barriers for inpatient palliative care in patients with metastatic bladder cancer receiving critical care therapies. *J Natl Compr Canc Netw* (2019) 17:1344–52. doi: 10.6004/jnccn.2019.7319

22. *NIS database documentation*. Available at: www.hcup-us.ahrq.gov.

23. Nordstrom BL, Whyte JL, Stolar M, Mercaldi C and Kallich JD. Identification of metastatic cancer in claims data. *Pharmacoepidemiol Drug Saf* (2012) 21 Suppl 2:21–8. doi: 10.1002/pds.3247

24. Southern DA, Quan H and Ghali WA. Comparison of the Elixhauser and Charlson/Deyo methods of comorbidity measurement in administrative data. *Med Care* (2004) 42:355–60. doi: 10.1097/01.mlr.0000118861.56848.ee

25. Feder SL, Redeker NS, Jeon S, Schulman-Green D, Womack JA, Tate JP, et al. Validation of the ICD-9 diagnostic code for palliative care in patients hospitalized with heart failure within the veterans health administration. *Am J Hosp Palliat Care* (2018) 35:959–65. doi: 10.1177/1049909117747519

26. Hua M, Li G, Clancy C, Morrison RS and Wunsch H. Validation of the V66.7 code for palliative care consultation in a single academic medical center. *J Palliat Med* (2017) 20:372–7. doi: 10.1089/jpm.2016.0363

27. Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA* (2009) 302:741–9. doi: 10.1001/jama.2009.1198

28. Barnato AE, Anthony DL, Skinner J, Gallagher PM and Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med* (2009) 24:695–701. doi: 10.1007/s11606-009-0952-6

29. Lefkowits C, Binstock AB, Courtney-Brooks M, Teuteberg WG, Leahy J, Sukumvanich P and Kelley JL. Predictors of palliative care consultation on an inpatient gynecologic oncology service: are we following ASCO recommendations? *Gynecol Oncol* (2014) 133:319–25. doi: 10.1016/j.ygyno.2014.02.031

30. Salani R, Khanna N, Frimer M, Bristow RE and Chen LM. An update on post-treatment surveillance and diagnosis of recurrence in women with gynecologic Malignancies: Society of Gynecologic Oncology (SGO) recommendations. *Gynecol Oncol* (2017) 146:3–10. doi: 10.1016/j.ygyno.2017.03.022

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Effectiveness of a home health monitoring and education program for complex chronic patients, led by primary care nurses

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Background: The challenge of chronicity has led developed countries to design strategies to respond to the new needs of complex chronic patients (CCP). There is evidence supporting better beneficial effects and more efficient care for CCP when home-base care programs are provided by Primary Health Care professionals. The main objective of the present study was to assess the effectiveness of a nursing intervention program of home visits for CCP analyzing the use of health services in terms of hospital admissions, emergency care unit visits, and mortality rate.

Methods: A quasi-experimental study was designed to retrospectively evaluate the effectiveness of a 3-year proactive, individualized nursing intervention in improving health outcomes measured by health service utilization (hospitalization, emergency care, and nursing home visits) in these patients. Of the 344 complex chronic patients participating in the study, 93 were assigned to the intervention group (IG) and 251 to the control group (CG).

Results: Along the period of study, the number of home visits in the IG almost tripled in relation to the CG (14.29 ± 4.49 vs. 4.17 ± 2.68, $p < 0.001$). Admissions in the first and second year of the study period were lower in the intervention group $p = 0.002$ and $p < 0.001$ respectively. All the participants in the control group were admitted at least once during the study period. In contrast, 29.0% of the participants in the intervention group never had a hospital admission during the 3-years study period. The number of ED visits to the emergency department was significantly lower in the IG during the 3 years of the study periods. The cumulative number of emergency visits in the IG was half that in the CG (5.66 ± 4. vs. 11.11 ± 4.45, $p < 0.001$, Cohen'd,1.53). A total of 35.5% of the participants in the intervention group visited the emergency department on three or fewer occasions compared to 98% of the subjects in the control group who visited the emergency department on more than six occasions ($p < 0.001$). The 3-year overall mortality rate was 23.5% in the control group and 21.6% in the nursing home visit program. These differences were not statistically significant.

Conclusion: The program demonstrated its effectiveness in reduction of hospital admissions and visits to the emergency department. The program had no impact on mortality rate. This program of home visits reinforces the role of primary care nurses in advanced competencies in chronicity.

KEYWORDS

nursing home visits, chronic disease, primary health care, health services, older adult, mortality, hospital admissions, emergency care

1. Introduction

Patients with complex chronic diseases are broadly defined as those having various combined morbidities, implying severe disabilities or functional limitations that require multidisciplinary health care providers (1). In the later stages, there is a reciprocal exacerbation between chronicity and loss of independence, further deteriorating patient well-being. This category of complex chronic patients (CCP) contributes substantially to increased morbidity and mortality (2). The progressive increase in the prevalence of multimorbidity has become a great challenge for healthcare systems in developed countries. The escalating prevalence of multiple concurrent health conditions presents a significant hurdle for healthcare systems in industrialized nations. This upsurge in enduring health problems results in amplified utilization of medical provisions and personnel, consequently leading to elevated healthcare expenditures for governments.

In the last two decades, different strategies to address pluripathology and frailty have been implemented, particularly in CCP (3–5). Many developed countries have allocated health resources to identify this segment of the CCP population and develop responses according to their needs, introducing new specific care models (3, 6). Basically, these models can be grouped into 2 different types: (i) Systemic models, focused on reorienting the health system such as the Chronic Care Model developed by the MacColl Center for Health Care Innovation, and commonly referred to as the Wagner chronic care model (6, 7). These models propose a case management strategy from Primary Care to prevent complications and exacerbations to improve health outcomes and quality of life and to decrease the use of high-cost resources; (ii) population models, which focus on identifying and responding to the needs of chronic patients, such as those of the Kaiser Permanente organization (8). These last models are based on strategies for segmenting the population based on complexity and level of care. Complexity was defined as comorbidity, readmission, polypharmacy, and dependency (9).

In 2012, the Spanish Ministry of Health, Social Services, and Equality published a strategy to approach chronicity in the National Health System and encouraged Autonomous Communities to deploy territorial programs for the care of complex chronic patients. In 2014, the Valencia Regional Government published its own strategy for the care of chronic patients, leaving it up to each Health Department to specify its implementation (10, 11).

To the best of our knowledge, there is little evidence of the effectiveness of new models of chronic patient care. Rather than a reorganization of the care model, the development of these plans has been based, in general, on the use of different instruments (stratification, case management, liaison nursing, home care, telemedicine, etc.) that demonstrate variable and controversial effectiveness and efficiency (12). The evaluation of health service interventions typically involves the assessment of a comprehensive package of services, and it is often challenging to isolate the individual effects of specific components within these interventions (13). Consequently, even in cases where statistically significant effects of interventions are not observed, it is essential to acknowledge that some components may still be beneficial.

Managing complex chronic patients in hospitals imposes significant financial and healthcare system burdens. These patients often incur higher costs (14, 15), experience longer hospital stays, and contribute to readmissions, necessitating significant resource allocation (16–18). Addressing these challenges is crucial for maintaining the financial sustainability of healthcare systems and ensuring high-quality care for complex chronic patients. A comprehensive report by The Commonwealth Fund in 202, titled "United States Health Care from a Global Perspective, 2022: Accelerating Spending, Worsening Outcome" emphasized that the management of complex chronic patients requires significant resource allocation, including specialized staff, technology, and care coordination efforts, contributing to the overall financial burden on healthcare systems (19).

In contrast, there is multiple evidence supporting better beneficial effects and more efficient care for CCP when home-base care programs provided by Primary Health Care professionals are designed (20). The main objective of home care interventions is to reduce institutionalized care (e.g., nursing homes and hospitals) (8, 9). Most home-care services are provided by primary care practitioners, geriatricians, nurses, and social workers. However, primary care or community nurses serve as central coordinators of care for complex chronic patients. They can coordinate appointments, medications, and referrals, ensuring that patients receive timely and appropriate care. Nursing home care visits should include not only health assessments focused on treating observed problems but also health education and social and psychological support (21–24). In their home visits, primary care nurses also play a key role in medication management, ensuring that patients understand and adhere to their medication regimens. Improved adherence can prevent exacerbations and hospitalizations.

To date, nursing interventions that seem to have the greatest impact on the strategy of chronic care in Spain are case management, home care programs from primary care, and telemonitoring (12, 25). Although they demonstrated favorable results in terms of effectiveness and satisfaction, more studies are needed to prove the efficiency of nursing contribution in chronicity. If interventions of home health care for chronicity provided by home nurses obtain better results, it could be asked whether the most efficient plan would be to explicitly strengthen the figure of the home nurse with advanced competence in chronicity within the scope of PC.

Aligned with the National strategy for addressing chronicity, the La Ribera Health Department decided to implement it in January 2017, adapting it to its own idiosyncrasies. The program was implemented until March 2020, when nurse home visits were interrupted due to forced confinement related to the first wave of the Sars-CoV2 pandemic. In 2021, the need for reorientation and implementation of home care prompted exploration of the effects of these nursing interventions. In addition, questions arise concerning how that change in the culture of the approach to chronicity was perpetuated in the daily practice of professionals and how it was the current impact on health outcomes for chronic patients.

To address these issues, the main objective of the present study was to retrospectively assess the effectiveness of a proactive intervention program of home visits implemented by community nurses for patients with combined chronic conditions as compared to a control group with similar diseases. This analysis spans a 3-year period, from 2017 to 2019. Effectiveness was assessed in terms of service utilization, including hospital admissions, emergency department (ED) visits, and mortality rates, and home visits conducted by nursing staff.

2. Materials and methods

2.1. Study design

This was a quasi-experimental study with a control group and non-probabilistic convenience sampling. In January 2017, the total population of Sueca's health area (Valencia, Spain) was 27,598 inhabitants. The total population was classified by health status and associated comorbidities using the records of the Valencian Community Patient Classification System (SCP-CV), which is based on the International Statistical Classification of Diseases and Related Health Problems and 3 M Clinical Risk Groups tool (CRG) (26, 27). Using established demographic, diagnostic, and procedural information, the CRG classification system categorizes individuals into one of nine primary health status groups. These groups ranged from severe (e.g., individuals with a history of heart transplant) to well (e.g., those with no chronic health issues or other discernible risk factors). Patients included in CRG 6 suffer from chronic disease in two or more organ systems (diabetes mellitus and congestive heart failure for example). Patients with multiple dominant chronic diseases (three or more) such as diabetes mellitus, congestive heart failure, and chronic obstructive pulmonary disease are included in CRG 7. Within each CRG, chronic illnesses and conditions are additionally segmented into six distinct levels of Severity of Illness (SOI).

2.2. Inclusion and exclusion criteria

In the current study, the target groups were CRG 6 and CRG 7 patients with severities of 5 (severe illness) and 6 (extremely severe) respectively. Additional inclusion criteria were age over 65 years, following a classic home care at demand, Charlson's comorbidity status ≥3, and high cost of pharmacy prescriptions (>p95) (28). Individuals in the end-of-life stage (CRG 8–9), those receiving treatment for their conditions through private health insurance companies, and mobile population (individuals who do not reside at their usual residence for more than 3 months per year) were excluded from the study.

2.3. Final sample selection

A sample of 653 patients was considered to have CCP included in the CRG 6–7 was finally considered for allocation to the intervention and the control group (Figure 1). Out of these 653 CCP, residents of Health Zone B11 of the La Ribera Health Department (Sueca), 174 (26.6%) were initially selected at random to follow the intervention protocol (IG) in January 2017. Our primary healthcare area is composed by 10 Basic Care Units (BCU), which involve a general practitioner and a nurse responsible for patients aged 15 and above. Each BCU is tasked with delivering care to a designated group of individuals, typically ranging from 1,350 to 1,550 patients. Members of each BCU selected at random at least 20 individuals from their pool of CCPs.

The remaining 479 CCPs were considered as the control group (CG). At the time to retrospectively evaluate the sample in 2021, and excluding patients with incomplete data, those lost because of changes in the healthcare area or discontinuity of the nurse home visits program, a sample of 93 alive patients could be finally analyzed in the IG (Figure 1). In this IG, 44 patients died during the period of study, and other 19 died during the first pandemic year, just before analyze data. Among the 479 patients who did not receive programmed nursing home visits and followed the usual care when they ask for home visit, data were finally recorded from 251 subjects who formed the CG. Among control patients, 144 died during the period 2017–2019, other 66 in 2020, the first pandemic year (Figure 1).

2.4. Sample size

Even though the present study is based on a non-probabilistic convenience sampling method, the sample size was calculated to ensure its representativeness. The sample size was estimated to detect a difference between two means using "annual hospital admissions" as the most relevant variable and considering a difference greater than 1 unit as clinically relevant. Accepting an alpha risk of 0.05 and a beta risk of 0.2 in a two-tailed test, we require 67 subjects in the first group and 180 in the second group to detect a difference equal to or greater than 1 unit. It is assumed that the common standard deviation is 2.35. A follow-up loss rate of 10% has been estimated. A balance factor of 2.7 has been established between the groups. Participants under the current study exceeds sample size calculations and therefore the results obtained could have stronger value.

2.5. Intervention

Three years of intervention were considered. The first two-year period was from March 2017 to March 2019. The third year covered from March 2019 to March 2020 when the program was interrupted because of the appearance of the first wave of the Sars-CoV2. Therefore, the first 2 years were considered regular health-care years; the third year reflected the pre-pandemic year. Data from the 3-year intervention period were evaluated in January 2021 just after the last wave of the Sars-CoV2 pandemic.

Active recruitment of patients throughout the database of the health department was performed using the reference nurse key. The intervention consisted of at least 3 structured home visits per year. The main objectives of these visits are summarized in Table 1. During the first visit, the patient's characteristics and health situation were assessed, and relevant changes were implemented - in consensus with the patient and primary caregiver - after identifying specific

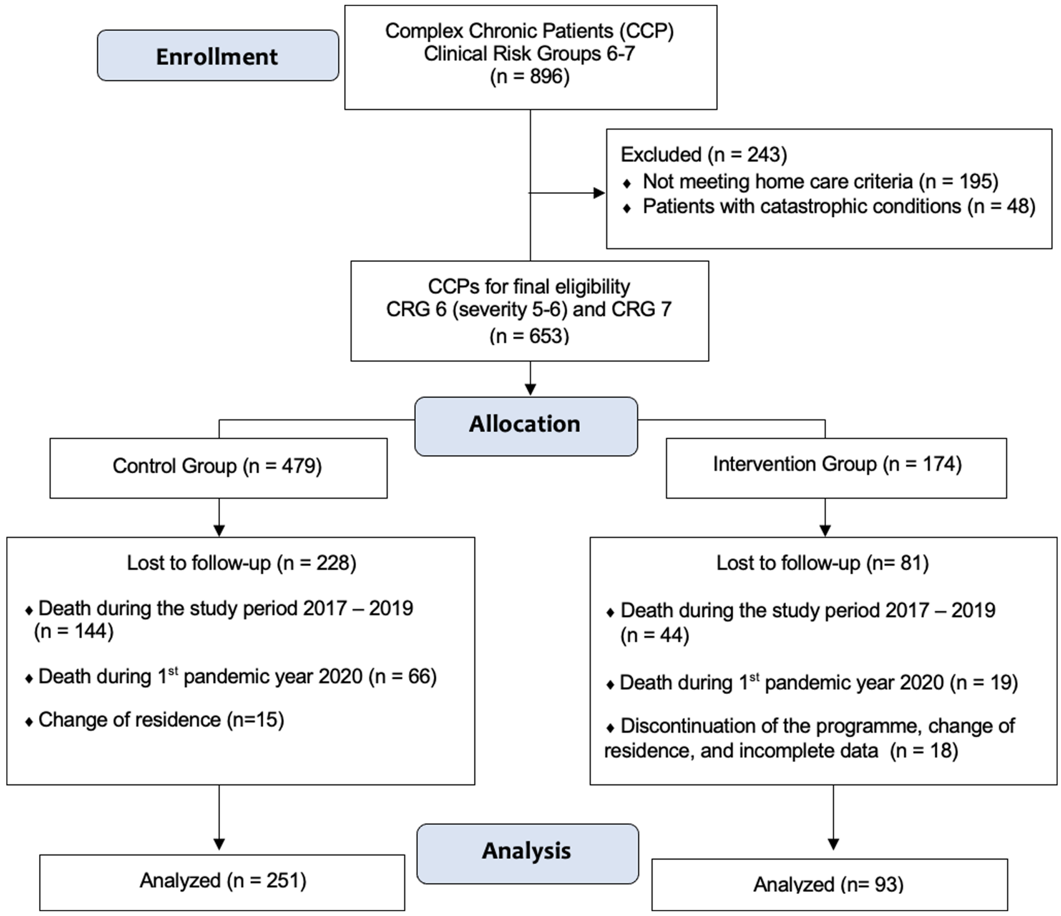

FIGURE 1
Trial flow chart.

problems and needs. The successive visits involved reevaluation of the situation introducing new preventing and therapeutic measures if required. Each visit followed similar methodology involving three stages:

Stage 1 (Person-centered Review)

- Define therapeutic goals aligned with the patient's life prognosis.
- Empower patients: Involve the patient or primary caregiver in decision-making. Feedback is considered a strong point of the intervention.

Stage 2 (Particular Health Problems)

- Identify the most relevant health problems.
- Determine the patient's or primary caregiver's level of knowledge about their most relevant health problem.
- Conduct a functional, cognitive, and social environment assessment:

o Functional (Barthel scale)
o Cognitive (Pfeiffer scale)
o Social (Family Apgar)

- Identify other relevant problems/needs/risks.

o Palliative Needs (NECPAL scale)
o Fall Risk (Downton scale)
o Risk of Pressure Ulcer Development (Norton scale)
o Risk of Malnutrition (MNA scale)

- Systematic medication review.
- Identify the primary caregiver.

Stage 3 (Care giving)

- Monitoring of clinical and analytical parameters.

o Vital signs measurement.
o Blood sample collection at home and determination of INR.

- Planning of scheduled home-based techniques.

o Catheter changes, PEG tube changes, etc.
o Cleaning of subcutaneous reservoirs, central venous catheter cleaning.
o Administration of scheduled medication with a prescribed frequency, by a different route of administration than oral.
o Immunizations: influenza, and pneumococcus vaccination campaigns.

- Symptom control, with special attention to pain.
- Promotion of healthy eating using the "plate method."
- Encouragement of physical activity.
- Empower self-care: Training in disease management skills if needed.

o Inhaler usage.

TABLE 1 Intervention objectives of the 3 scheduled structured visits per year.

• Perform a comprehensive assessment of the patient, including functional and cognitive assessment, family Apgar, and nutritional assessment using the MNA questionnaire (29)
• Establish contact at least within 48 h post admission to the hospital or the emergency department to ensure continuity of care process, maintain care at home, social-health center or residence and prevent readmission.
• Training the patient's motivation and adherence to treatment so that he/she becomes involved in his/her self-care, promoting self-efficacy.
• Systematic review of medication
• Assessing pain in patients
• Prescription of programs that promote patient autonomy: walking exercise, fall prevention, and pressure ulcer prevention.
• Promoting healthy eating
• More specifically: use of inhalers, weight, insulin administration, and diuretics in congestive heart failure
• Early mobilization of resources if needed.

o Weight monitoring for heart failure patients and adjusting diuretic doses.

2.6. Data analysis

Data were analyzed retrospectively after the intervention in the three different periods of study (2017 and 2018 regular years, and 2019 pre-pandemic year). Data were obtained from the outpatient care information system (SIA) and the information system of hospital admission (Nou-SIS) of the health department. Participation in the assigned group was an independent variable. Other independent variables with modifying effects were patient age, sex, and degree of dependence. The other dependent variables were related to the use of services: hospitalization, emergency care, mortality, and nursing home visits.

For the statistical analysis of results, quantitative variables were described as the mean, standard deviation (SD), and 95% confidence interval (CI). Measures of central tendency were compared using the *t*-test for independent samples or ANOVA. For effect size analysis, Cohen's d was calculated. Categorical variables were described as frequencies and percentages. These variables were compared using the Chi-square test or Fisher's exact test. The statistical program used was the IBM SPSS software v22. Statistical significance was set at $p < 0.05$.

2.7. Ethical considerations

Since this was a retrospective study, which was performed under the conditions of routine clinical practice, informed consent was not required from the patients. This study was approved by the Ethics Committee for Clinical Research of the Department of Health, La Ribera, Valencian Community, Spain.

3. Results

3.1. Participants profile

The distribution by sex, age, anthropometric profile, and level of disability is shown in Table 2. The percentages of males and females were very similar in both groups, with 51.0% of males in the control group and 53.8% in the intervention group. The mean age was slightly higher in the intervention group; however, the difference was not statistically significant ($p = 0.158$). Regarding anthropometric characteristics, differences between the two groups were only found in weight, with the mean weight being lower in the intervention group (76.4 ± 13.3 vs. 80.1 ± 12.2, $p = 0.026$). There were no differences between the two groups in the percentage of moderate or severe disability according to the Barthel scale (18.4% in the intervention group vs. 19.9% in the control group). However, mean Barthel scale scores were higher in the intervention group (73.5 ± 18.1 vs. 66.0 ± 18.2, $p < 0.001$). The distribution of participants according to clinical risk groups was almost similar in the control and intervention samples. Most of the patients (87.2% in CG, and 87.1% in IG) were classified into the CRG 6 (2 chronic diseases). The most prevalent chronic diseases in both groups were combination of cardiologic illnesses (congestive heart failure, ischemic cardiopathy), chronic obstructive pulmonary disease, neurodegenerative diseases (Alzheimer and dementias), and diabetes mellitus.

When the sample was analyzed separately by sex, there were more differences between women in both groups than between men (Table 3). Women in the intervention group were older than those in the control group ($p = 0.006$) and had lower weight and BMI ($p < 0.001$ and $p = 0.001$, respectively). However, there were no differences in the Barthel index scores. Among the men in both groups, the mean age did not show significant differences, and the only difference in anthropometric measures was a slightly lower mean height in the intervention group. In contrast to the women, there were statistically significant differences between the two groups of men in the mean Barthel index score, which was lower in the control group (63.3 ± 18.6 vs. 79.0 ± 15.4, $p < 0.001$).

3.2. Nurse home visits

Table 4 shows the number of nursing home visits to the participants in the control and intervention groups. In the latter group, as required by the intervention, the total number of visits to the participants almost tripled in relation to the control group (14.29 ± 4.49 vs. 4.17 ± 2.68, $p < 0.001$). In the intervention group, a minimum of two and a maximum of 18 visits were performed during the entire period, with a 95% confidence interval between 13.77 and 15.43. In this group,

TABLE 2 **Distribution by sex, age, anthropometric profile, and level of disability of the sample.**

	Control group (n = 251)	Intervention group (n = 93)	p (Cohen's d)
Males Females	128 (51.0%) 123 (49.0%)	50 (53.8%) 43 (46.2%)	0.648
Age (yr)	78.9 ± 8.6 (77.9–79.97)	80.6 ± 11.3 (78.2–82.8)	0.154 (0.16)
Weight (kg)	80.1 ± 12.2 (78.6–81.6)	76.4 ± 13.3 (73.3–79.5)	0.026 (0.28)
Stature (cm)	161.9 ± 8.1 (160.9–162.9)	160.8 ± 9.0 (158.7–162.9)	0.325 (0.12)
BMI	30.9 ± 5.9 (30.1–31.6)	29.5 ± 4.6 (28.4–30.6)	0.070 (0.26)
Disability (Barthel) Independents Light Moderate Severe	15 (6.0%) 186 (74.1%) 34 (13.5%) 16 (6.4%)	8 (8.6%) 67 (72.0%) 12 (12.9%) 6 (6.5%)	0.059
Barthel score	66.0 ± 18.2 (62.8–67.6)	73.5 ± 18.1 (69.6–77.1)	<0.001 (0.41)
Comorbidities CRG 6 (2 Chronic diseases) CRG 7 (3 Chronic diseases)	219 (87.2%) 81 (87.1%)	32 (12.8%) 12 (12.9%)	0.969

BMI, body mass index; CRG, clinical risk groups.

TABLE 3 **Characteristics of the sample depending on the sex of the participants.**

	Males			Females		
	Control (n = 128)	Intervention (n = 50)	p (Cohen's d)	Control (n = 123)	Intervention (n = 43)	p (Cohen's d)
Age (yr)	80.0 ± 7.0 (78.6–81.0)	78.6 ± 12.2 (66.8–83.0)	0.360 (0.14)	77.9 ± 9.8 (76.1–79-6)	82.8 ± 10.0 (79.6–85.7)	0.006 (0.49)
Weight (kg)	79.2 ± 12.6 (76.9–81.3)	79.6 ± 11.8 (75.9–83.2)	0.835 (0.03)	81.1 ± 11.8 (78.9–83.2)	72.0 ± 14.3 (66.7–77.25)	<0.001 (0.69)
Stature (cm)	168.7 ± 3.7 (168.0–169.3)	166.2 ± 6.9 (164.1–168.3)	0.004 (0.45)	154.5 ± 4.5 (153.7–155.4)	153.4 ± 5.8 (151.2–155.5)	0.228 (0.21)
BMI	27.8 ± 4.5 (27.0–28.6)	28.8 ± 3.7 (27.6–28.6)	0.218 (0.24)	34.1 ± 5.4 (33.1–35.1)	30.5 ± 5.5 (28.5–32.5)	0.001 (0.66)
Barthel score	63.3 ± 18.6 (50.02–65.82)	79.0 ± 15.4 (75.62–83.96)	<0.001 (2.56)	68.9 ± 17.3 (64.80–71.50)	67.1 ± 19.0 (61.01–72.8)	0.558 (0.09)

66% of the participants received more than 12 visits during the 3-year period. In the control group, the confidence interval for the mean of total home visits was 3.84–4.51 visits. In this group, 12.5% of the participants received only a single nursing home visit during the entire period, and 87.1% received a maximum of two home visits per year.

3.3. Hospital admissions

Regarding the number of hospital admissions, the intervention group had a lower mean number of admissions during the first year of follow-up (2017/18) compared to the control group (0.50 ± 0.95 vs. 0.86 ± 0.95, $p = 0.002$). The same finding was observed during the second period (2018/19) where a relevant increase of hospital admission was found in the control group (0.61 ± 0.74 vs. 2.00 ± 0.75, $p < 0.001$). However, there was no difference between the groups in the third study period (pre-pandemic year 2019), but not in the total number of admissions in the three periods (Table 4). Considering the whole period of study, the intervention led by nurses showed a large beneficial effect in reducing hospital admissions in CCPs (Cohen's d: 0.86).

Regarding hospital admission, all participants in the control group were admitted at least once during the study period. On the contrary, a 29.0% of the participants in the intervention group never had a hospital admission during the 3-years study period, and another 40.9% had a maximum of two admissions (Figure 2). In the control group, 75.9% of the participants were admitted to the hospital three or more times, while only 30.2% of the participants in the intervention groups required such a frequency of admissions ($p < 0.001$).

3.4. Visits to the emergency department

Both cumulative visits to the emergency department and those corresponding to the three study periods were approximately 50% less frequent in the intervention group, and the differences were statistically significant in relation to the control group (Table 4). The effect size of the intervention concerning the total number of visits to

TABLE 4 Mean number of nursing home visits to participants in each group and number of hospital admissions and emergency room visits during the study periods.

	Control (*n* = 251)	Intervention (*n* = 93)	
Nurse home visits	Mean ± SD (95% CI)	Mean ± SD (95% CI)	p (Cohen's d)
total cumulative	4.17 ± 2.68 (3.84–4.51)	14.29 ± 4.49 (13.77–15.43)	<0.001 (2.73)
visits / year	1.39 ± 0.89 (1.28–1.50)	4.76 ± 1.49 (4.59–5.14)	<0.001 (2.74)
Hospital admissions			
1st year (2017)	0.86 ± 0.95 (0.75–0.99)	0.50 ± 0.95 (0.31–0.70)	0.002 (0.37)
2nd year (2018)	2.00 ± 0.75 (1.89–2.08)	0.61 ± 0.74 (0.46–0.77)	<0.001 (1.86)
3rd year (pre pandemic 2019)	0.76 ± 0.77 (0.65–0.84)	0.91 ± 1.57 (0.57–1.22)	0.245 (0.12)
Total admissions	3.63 ± 1.53 (3.42–3.80)	2.02 ± 2.16 (1.58–2.48)	<0.001 (0.86)
Emergency department visits			
1st year (2017)	2.89 ± 1.71 (2.67–3.10)	1.08 ± 1.74 (0.73–1.46)	<0.001 (1.04)
2nd year (2018)	5.25 ± 1.49 (5.06–5.44)	2.74 ± 1.56 (2.41–3.05)	<0.001 (1.64)
3rd year (pre pandemic 2019)	2.98 ± 1.35 (2.80–3.14)	1.64 ± 2.36 (1.15–2.13)	<0.001 (0.69)
Total ED visits	11.11 ± 3.31 (10.70–11.53)	5.65 ± 4.45 (4.74–6.57)	<0.001 (1.53)

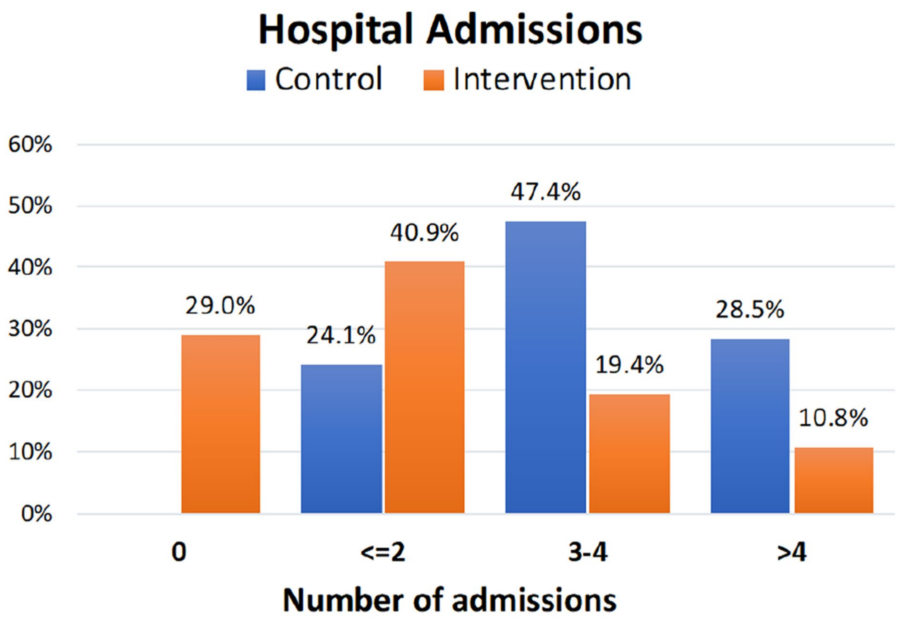

FIGURE 2
Percentage of cumulative hospital admissions during the study period in the control and intervention groups.

the ED was large (Cohen's d: 1.53). A total of 35.5% of the participants in the intervention group visited the emergency department on three or fewer occasions compared to 98% of the subjects in the control group who visited the emergency department on more than six occasions ($p < 0.001$). Figure 3 shows the percentage of participants who visited the emergency room on different occasions. Interestingly, 51.8% of the subjects in the control group visited the Emergency Department on more than 10 occasions throughout the study period

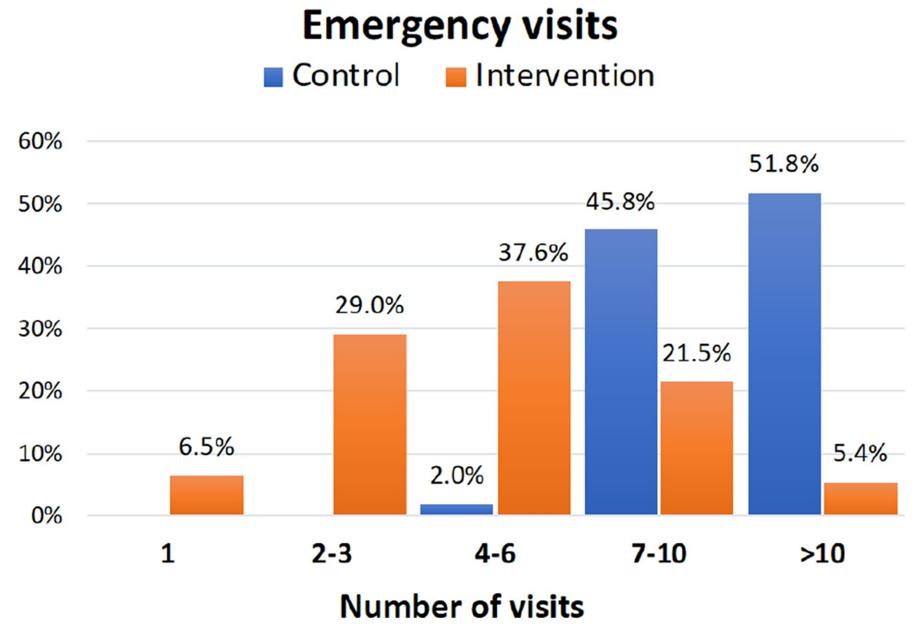

FIGURE 3
Cumulative percentage of visits to the emergency department during the study period in the control and intervention groups.

compared to 5.4% of the participants in the intervention group ($p < 0.001$).

3.5. Impact of sex

When the mean number of hospital admissions and visits to the emergency department during the study period was analyzed by sex and group, it was observed that in both men and women, there were statistically significant differences in the cumulative frequency of hospital admissions and visits to the emergency department, which were higher in men and women in the control group (Table 5). There were no differences between the men and women within both the control and intervention groups. In the women in the intervention group, it was also observed that the mean number of hospital admissions was lower than that of the control group in the first two study periods. The largest effect size of the intervention was found in both the total number of hospital admissions and total visits to the ED (Cohen's d: 1.29 in males; Cohen's d: 1.31 in females).

3.6. Influence of the level of dependence

The results were analyzed according to the participants' level of dependence (Table 6). In the independent or slightly disabled patient group, statistically significant differences were observed between the participants in the control and intervention groups in the mean cumulative number of visits to the emergency department throughout the study. In the intervention group, these values decreased by more than 50%. There were also differences in the cumulative number of hospital admissions, but no during the third phase of the study, in which the intervention group was significantly higher. In the high- or moderate-dependency groups, the intervention only produced differences in the number of visits to the emergency department during the first and second study periods ($p = 0.012$ and $p < 0.001$, respectively). Considering the whole period of study, the largest effect size of the intervention on the total number of hospital admissions was found in patients with severe/moderate disability (Cohen's d: 1.22). Concerning total visits to the ED, the largest effect size was found in independent patients and those slight disability (Cohen's d: 1.76). There were no differences in the mean number of home nursing visits per years between patients with no or slight dependence and those with high/moderate dependence in the intervention group (4.54 ± 2.32 vs. 4.81 ± 1.26, $p > 0.05$).

3.7. Mortality

During the 3 years of the study, 188 patients died (144 in the CG and 44 in the IG). These figures represent a mean of 9.6% per year of deaths in the entire sample. Figure 4 shows the mortality rate during the years of the nursing home intervention. The 3-year overall mortality rate was 30.6% in the control group and 25.3% in the nursing home visit program. These differences were not statistically significant ($p = 0.274$). At the time of analyzing the retrospective data in January 2021, other 85 participants died during 2020, the first year of the pandemic (66 in the control group and 19 in the intervention group), representing a mortality rate of 20.6% in the control group and 17.1% in the intervention group ($p = 0.459$). Therefore, the nurse-home visits program had no impact on the mortality rate.

4. Discussion

This study evaluated the efficacy of a nursing intervention program on a group of complex chronic patients and the residual

TABLE 5 Mean number of hospital admissions and emergency room visits in the study periods, broken down by sex and group.

	Males			Females		
	Control (*n* = 128)	Intervention (*n* = 50)		Control (*n* = 123)	Intervention (*n* = 43)	
Hospital admissions	Mean ± SD (95% CI)	Mean ± SD (95% CI)	*p*	Mean ± SD (95% CI)	Mean ± SD (95% CI)	*p*
1st year (2017)	0.88 ± 0.98 (0.74–1.08)	0.72 ± 1.16 (0.40–1.09)	0.350 (0.14)	0.85 ± 0.92 (0.67–1.00)	0.25 ± 0.53 (0.08–0.41)	<0.001 (0.79)
2nd year (2018)	1.94 ± 0.77 (1.81–2.07)	0.70 ± 0.76 (0.50–0.95)	<0.001 (1.62)	2.06 ± 0.73 (1.90–2.16)	0.50 ± 0.69 (0.28–0.71)	<0.001 (2.19)
3rd year (pre pandemic 2019)	0.79 ± 0.76 (0.64–0.90)	0.82 ± 1.40 (0.38–1.19)	0.889 (0.02)	0.73 ± 0.79 (0.58–0.87)	1.02 ± 1.76 (0.49–1.55)	0.145 (0.21)
Total admissions	3.62 ± 1–57 (3.35–3.90)	2.24 ± 2.13 (1.64–2.98)	<0.001 (0.73)	3.65 ± 1.49 (3.30–3.86)	1.77 ± 2.18 (1.10–2.43)	<0.001 (1.00)
Emergency department visits						
1st year (2017)	2.88 ± 1.72 (2.61–3.21)	1.02 ± 1.67 (0.57–1.55)	<0.001 (1.09)	2.90 ± 1.71 (2.54–3.17)	1.16 ± 1.85 (0.57–1.59)	<0.001 (0.96)
2nd year (2018)	5.17 ± 1.37 (4.93–5.42)	2.96 ± 1.59 (2.50–3.41)	<0.001 (1.48)	5.32 ± 1.61 (5.04–5.62)	2.50 ± 1.50 (2.04–2.95)	<0.001 (1.81)
3rd year (pre pandemic 2019)	3.06 ± 1.32 (2.80–3.27)	1.58 ± 2.16 (0.95–2.21)	0.002 (0.82)	2.90 ± 1.38 (2.66–3.15)	1.60 ± 2.57 (0.91–2.49)	<0.001 (0.97)
Total ED visits	11.13 ± 3.04 (10.59–11.66)	5.94 ± 4.80 (4.44–6.78)	<0.001 (1.29)	11.08 ± 3.57 (10.46–11.74)	5.34 ± 5.05 (4.10–6.57)	<0.001 (1.31)

TABLE 6 Number of admissions and visits to the emergency room in both groups, control and intervention, stratified by level of dependency.

	Independent or slight disability			Severe/moderate disability		
	Control (*n* = 201)	Intervention (*n* = 75)		Control (*n* = 50)	Intervention (*n* = 18)	
Hospital admissions	Mean ± SD (95% CI)	Mean ± SD (95% CI)	*p*	Mean ± SD (95% CI)	Mean ± SD (95% CI)	*p*
1st year (2017)	0.89 ± 0.94 (0.70–0.96)	0.52 ± 0.97 (0.239–0.74)	0.005 (0.38)	1.01 ± 0.96 (0.76–1.27)	0.47 ± 0.87 (0.02–0.92)	0.027 (0.58)
2nd year (2018)	2.00 ± 0.76 (1.90–2.12)	0.74 ± 0.75 (0.58–0.93)	<0.001 (1.65)	1.89 ± 0.65 (1.71–2.06)	0	<0.001
3rd year (pre pandemic 2019)	0.70 ± 0.78 (0.61–0.83)	0.90 ± 1.57 (0.55–1.28)	0.163 (0.16)	0.83 ± 0.78 (0.63–1.04)	0.82 ± 1.59 (0.00–1.64)	0.711 (0.01)
Total admissions	3.60 ± 1.52 (3.36–3.78)	2.17 ± 2.13 (1.70–2.79)	<0.001 (0.77)	3.65 ± 1.64 (3.31–4.19)	1.29 ± 2.17 (0.17–2.41)	<0.001 (1.22)
Emergency department visits						
1st year (2017)	2.90 ± 1.67 (2.62–3.09)	1.00 ± 1.45 (0.66–1.33)	<0.001 (1.21)	2.98 ± 2.01 (2.44–3.52)	1.52 ± 2.74 (0.12–2.93)	0.012 (0.64)
2nd year (2018)	5.24 ± 1.53 (5.01–5.43)	2.70 ± 1.62 (2.34–3.09)	<0.001 (1.61)	5.35 ± 1.62 (4.92–5.79)	2.82 ± 1.13 (2.24–3.40)	<0.001 (1.81)
3rd year (pre pandemic 2019)	3.04 ± 1.39 (2,76–3.13)	1.41 ± 2.19 (0.90–1.89)	<0.001 (0.88)	3.07 ± 1.52 (2.66–3.47)	2.70 ± 2.91 (1.20–4.20)	0.428 (0.46)
Total ED visits	11.17 ± 3.41 (10.58–11.48)	5.11 ± 3.46 (4.31–5.92)	<0.001 (1.76)	11.41 ± 3.75 (10.40–12.41)	7.05 ± 5.62 (4.16–9.95)	0.010 (0.91)

effects of this intervention on patients for up to 3 years after implementation. The impact of the intervention on patients' health was assessed by analyzing health resource utilization as measured by hospital admissions, emergency care, and home visits by primary care nurses. The global intervention was based on the following pillars: person-centered care, proactive recruitment by nurses of reference, and planning a minimum of three home visits per year. In this home visit, a holistic and comprehensive assessment of patients was performed, analyzing the degree of independence for daily living activities, cognitive impairment, and social support, together with knowledge about their nursing, therapeutic adherence, medication reconciliation, anticipation of decompensation, mobilizing resources

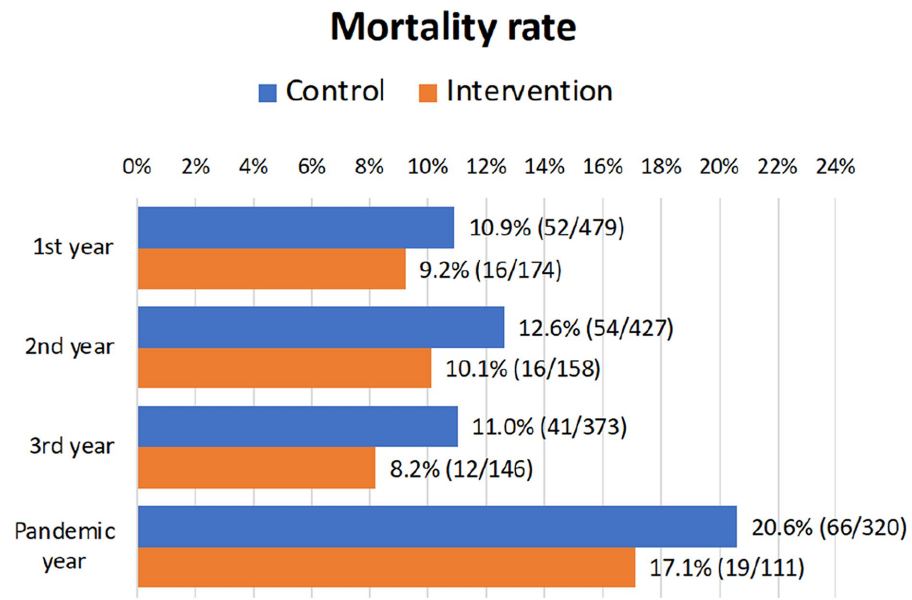

FIGURE 4
Mortality rate during the 3 years of nursing home intervention. Mortality rates during the pandemic year 2020 post-intervention are also shown.

early, establishing telephone contact 48 h post-admission with patients, identifying potential risks (i.e., falls, appearance of pressure scars), and adopting preventive measures.

The intervention program demonstrated its effectiveness in a substantial reduction of hospital admissions and visits to the emergency department. These findings are clinically relevant particularly in two aspects. First, healthcare management of CCP can be carried out by properly trained nurses providing high-quality care that decreases the needs of primary care physicians (30) and second, nursing home visits contribute to save costs by reducing the utilization of expensive health resources. Our study substantially reinforces the role of primary or community care nurses and advocates for increasing resources to incorporate new nursing services and acquire new competencies to respond to the challenges that primary care face today.

According to the results, both the intervention and control groups have similar characteristics, with a comparable distribution in terms of sex, average age, and the profile of complex chronic patients described in previous studies (31–33). One of the main effects observed in the intervention group was a significant decrease in hospital admissions, particularly during the two first periods of the study. The current results are comparable to previous investigations, where a lower number of hospital stays was also observed during the first year of program implementation and a moderate reduction of this effect in patients after the second year (32). This effect on the reduction of hospital admissions and visits to the emergency department could be due to the more exhaustive follow-up by primary care nurses, who would prevent patients from arriving at the hospital with more advanced degrees of decompensation by identifying and treating exacerbations earlier.

One of the most significant practical impacts of reducing hospital admissions and ED visits is cost savings. Hospital care is expensive, and a significant portion of healthcare spending is attributed to inpatient care and emergency services. In some cases, hospital admissions and ED visits may result from overutilization of healthcare services. By reducing hospital admissions and ED visits, healthcare facilities can allocate their resources more efficiently. This includes staff, beds, equipment, and supplies. When resources are used more effectively, healthcare organizations can operate more cost-effectively with substantial cost reductions. All these economic factors derived from the decrease in hospital admissions and ED visits were not analyzed in our study. However, our results emphasize the importance of primary care nurses' role in managing CCP, especially in reducing healthcare resource utilization and consequently reducing expenditures (33).

Data from a recently synthesized analysis of several systematic reviews (the umbrella review), including a large population of older people (>60 years), demonstrated a small favorable effect of home-visit nursing on reducing the number of hospital admissions, but no quality of life and mortality rate (34). Most of the studies covered by the umbrella review did not include a clear description of the content of home visits, qualification of nurses, intensity of intervention, or follow-up intervals. The limited benefit concerning the reduction of hospital admissions was not related to the profile and frequency of home visits or follow-up intervals. Furthermore, in many studies, there were important differences in compliance with the intervention, and there was a lack of information concerning the usual care received by the comparison groups.

According to the authors of the umbrella review, the limited effectiveness of home-visit nursing in reducing hospital admissions may be attributed to a combination of factors with opposing impacts. First, the increase in admissions of older individuals who needed hospital or institutional care, but were previously overlooked, could have contributed to this outcome. On the other hand, some admissions might have been prevented through home visits, which could explain the positive effect of reducing hospital admissions (35). Additionally, variations in admission policies across different countries might also play a role in the lack of significant impact of home visit nursing on admission rates to hospitals and long-term care institutions. These policy differences may lead to varying outcomes in different regions and could potentially obscure the overall effectiveness of home-visit nursing in reducing hospital admissions.

Some reviews have indicated that the effectiveness of nursing home interventions might be more pronounced for older individuals with poorer health, younger study populations, or individuals at a lower risk of death (21). However, the specific reasons for these discrepancies among reviews regarding factors influencing intervention effectiveness remain unclear and warrant further investigation. In the current study, the effect of the intervention was more evident among participants with null or low disability status than among those with moderate or high disability status.

Significant results were also obtained in terms of the number of hospital emergency department visits in the 3 years after program implementation. Patients in the intervention group visited hospital emergency departments less than those in the control group. This effect could also be attributable to better control by their nurse of reference and to the knowledge acquired regarding the self-management of their underlying pathology, favoring the self-efficacy of the patients and/or main caregivers in the self-management of their disease (36). In this sense, the results obtained are also similar to the conclusions reached by other studies carried out in similar settings but in different countries reporting a reduction in the number of emergency room visits and hospital admissions (37, 38).

It is true that when relating emergency department visits to the degree of dependence of the patients, the figures between the control group and the intervention group for visits to the emergency department of the most dependent patients tended to equalize from the second period onwards. This could be explained by the passage of time and the increase in fragility and dependence of these patients, which in turn is related to the increase in morbimortality (21, 39, 40). The current findings support the need to reinforce preventive interventions much more and, therefore, emphasize the importance of Primary Care nurses with advanced competencies in chronicity, particularly in the group with more independent CCP. Furthermore, it seems relevant to reinforce more technical and clinical interventions to avoid decompensation in dependent patients.

Regarding the influence of the home visits program on the mortality rate, the lack of effect in our intervention aligns with findings from two extensive systematic reviews and meta-analyzes (4, 34). In the first review, which included 53 studies with over 23,000 participants, home visiting did not consistently show an association with differences in mortality. There were no significant variations observed among subgroups when studies were stratified by the focus of intervention, average age, or number of visits. Ten studies, comprising a total of 2,563 control participants without interventions and 2,491 home-visited patients, reported mortality rates at 3-year follow-up, that is the period covered by our series. Notably, there were no differences in mortality between the two groups (risk ratio = 0.82 [0.66, 1.00], Chi2 = 1.29, df = 9, $p = 0.15$; I2 = 32%). The mortality rate (11.5% in the control group and 9.5% in the home visits group) was lower than that observed in our study, although most of the included series did not report the prevalence of complex chronic patients.

In a more recent comprehensive review of the impact of home visit nursing on mortality, nine systematic reviews (4, 13, 22, 23, 35, 41–44) integrated data from 20 relevant randomized controlled trials, encompassing a total of 10,455 participants (34). Notably, only one old Danish trial (45) with 572 participants, aged 75 years or older and residing in a suburb of a major Nordic city, reported a lower mortality rate at the 3-year follow-up for patients receiving home visits compared to those receiving standard care or no intervention (19.6% versus 26.1%, $p < 0.05$). However, all other trials did not demonstrate a significant impact on mortality. When considering all these trials collectively, factors such as the nature of home visits, the intensity of interventions, and the duration of follow-up did not appear to influence mortality. In summary, our results agree with the cumulative evidence suggesting that home visit nursing had no substantial effect on mortality. In fact, the decrease in mortality in these chronic patients was not included in the main objectives of the program.

A limitation of the present study concerns to its retrospective nature. Conducting a randomized clinical trial was unfeasible due to the specific population being studied (CCPs) and the limited human resources available to deliver the desired services. This study involves a comparison between the traditional approach for managing CCPs in a specific Primary Healthcare area and an innovative healthcare model involving standardized nurse home visits in the same area. It is noteworthy that both groups exhibited no significant differences in comorbidity and dependency levels at the baseline, thereby enhancing the importance of the obtained results. Like other quasi-experimental studies, it is important to acknowledge the potential introduction of a Hawthorne effect, where participants may modify their behavior when aware of being observed. Regrettably, this is an inherent factor that cannot be eliminated.

Another limitation of the study lies in the absence of an evaluation of the effectiveness of home visit nursing in terms of other relevant outcomes, such as patient satisfaction, quality of life, the duration of hospital admissions, and the location or cause of death. In addition, it was not possible to independently assess the impact of the three stages that constitute the nurse home visits on patient health outcomes. Finally, although it is true that an economic evaluation of the program has not been carried out–which is one of the limitations of our study–it can be assured that while in specialized care, the program resulted in savings, in primary care, the costs would have increased due to the increase in home visits. The difference has been found to be cost-effective when related to avoided hospital admissions (33, 46).

Future research is still necessary to explore the optimal intensity of home visits and identify specific populations that can benefit the most from this approach. A comprehensive and detailed description of the care delivery process, including intervention compliance, qualifications and training of care providers, and standard care received by comparison groups, is essential. Such reporting will provide valuable insights into elements that may be beneficial to home-visit programs. Countries that have integrated home-visit services into their national healthcare policies should carefully assess the merits of these services, considering their local healthcare system objectives and contextual factors. Adopting a thoughtful and context-specific approach will ensure that the implementation of home-visit programs aligns with the unique healthcare needs and goals of each region.

5. Conclusion

The comprehensive CCP program that was evaluated demonstrated its effectiveness in terms of reduced use of health services, particularly hospital admissions and visits to the emergency department. This study demonstrates the crucial and often underappreciated role of primary care nurses in managing complex chronic patients. Their contributions in coordinating care, educating patients, and promoting preventive measures can lead to substantial reduction of expensive healthcare resources. More studies are needed to analyze the true cost-effectiveness of these interventions in the primary care setting and to promote health policies that reinforce primary care.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Ethics Committee for Clinical Research of the Department of Health, La Ribera, Valencian Community, Spain. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MSS: Conceptualization, Data curation, Methodology, Writing – original draft. JC-L: Methodology, Investigation, Writing – review & editing. CB: Writing – review & editing, Conceptualization, Formal analysis, Supervision.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Sevick MA, Trauth JM, Ling BS, Anderson RT, Piatt GA, Kilbourne AM, et al. Patients with complex chronic diseases: perspectives on supporting self-management. *J Gen Intern Med*. (2007) 22:438–44. doi: 10.1007/s11606-007-0316-z

2. Wolff JL, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in elderly. *Arch Intern Med*. (2002) 162:2269–76. doi: 10.1001/archinte.162.20.2269

3. Smith SM, Wallace E, O'Dowd T, Fortin M. Interventions for improving outcomes in patients with multimorbidity in primary care and community settings. *Cochrane Database Syst Rev*. (2021) 2021:CD006560. doi: 10.1002/14651858.CD006560.pub4

4. Mayo-Wilson E, Grant S, Burton J, Parsons A, Underhill K, Montgomery P. Preventive home visits for mortality, morbidity, and institutionalization in older adults: a systematic review and meta-analysis. *PLoS One*. (2014) 9:e89257. doi: 10.1371/journal.pone.0089257

5. Conneely M, Leahy S, Dore L, Trépel D, Robinson K, Jordan F, et al. The effectiveness of interventions to reduce adverse outcomes among older adults following emergency department discharge: umbrella review. *BMC Geriatr*. (2022) 22:462. doi: 10.1186/s12877-022-03007-5

6. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, part 2. *JAMA*. (2002) 288:1909–14. doi: 10.1001/jama.288.15.1909

7. Davy C, Bleasel J, Liu H, Tchan M, Ponniah S, Brown A. Effectiveness of chronic care models: opportunities for improving healthcare practice and health outcomes: a systematic review. *BMC Health Serv Res*. (2015) 15:194. doi: 10.1186/s12913-015-0854-8

8. Ham C, York N, Sutch S, Shaw R. Hospital bed utilization in the NHS, Kaiser Permanente, and the US Medicare programme: analysis of routine data. *Br Med J*. (2003) 327:1257–0. doi: 10.1136/bmj.327.7426.1257

9. Porter M, Kellog M. Kaiser permanente: an integrated health care experience. *Rev Innov Sanit Atención Integr*. (2007) 1:1–8.

10. Nuño-Solinís R, Fernández-Cano P, Mira-Solves JJ, Toro-Polanco N, Carlos Contel J, Guilabert Mora M, et al. Un Instrumento Para la Evaluación de Modelos De Atención ante la Cronicidad [development of an instrument for the assessment of chronic care models]. *Gac Sanit*. (2013) 27:128–34. doi: 10.1016/j.gaceta.2012.05.012

11. Comunitat Valenciana. *Conselleria de Sanitat. Dirección General de Asistencia Sanitaria. Estrategia para la atención a pacientes crónicos en la Comunitat Valenciana. Conselleria de Sanitat, editor*. Conselleria de Sanitat: Valencia (2014).

12. Minue-Lorenzo S, Fernandez-Aguilar C. Critical view and argumentation on chronic care programs in primary and community care. *Aten Primaria*. (2018) 50:114–29. doi: 10.1016/j.aprim.2017.09.001

13. Ploeg J, Feightner J, Hutchison B, Patterson C, Sigouin C, Gauld M. Effectiveness of preventive primary care outreach interventions aimed at older people: meta-analysis of randomized controlled trials. *Can Fam Physician*. (2005) 51:1244–5.

14. Chang AY, Bryazka D, Dieleman JL. Estimating health spending associated with chronic multimorbidity in 2018: an observational study among adults in the United States. *PLoS Med*. (2023) 20:e1004205. doi: 10.1371/journal.pmed.1004205

15. Dieleman JL, Cao J, Chapin A, Chen C, Li Z, Liu A, et al. US health care spending by payer and health condition, 1996-2016. *JAMA*. (2020) 323:863–84. doi: 10.1001/jama.2020.0734

16. Anderson ME, Glasheen JJ, Anoff D, Pierce R, Capp R, Jones CD. Understanding predictors of prolonged hospitalizations among general medicine patients: a guide and preliminary analysis. *J Hosp Med*. (2015) 10:623–6. doi: 10.1002/jhm.2414

17. Barba R, Marco J, Canora J, Plaza S, Juncos SN, Hinojosa J, et al. Prolonged length of stay in hospitalized internal medicine patients. *Eur J Intern Med*. (2015) 26:772–5. doi: 10.1016/j.ejim.2015.10.011

18. Bo M, Fonte G, Pivaro F, Bonetto M, Comi C, Giorgis V, et al. Prevalence of and factors associated with prolonged length of stay in older hospitalized medical patients. *Geriatr Gerontol Int*. (2016) 16:314–21. doi: 10.1111/ggi.12471

19. The Commonwealth Foundation U.S. *Health care from a global perspective, 2022: Accelerating spending, worsening outcome. Issue briefs*. (2023). Available at: https://www.commonwealthfund.org/publications/issue-briefs/2023/jan/us-health-care-global-perspective-2022.

20. Kringos DS, Boerma WGW, Hutchinson A, Saltman RB. *Building primary care in a changing Europe*. Copenhagen, Denmark: European Observatory on Health Systems and Policies (2015).

21. Stuck AE, Egger M, Hammer A, Minder CE, Beck JC. Home visits to prevent nursing home admission and functional decline in elderly people: systematic review and Meta-regression analysis. *JAMA*. (2002) 287:1022–8. doi: 10.1001/jama.287.8.1022

22. Markle-Reid M, Browne G, Weir R, Gafni A, Roberts J, Henderson SR. The effectiveness and efficiency of home-based nursing health promotion for older people:

a review of the literature. *Med Care Res Rev*. (2006) 63:531–69. doi: 10.1177/1077558706290941

23. Bouman A, van Rossum E, Nelemans P, Kempen GI, Knipschild P. Effects of intensive home visiting programs for older people with poor health status: a systematic review. *BMC Health Serv Res*. (2008) 8:74. doi: 10.1186/1472-6963-8-74

24. Duan-Porter W, Ullman K, Rosebush C, McKenzie L, Ensrud KE, Ratner E, et al. Interventions to prevent or delay long-term nursing home placement for adults with impairments-a systematic review of reviews. *J Gen Intern Med*. (2020) 35:2118–29. doi: 10.1007/s11606-019-05568-5

25. Mármol-López MI, Miguel-Montoya I, Montejano-Lozoya R, Escribano-Pérez A, Gea-Caballero V, Ruiz-Hontangas A. Population impact of nurses in care interventions chronicity in Spain. Systematic review. *Rev Esp Salud Publica*. (2018) 92: e201806032.

26. Hughes JS, Averill RF, Eisenhandler J, Goldfield NI, Muldoon J, Neff JM, et al. Clinical risk groups (CRGs): a classification system for risk-adjusted capitation-based payment and health care management. *Med Care*. (2004) 42:81–90. doi: 10.1097/01.mlr.0000102367.93252.70

27. Vivas-Consuelo D, Usó-Talamantes R, Guadalajara-Olmeda N, Trillo-Mata JL, Sancho-Mestre C, Buigues-Pastor L. Pharmaceutical cost management in an ambulatory setting using a risk adjustment tool. *BMC Health Serv Res*. (2014) 14:462. doi: 10.1186/1472-6963-14-462

28. Coderch J, Sanchez-Perez I, Ibern P, Carreras M, Perez-Berruezo X, Inoriza JM. Predicting individual risk of high healthcare cost to identify complex chronic patients. *Gac Sanit*. (2014) 28:292–300. doi: 10.1016/j.gaceta.2014.03.003

29. Rubenstein LZ, Harker JO, Salva A, Guigoz Y, Vellas B. Screening for undernutrition in geriatric practice: developing the short-form Mini nutritional assessment (MNASF). *J Geront*. (2001) 56:M366–72. doi: 10.1093/gerona/56.6.M366

30. Laurant M, Reeves D, Hermens R, Braspenning J, Grol R, Sibbald B. Substitution of doctors by nurses in primary care. *Cochrane Database Syst Rev*. (2005) 2:CD001271. doi: 10.1002/14651858.CD001271.pub2

31. Barrio-Cortes J, Soria-Ruiz-Ogarrio M, Martínez-Cuevas M, Castaño-Reguillo A, Bandeira-de Oliveira M, Beca-Martínez MT, et al. Use of primary and hospital care health services by chronic patients according to risk level by adjusted morbidity groups. *BMC Health Serv Res*. (2021) 21:1046. doi: 10.1186/s12913-021-07020-z

32. Coderch J, Pérez-Berruezo X, Sánchez-Pérez I, Sánchez E, Ibern P, Pérez M, et al. Evaluación de la efectividad de un programa de atención integrada y proactiva a pacientes crónicos complejos [assessment of the effectiveness of a proactive and integrated healthcare programme for chronic complex patients]. *Gac Sanit*. (2018) 32:18–26. Spanish. doi: 10.1016/j.gaceta.2016.07.014

33. Allepuz-Palau A, Piñeiro-Méndez P, Molina-Hinojosa JC, Jou-Ferre V, Gabarró-Julià L. Economic evaluation of a program of coordination between levels for complex chronic patients' management. *Aten Primaria*. (2015) 47:134–40. doi: 10.1016/j.aprim.2014.05.002

34. Eltaybani S, Kawase K, Kato R, Inagaki A, Li CC, Shinohara M, et al. Effectiveness of home visit nursing on improving mortality, hospitalization, institutionalization, satisfaction, and quality of life among older people: umbrella review. *Geriatr Nurs*. (2023) 51:330–45. doi: 10.1016/j.gerinurse.2023.03.018

35. Elkan R, Kendrick D, Dewey M, Hewitt M, Robinson J, Blair M, et al. Effectiveness of home based support for older people: systematic review and meta-analysis. *BMJ*. (2001) 323:719–25. doi: 10.1136/bmj.323.7315.719

36. Tharani A, Van Hecke A, Ali TS, Duprez V. Factors influencing nurses' provision of self-management support for patients with chronic illnesses: a systematic mixed studies review. *Int J Nurs Stud*. (2021) 120:103983. doi: 10.1016/j.ijnurstu.2021.103983

37. Ruiz S, Snyder LP, Rotondo C, Cross-Barnet C, Colligan EM, Giuriceo K. Innovative home visit models associated with reductions in costs, hospitalizations, and emergency department use. *Health Aff (Millwood)*. (2017) 36:425–32. doi: 10.1377/hlthaff.2016.1305

38. Campagna S, Conti A, Dimonte V, Berchialla P, Borraccino A, Gianino MM. Emergency department visits before, after and during integrated home care: a time series analyses in Italy. *Int J Health Policy Manag*. (2022) 11:3012–8. doi: 10.34172/ijhpm.2022.6662

39. Coventry PA, Grande GE, Richards DA, Todd CJ. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. *Age Ageing*. (2005) 34:218–27. doi: 10.1093/ageing/afi054

40. Marengoni A, Angleman S, Melis R, Mangialasche F, Karp A, Garmen A, et al. Aging with multimorbidity: a systematic review of the literature. *Ageing Res Rev*. (2011) 10:430–9. doi: 10.1016/j.arr.2011.03.003

41. Apóstolo J, Cooke R, Bobrowicz-Campos E, Santana S, Marcucci M, Cano A, et al. Effectiveness of interventions to prevent pre-frailty and frailty progression in older adults: a systematic review. *JBI Database System Rev Implement Rep*. (2018) 16:140–232. doi: 10.11124/JBISRIR-2017-003382

42. Tappenden P, Campbell F, Rawdin A, Wong R, Kalita N. The clinical effectiveness and cost-effectiveness of home-based, nurse-led health promotion for older people: a systematic review. *Health Technol Assess*. (2012) 16:1–72. doi: 10.3310/hta16200

43. Huss A, Stuck AE, Rubenstein LZ, Egger M, Clough-Gorr KM. Multidimensional preventive home visit programs for community-dwelling older adults: a systematic review and meta-analysis of randomized controlled trials. *J Gerontol A Biol Sci Med Sci*. (2008) 63:298–307. doi: 10.1093/gerona/63.3.298

44. Van Haastregt JC, Diederiks JP, Van Rossum E, De Witte LP, Crebolder HF. Effects of preventive home visits to elderly people living in the community: systematic review. *BMJ*. (2000) 320:754–8. doi: 10.1136/bmj.320.7237.754

45. Hendriksen C, Lund E, Strømgård E. Consequences of assessment and intervention among elderly people: a three year randomised controlled trial. *Br Med J (Clin Res Ed)*. (1984) 289:1522–4. doi: 10.1136/bmj.289.6457.1522

46. Shepperd S, Cradduck-Bamford A, Butler C, Ellis G, Godfrey M, Gray A, et al. *Hospital at Home admission avoidance with comprehensive geriatric assessment to maintain living at home for people aged 65 years and over: A RCT*. *10*. Southampton, UK: NIHR Journals Library, pp. 1–124. (2022).

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Impact of patient-centered communication on patient satisfaction scores in patients with chronic life-limiting illnesses: an experience from Kenya

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Background: Patient satisfaction remains a key area of interest worldwide; utilizing a patient-centered communication approach, particularly with patients with chronic life-limiting illnesses may be one way to achieve this. However, there is a dearth of empirical information on the effect of patient-centered communication strategies in patients with chronic life-limiting illnesses in Kenya on patient satisfaction.

Objectives: The objective of this study was to assess the impact of patient-centered communication on patient satisfaction.

Methods: We conducted our study at a tertiary teaching and referral hospital in Kenya. We utilized a quasi-experimental pre-test post-test study design and engaged 301 adult medical in-patients with chronic life limiting conditions. We randomized them to receive patient-centered communication, and evaluated the change in patient satisfaction scores using an adapted Medical Interview satisfaction Scale 21 (MISS 21).

Results: Two hundred and seventy-eight out of 301 recruited participants completed the study. The baseline characteristics of the participants randomized to the control and intervention arms were similar. Although both the control and intervention arms had a decline in the mean difference scores, the intervention arm recorded a larger decline, –15.04 (–20.6, –9.47) compared to –7.87 (–13.63, –2.12), with a statistically significant mean difference between the two groups at –7.16 (–9.67, –4.46). Participants in the intervention arm were less likely to: understand the cause of their illness ($p < 0.001$), understand aspects of their illness ($p < 0.001$), understand the management plan ($p < 0.001$), receive all the relevant information on their health ($p < 0.001$), and to receive adequate self-care information ($p < 0.001$). They were also less likely to acknowledge a good interpersonal relationship with the healthcare providers ($p < 0.001$), to feel comfortable discussing private issues ($p < 0.004$), and to feel that the consultation time was adequate ($p < 0.001$).

Conclusion and recommendation: Contrary to expectation, patient-centered communication did not result in improved patient satisfaction scores. Further studies can evaluate factors affecting and explaining this relationship and assess intermediate and long-term effects of provision of a patient-centered communication in diverse global contexts.

KEYWORDS

patient-centered communication, patient satisfaction, chronic life-limiting illness, patient-doctor interaction, sub-Saharan Africa

Introduction

Patient satisfaction is how closely the patient's vision of ideal care matches the perceptions of the care received (1). Patient satisfaction is the outcome measure which best evaluates the overall provision of quality healthcare (2) and it also provides important insights for healthcare professionals and health managers on health-seeking behavior and retention in care (3). This helps us to focus on the patients' needs as well as to develop strategies to improve the quality of care provided.

One way of improving patient satisfaction is by viewing the patient as the center of care- an important stakeholder and a collaborator in good health outcomes with the right to make important decisions about the services rendered based on an informed understanding of their condition, treatment options and possible outcomes. This patient-centered approach considers the patient's needs, views and preferences in the care provided (1). While the concept of patient-centered care is not new, there has been an increasing interest in its utilization the last decade to ensure that the care provided (i) aligns with the patient's preferences and values and (ii) results in better quality and more cost effective care (1, 4). Fostering a patient-centered approach remains a highly desirable component of providing high-quality healthcare that is associated with greater patient satisfaction. Higher patient satisfaction rates have been associated with better retention to care, better adherence to management plans, and loyalty toward the institution and the doctor (1, 2).

A key component of this approach is effective provider-patient communication with respect for autonomy in the entire decision-making process (5). Several studies have illustrated the relationship between communication between patients and healthcare providers and patient satisfaction; patients who report good communication with healthcare providers trust the healthcare providers more and report better satisfaction with the healthcare process (6, 7). Although patient satisfaction is influenced by other factors such as infrastructure, hospital processes and clinical outcomes, a key area driving dissatisfaction is the doctor-patient interaction. In one study, 41% of respondents identified deficits in communication as a driver of dissatisfaction (8). This and other regional studies recommend utilizing a patient-centered communication strategy that allows better communication between patients and their healthcare providers and integrates patient involvement in the care process as a way to improve patient satisfaction (8–10).

Several strategies can be utilized to achieve patient-centered communication in a structured and empathetic manner. These include the SPIKES protocol, the Ask-Tell-Ask and the REMAP protocol. SPIKES is an acronym for a six-step sequence where S stands for setting, P for perception, I for invitation or information, K for knowledge, E for empathy, and S for summarize or strategize. This protocol involves providing the appropriate environmental setting for conducting healthcare discussions, evaluating the patient's understanding of the disease and anticipated prognosis, obtaining an invitation to provide further information, addressing any emotion portrayed, and an opportunity to summarize the discussion points (11, 12). The Ask-Tell-Ask approach allows the healthcare practitioner to establish the patients and care-givers' perception on the diagnosis made, provide them information, and establish the level of understanding (13). Finally, the REMAP stands for reframe, expect emotion, map out values, align with your patients' values/goals, and propose a plan. This is a five step approach that provides an opportunity to contextualize the clinical state and provides an opportunity for further discussion and mapping out of further management plans based on the patient's goals and values (14). The SPIKES protocol has been widely used in various clinical contexts including in Low and Middle income countries (LMIC). This approach ensures both the process and content of good communication in the interaction between the patient and healthcare providers and allows the patient to decide what information they receive.

The impact of communication strategies on patient satisfaction is assessed using various qualitative and quantitative approaches. Tools evaluating key performance indicators on patient satisfaction such as Picker Patient Experience Questionnaire (PSQ-18), the consumer assessment health plans (CAHPS), and the Functional Assessment of Chronic illness Therapy (FACT) satisfaction tools (15) include sections on communication between patients and their providers. The Medical Interview Satisfaction Scale (MISS-21), is a 21-item questionnaire that focusses primarily on the processes and content of good communication and its impact on patient satisfaction. The adapted version has been used in sub-Saharan Africa with good construct validity and internal consistency (16, 17).

Data on the effect of patient-centered communication on patient is derived from studies conducted in High Income and western countries and there is a paucity of evidence that this approach will result in increased patient satisfaction in Kenya. Therefore, the objective of this study was to assess the impact of patient-centered communication on patient satisfaction in patients admitted with chronic life-limiting illnesses in a tertiary teaching and referral hospital in Kenya.

Methodology

Study design

We utilized a quasi-experimental pretest- post-test design with randomized allocation to the control and intervention arms of the study arms to evaluate the impact of a patient-centered communication strategy on patient satisfaction among patients with chronic life-limiting illnesses.

The control arm of the study received standard of care with discussion of the patients' clinical conditions driven by the healthcare providers and the content of the information shared at the discretion of the individual healthcare provider. Additionally consultation with the palliative care team, which utilizes a patient-centered communication approach, was also available at the discretion of the healthcare providers.

The intervention arm received patient-centered communication through goals of care discussions. An intervention discussion guide (Supplementary Appendix 7) was used to ensure the following six domains were included: a discussion on the documented clinical diagnosis to ensure the participants understood their diagnosis; the results of investigations done; the proposed management plan; the discussion that the anticipated illness trajectory was a chronic one; review of the participant's needs and concerns; and the role the participants wanted their families to play in their care and associated care plans.

This intervention involved two sessions and both sessions were conducted during the in-patient stay of the participants. The first of the two sessions covered the six discussion domains provided above, while the second session was used to address any new concerns and provide an opportunity to address any follow-up questions.

The strategy used for patient-centered communication during the intervention was the SPIKES protocol that involves setting up the scene for the discussion; establishing the patients perception of their medical condition; obtaining and invitation to start a discussion; sharing knowledge with the patient and empathetically addressing emotion; and finally summarizing the discussion and strategizing or planning next steps (12).

Study context and location

The study location was a 194-bed, general inpatient medical ward at a public tertiary referral hospital in Kenya.

Study population

We recruited patients older than 18 years of age admitted to the inpatient medical service between August and December 2019 with a documented diagnosis of a chronic life-limiting illness as identified by the Supportive and Palliative Care Indicator tool (SPICT™)[1]. This included patients with end stage renal disease who were not kidney transplant candidates, patients with advanced heart failure, complicated and advanced human immunodeficiency virus (HIV), chronic respiratory failure and chronic liver failure. We used a Karnofsky performance score higher than 30 as the cut-off to identify individuals with chronic life-limiting illnesses who were at minimum, partially capable of participating in activities of self-care (Supplementary Appendix 4).

We excluded patients with advanced cancer, as a patient-centered communication approach, through goals of care discussions, is the recommended standard of care for this group of patients according to the Kenya National Cancer treatment protocol 2019. Patients with impaired cognition as determined using the six-item cognitive impairment test (6CIT) (Supplementary Appendix 3) and those unable to converse in English or 'spoken Kiswahili' were excluded.

Sample size calculation

The sample size was calculated to compare the proportion of patients with good post-test satisfaction scores (≥4) between the two study groups. The calculated sample size of 255 participants was adjusted for a 20% attrition rate to a total of 306 participants. This provided adequate power to detect an intervention effect was used. By using a 1:1 allocation ratio, we anticipated the total number of participants per arm to be 153. We hypothesized that the participants receiving patient-centered communication, i.e., those in the intervention arm would have a higher proportion of participants with good post-test satisfaction scores compared to those in the control arm.

Study variables and measures

The study outcome was the perceived patient satisfaction with the patient-healthcare provider communication as evaluated using an interviewer-administered adapted version of the Medical Interview Satisfaction Scale 21 (MISS 21) (Supplementary Appendix 6). We chose this tool as it considers both the processes and contents of good communication in the healthcare setting. It evaluates four key elements: information provision (four items), communication skills (nine items), confidence in the doctor (six items) and consultation time (one item) on a five-point Likert scale of responses.

The questions in the communication skills subsection of the MISS-21 questionnaire focuses on the components, both style and content, that are major determinants of good communication with healthcare providers. These include establishing rapport, provision of adequate health-associated information, and the consideration of the patient's perspective, appreciation of the patient's feelings and showing empathy, active listening and maintaining respect throughout the whole process (18).

The information provision section of the MISS-21 tool evaluates the effect of four components of information provision on patient satisfaction scores: understanding of the diagnosis and test results, understanding of the management plans, and provision of information on self-care and provision of all health information deemed necessary by the patient.

The patients' confidence section assesses the participants' perception of the treatment plan given, the advice given by healthcare providers and the ability of the healthcare providers to relieve the concerns of the participants on their illness. It also assesses the participants feeling of ease when communicating with the healthcare providers, ease of the participants to discuss personal information and the participants' perception that their privacy was considered during the interaction.

The responses in the adapted questionnaire are scored between one and five, where a score of five corresponds to the most positive responses. To avoid confusion, a score of five connoted strong agreement and a score of one corresponded to strong disagreement with the phrase given. For each respondent, the overall score was the sum of all the 21 choices. For each item, we considered a score of four or more to correspond to satisfaction.

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[1] https://www.spict.org.uk/

We evaluated the face validity and content validity of this questionnaire before the start of data collection by running a pilot test with 15 patients from the outpatient department of the hospital with chronic life-limiting illnesses. Following this, we adjusted the study tool by rewording the phrases and adjusting the order of the questions to ensure a good flow of the items during the filling of the questionnaire.

In addition to the adapted version of the Medical Interview Satisfaction Scale 21 (MISS 21), demographic data such as the age, gender, level of education, employment status/occupation and marital status and documented clinical diagnosis on all enrolled patients was also obtained.

The adapted MISS-21 questionnaires was administered twice (pre-test and post-test) for each participant in the control and the intervention group, with the patient-centered communication intervention being done in between for the intervention group. We conducted the post-test questionnaire administration on average, 10 days after the pre-test and before hospital discharge.

Enrolment procedure

At the beginning of the study, the research team obtained formal permission to access patients' identifying data for use in this research. The research team recorded names of all new patients admitted to the medical ward. One trained research assistant approached the patients to obtain informed consent and screened to identify patients who met the study's inclusion criteria. This included those with documented diagnosis of a chronic life-limiting illness as identified by the Supportive and Palliative Care Indicator tool (SPICT™) (Supplementary Appendix 3), a Karnofsky performance score higher than 30 (Supplementary Appendix 4) and without significant cognitive impairment as determined using the six-item cognitive impairment test (6CIT) (Supplementary Appendix 3). We entered this information into a form capturing the patient's demographic data and diagnosis. This form also contained a section to allow for documentation of the reason for the ineligibility of potential participants. The patient's hospital registration number was included in the screening form to allow for easier identification of the patient's file in case clarifications were required and for the process of documentation of any recommendations made.

The participants who met the eligibility criteria and gave consent were given a unique personal identifier/number. They then selected a sealed envelope with a random number with a 1:1 individual randomization strategy generated using the RAND function in the Microsoft Excel program prior to the start of the study. Participants with odd random numbers were in the control arm and those with even numbers were in the intervention arm of the study. A list containing the name and bed number of the participants in the intervention arm was provided to the research team members administering the intervention each day to facilitate the planning and implementation of the intervention.

Recruitment schema

From the beginning of August to the end of December 2019, we approached 1,240 patients of whom 640 met the inclusion criteria. We recruited 301 participants in the study, with the anticipated recruitment of a 306 participants; this was 98% of the calculated sample size with attrition factored. Out of the 301 participants, 278 participants completed both phases of the study (pre-test and post-test) which comprises 91% of the initial anticipated participants. This was adequate to address study objectives. The Figure 1 summarizes the recruitment process of the study.

Data collection and handling

Two trained research assistants administered both the adapted MISS-21 pre-test and post-test questionnaires from the beginning of August to the end of December 2019. The questionnaires were administered in English and "conversational Kiswahili" at the wellness tent or by the bedside for participants confined to bed. The "wellness tent" is a semi-permanent structure located within the medical ward complex that is used by the healthcare providers in the inpatient medical ward to provide a private and comfortable space for patient sessions such as counseling session and family conferences.

We collected and directly entered the demographic data, clinical diagnosis and the results of the MISS-21 questionnaire into REDCapR, a web-based application used to record data from research for ease of data cleaning and handling. At the end of the study, we exported the results to Microsoft Excel for analysis. The average duration for the completion of the MISS-21 questionnaire was 35–40 min.

Intervention administration

In preparation for this study, one of the research assistants, a registered clinical officer and a Master in psychology student and the primary researcher, a Masters of Internal medicine student, undertook an online training course with the Center to Advanced Palliative Care (CAPC) on the approach to patient-centered communication and ways to improve our communication skills. CAPC is an organization whose mission is to improve access to quality palliative care for patients with life-limiting illnesses by offering tools and training opportunities for healthcare workers all over the world. The research team members providing the intervention also worked alongside the palliative care providers at the hospital to gain some experience on approaches utilized in the hospital during patient evaluation and reviews.

Majority of the patient-centered communication interventions were held in the 'wellness tent,' a semi-permanent structure located within the medical ward complex. This site allowed for a private, comfortable and non-threatening setting, the ideal setting for complex conversations. For participants confined to their beds, we provided the intervention at the bedside during non-visiting hours. The participants were encouraged to invite members of their family or their caretaker for the discussions and all the participants in the intervention arm did this. On average, the first session took approximately 65–90 min and the follow-up session, done 24 h later for approximately 25–35 min.

Soon after the sessions, we documented the summaries of the discussions and any recommendations made in the patient's chart and directly communicated to the doctor in the primary team managing the patient. We reviewed copies of this documentation in the analysis phase to assess for alignment with the protocol. For the majority of the participants, 86%, we were able to complete the two discussions fully.

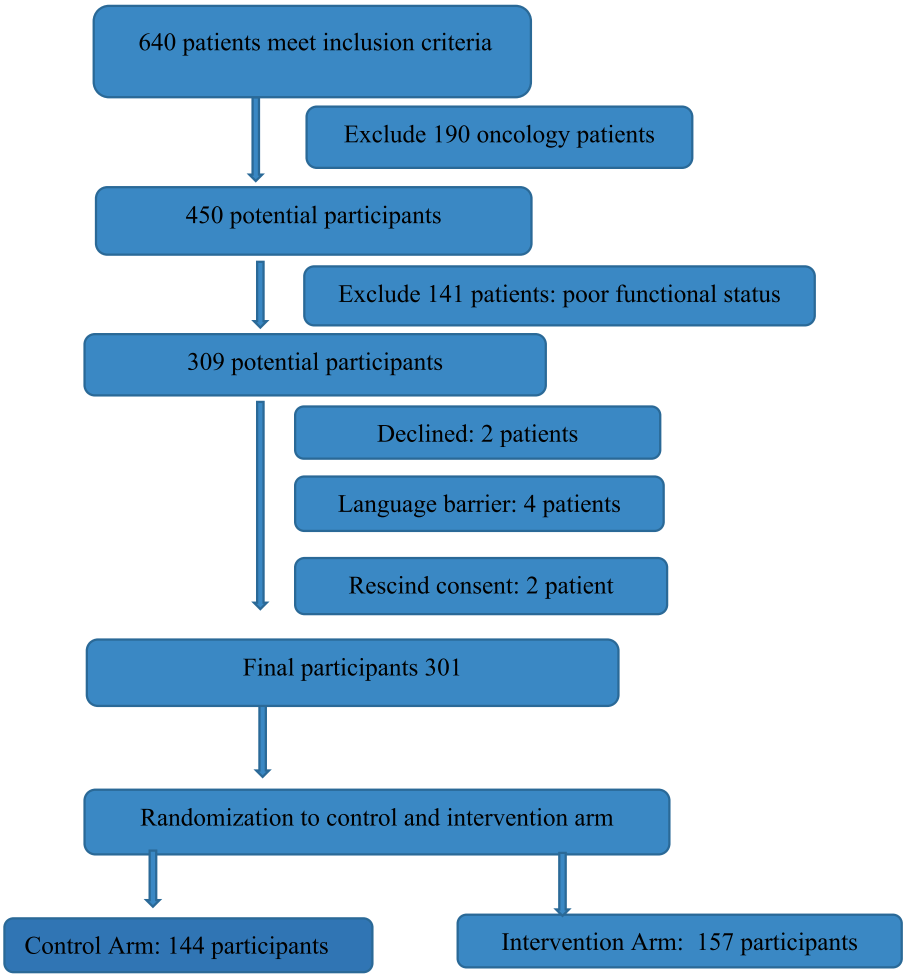

FIGURE 1
Recruitment schema.

For a proportion of the patients in the intervention group (36%), the primary team made further consultation with the palliative team for further discussion and planning follow-up in the outpatient setting and continued care. Only 7% of participants from the control arm received a consultation with the palliative care teams during the study period.

Data analysis

Out of the 301 recruited participants, 23 participants had missing data sets. From the intervention group, one participant did not have both the pre-test and post-test results and 10 participants did not have post-test results while 13 participants in the control group did not have the post-test results. The participants with the missing post-test data either were discharged home before the completion of the study (3 participants), transferred to critical care units (3 participants) or died (17 participants) before the post-test was administered.

For the missing post-test variables (6.97%), we used data missing completely at random approach at analysis, given that the proportion of missing data was small and we had adjusted for it during the sample calculation.

The data was analyzed using the R-statistical software package on an intention-to-treat protocol. We summarize the categorical variables as percentages and then compared by the different treatment groups in tables and charts for ease of presentation and interpretation.

Chi-squared and Fischer exact test of significance was used to determine relationships between the categorical variables with a level of significance at $p < 0.05$.

The outcome of the study was defined as the mean difference between the post-test overall score and the pre-test overall score of the MISS-21 questionnaire. The overall change was calculated as a function of the mean difference score by subtracting the total post-test scores from the total pre-test score. As this was a quasi-experimental study, the unadjusted (no control for the potential confounders) and adjusted (controlling for age, sex, education level, marital status and performance status of the participants) mean difference scores were also calculated.

As the questions in the MISS-21 are grouped into patients' confidence in the doctor (six items), communication skills (nine items) and information provision (four items); we calculated the unadjusted and adjusted change in score for each of these categories for both the pretest and posttest scores.

ANOVA models were used to test for differences between continuous variables in the intervention and control groups while the

Fisher exact test was used to perform the same test in categorical variables. *p*-values for these tests were evaluated at <0.05 to be statistically significant.

Analysis of covariance (ANCOVA) regression method was used to test for the mean difference in the MISS-21 scores for the control and intervention arms of the study and a 95% confidence interval was used to assess for statistical significance. The dependent variable in the regression was the change in the scores, where potential confounders such as age, sex, level of education, marital status, and the pretest scores were also adjusted for in the analysis.

Ethical considerations

The Moi University/MTRH-Institutional Research and Ethics Committee (IREC) approved this study with the approval number FAN: IREC 3228, permission to conduct the study was obtained from the hospital administration. All the participants of the study gave informed consent before participation in the study. Any concerns raised by the participants in the study and any recommendations made were discussed with the primary team managing the patient.

Results

Baseline characteristics of the participants

The key baseline characteristics of the participants in the intervention and the control group were largely similar. Table 1 summarizes the baseline characteristics of the participants. The mean age of the participants was 50.9 years with a predominance of male participants (57.8%). The majority of the participants, 58.8% had a low education level with either no education (23.6%) or incomplete primary (34.6%) and were married, 181 (60.1%). As such, age, gender, education and marital status were not significantly associated with randomization to the control or intervention group.

The participants recruited in the study had a wide range of chronic life-limiting conditions. The most common conditions were: end-stage renal disease on hemodialysis (28%), advanced HIV with clinical stage 4 disease (21%), advanced heart failure with poor functional status (17%), and advanced chronic respiratory disease (21%).

Table 2 summarizes the distribution of the various conditions among the participants in the two groups. The distribution of the various life-limiting conditions of the participants recruited and randomized to the intervention and control groups was fairly matched.

TABLE 1 Characteristics of trial study participants.

	Total 301	Control 144 (48%)	Treatment 157 (52%)	*P*-values
Age				
Mean (*sd*)	50.9 (17.6)	50.2 (17.4)	51.6 (17.8)	0.504*
Gender				
Female	127 (42.2%)	59 (41%)	68 (43.3%)	0.727@
Male	174 (57.8%)	85 (59%)	89 (56.7%)	
Education				
Tertiary education	28 (9.3%)	15 (10.4%)	13 (8.3%)	0.951
Completed secondary education	31 (10.3%)	15 (10.4%)	16 (10.2%)	
Completed primary education	67 (22.3%)	30 (20.8%)	37 (23.6%)	
Incomplete primary education	104 (34.6%)	51 (35.4%)	53 (33.8%)	
No schooling	71 (23.6%)	33 (22.9%)	38 (24.2%)	
Marital status				
Divorced	3 (1%)	2 (1.4%)	1 (0.6%)	0.087
Married	181 (60.1%)	82 (56.9%)	99 (63.1%)	
Separated	11 (3.7%)	8 (5.6%)	3 (1.9%)	
Single	59 (19.6%)	34 (23.6%)	25 (15.9%)	
Widowed	47 (15.6%)	18 (12.5%)	29 (18.5%)	
Karnofsky index				
20	1 (0.3%)	0 (0%)	1 (0.6%)	0.718
40	44 (14.6%)	25 (17.4%)	19 (12.1%)	
50	155 (51.5%)	72 (50%)	83 (52.9%)	
60	83 (27.6%)	38 (26.4%)	45 (28.7%)	
70	15 (5%)	7 (4.9%)	8 (5.1%)	
80	3 (1%)	2 (1.4%)	1 (0.6%)	

*ANOVA test, @Fisher exact test.

Estimate of the intervention effect on the outcomes measured

Overall satisfaction score

The overall proportion of satisfied participants (mean score ≥ 4) at baseline as evaluated by the pre-test scores was found to be at 50%, with 76 (52.7%) participants in the control and 74 (47.3%) participants in the intervention arms with good satisfaction scores. The calculated Fisher's Exact test for the two groups was calculated at 0.4186 which was not significant at a 95% confidence interval and the Odds ratio was 0.80 (0.50–1.30).There was a considerable reduction in overall patient satisfaction at the point of the administration of the post-test interview in both groups but worse in the intervention arm of the study. The participants with good satisfaction scores reduced to 28 (21.4%) participants in the control arm and 3 (2.04%) participants in the intervention arm (Figure 2). The Fisher's Exact Test was calculated at a value of <0.00001 at a 95% confidence interval that is statistically significant. The calculated Odds ratio was 0.08 (0.02–0.26) suggesting a 92% chance of less satisfaction in the intervention arm compared to the control arm.

Estimate of the intervention effect on the mean overall change in scores

In both the control and intervention groups, there was a decline in the overall scores, as shown in Table 3, with the control group reporting an adjusted score of −7.87 (−13.63, −2.12) while the intervention group reporting a greater decline of −15.04 (−20.6, −9.47). The difference between the intervention and control group was a decline of −7.16 (−9.67, −4.66) points, and based on the confidence interval that excludes zero, this was a statistically significant effect change.

TABLE 2 Diagnosis distribution among the participants.

Diagnosis	Total (*n* = 301)	Control (*n* = 144)	Intervention (*n* = 157)
End-stage renal disease	85 (28.2%)	38 (26.4%)	47 (29.9%)
Chronic respiratory disease with complication	63 (20.9%)	27(18.8%)	36 (22.9%)
Complicated HIV	63 (20.9%)	33 (22.9%)	30 (19.1%)
Heart failure	52 (17.2%)	26 (18.1%)	26 (16.6%)
Chronic liver disease	19 (6.3%)	9 (6.3%)	10 (6.4%)
Neurological disorder	17 (5.64%)	10 (6.9%)	7 (4.5%)
Others	2 (0.66%)	1 (0.7%)	1 (0.6%)

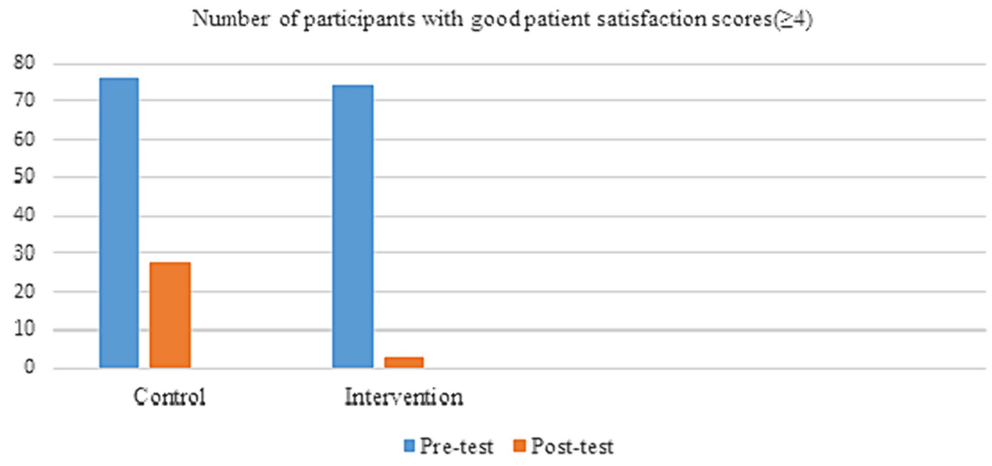

FIGURE 2
Change in the number of participants with an overall satisfaction score of ≥4.

TABLE 3 Overall change in MISS-21 scores.

	N	Control group	Treatment group	Treat − control
Unadjusted change score	278	−9.9 (−12.41, −7.39)	−18.65 (−21.01, −16.28)	−8.75 (−12.19, −5.3)
Adjusted change score	278	−7.87 (−13.63, −2.12)	−15.04 (−20.6, −9.47)	−7.16 (−9.67, −4.66)

TABLE 4 Analysis of single item pre- and post-test of the 21 Miss Likert Questionnaire.

Variable name		Total	Control	Intervention	*P*-value
Communication skills					
The doctor greeted me before addressing my complaints (CS)	Pre-test	1.5 (0.8)	1.5 (0.9)	1.5 (0.7)	0.559
	Post-test	1.2 (0.4)	1.2 (0.4)	1.2 (0.4)	0.44
The doctor explained the cause of my ill health well (CS)	Pre-test	3.4 (1.4)	3.4 (1.4)	3.5 (1.3)	0.587
	Post-test	2.2 (1.1)	2.6 (1.3)	1.8 (0.7)	<0.001
The doctor gave me a chance to say or ask all I wanted (CS)	Pre-test	3 (1.3)	2.9 (1.4)	3.1 (1.3)	0.139
	Post-test	1.9 (0.9)	2.1 (1)	1.8 (0.7)	0.006
The doctor listened patiently to me (CS)	Pre-test	2.2 (1.1)	2.1 (1.1)	2.3 (1.1)	0.181
	Post-test	1.7 (0.6)	1.8 (0.8)	1.6 (0.5)	0.007
The doctor did not ignore any of the things I said or the complaints I had (CS)	Pre-test	2.6 (1.3)	2.5 (1.3)	2.8 (1.4)	0.08
	Post-test	1.8 (0.9)	2 (1)	1.7 (0.8)	0.013
The doctor did not use any words that I did not understand (CS)	Pre-test	2 (1)	1.9 (1)	2.1 (1)	0.035
	Post-test	1.6 (0.6)	1.6 (0.6)	1.6 (0.6)	0.402
The doctor seemed interested in me as a person and not just my illness (CS)	Pre-test	2.4 (1.1)	2.3 (1)	2.4 (1.1)	0.571
	Post-test	1.7 (0.8)	1.9 (0.9)	1.6 (0.5)	<0.001
The doctor spoke politely to me (CS)	Pre-test	1.8 (0.8)	1.8 (0.8)	1.8 (0.9)	0.73
	Post-test	1.6 (0.5)	1.6 (0.5)	1.5 (0.5)	0.575
The doctor was warm and empathetic to me (CS)	Pre-test	2.1 (1)	2.1 (1.1)	2.1 (1)	0.714
	Post-test	1.6 (0.6)	1.6 (0.6)	1.6 (0.5)	0.413
Information provision					
I understood what the doctor wants us to do to manage my condition (IP)	Pre-test	2.9 (1.2)	2.8 (1.2)	2.9 (1.2)	0.465
	Post-test	2 (1)	2.3 (1.2)	1.8 (0.7)	<0.001
The doctor gave me all the information I was expecting to receive about my health (IP)	Pre-test	3.3 (1.2)	3.2 (1.3)	3.4 (1.1)	0.239
	Post-test	2.2 (1)	2.5 (1.2)	1.9 (0.8)	<0.001
I understand my illness (diagnosis, test results and treatment plan) better after talking to the doctor (IP)	Pre-test	3.3 (1.3)	3.2 (1.3)	3.4 (1.2)	0.229
	Post-test	2.1 (1.1)	2.4 (1.2)	1.8 (0.8)	<0.001
The doctor told me how to care for myself given my condition (IP)	Pre-test	3.2 (1.3)	3.1 (1.4)	3.2 (1.3)	0.729
	Post-test	2.1 (1.1)	2.4 (1.3)	1.8 (0.8)	<0.001
Patient's confidence					
The doctor seemed to know what to do about my problem (PC)	Pre-test	2.2 (0.9)	2.1 (0.9)	2.2 (0.9)	0.652
	Post-test	1.7 (0.7)	1.8 (0.8)	1.6 (0.6)	0.064
I think the doctor's advice is appropriate for my situation (PC)	Pre-test	2.7 (1.2)	2.6 (1.1)	2.8 (1.2)	0.201
	Post-test	2.1 (0.9)	2.2 (1)	2 (0.9)	0.133
The doctor relieved my worries about my illness (PC)	Pre-test	3.5 (1.4)	3.4 (1.4)	3.5 (1.3)	0.458
	Post-test	2.7 (1.3)	2.8 (1.4)	2.5 (1.3)	0.027
I felt comfortable talking to the doctor (PC)	Pre-test	2.2 (1)	2.2 (1)	2.3 (1.1)	0.401
	Post-test	1.7 (0.6)	1.8 (0.7)	1.6 (0.5)	0.009
I could talk freely to the doctor about my private issues (PC)	Pre-test	2.4 (1.2)	2.4 (1.2)	2.4 (1.2)	0.816
	Post-Test	1.7 (0.7)	1.9 (0.8)	1.6 (0.6)	0.004
The doctor paid enough attention to my privacy (PC)	Pre-test	2 (1)	2 (1)	2.1 (0.9)	0.737
	Post-test	1.7 (0.6)	1.7 (0.6)	1.6 (0.6)	0.591
Doctor's time					
I had enough time with the doctor (CT)	Pre-test	2.3 (1.1)	2.2 (1.2)	2.4 (1.1)	0.334
	Post-test	1.7 (0.8)	1.9 (0.9)	1.6 (0.6)	0.001
Overall satisfaction					
All things considered, I am satisfied with the interaction between the doctor and I	Pre-test	2.7 (1.1)	2.7 (1.1)	2.7 (1.1)	0.758
	Post-test	1.8 (0.7)	2 (0.8)	1.6 (0.5)	<0.001

MISS-21 individual item analysis

When evaluating the single items under the three main sub-items of patient confidence, information provision and patient confidence scores, it was noted that several individual items had statistical significance. Under the communication skill scores, two out of the nine items were found to have statistical significance with participants in the intervention arm being less likely to: understand the explanation given on the cause of ill health ($p < 0.001$) and to perceive that the healthcare provider was interested in more than just disease process ($p < 0.001$). Under the information provision score items, all four questions in this subsection were statistically significant. The participants in the intervention arm were less likely to feel that they; understood the cause of their illness ($p < 0.001$), understood all aspects of their illness ($p < 0.001$), understood their management plan ($p < 0.001$), had received all the relevant information on their health ($p < 0.001$), or had received adequate self-care information ($p < 0.001$). Under the patient confidence subset, only one out of the six questions was statistically significant; with the participants in the intervention arm more likely to report the participants' feeling uncomfortable discussing private issues with the healthcare providers ($p < 0.004$).

On the two individual questions, patients in the intervention group were less likely to feel that the consultation time was adequate ($p < 0.001$) and less likely to have overall patient satisfaction ($p < 0.001$) and both were found to be statistically significant.

Table 4 summarizes the results of the single items of the MISS-21 tool.

Discussion

To the best of our knowledge, this is the first study of its kind to evaluate the impact of patient-centered communication on patient satisfaction in the Kenya. At the start of the study, based on past studies (19–21), we thought the process of having comprehensive and candid discussions with the participants of the study would improve their perception of the patient-doctor interaction and therefore the perceived quality of care received. However, the findings of this study contradict the proposed hypothesis that patient-centered communication would result in improved patient satisfaction scores as the intervention arm performed worse compared to the control arm.

Reduction in overall proportion of participants with good satisfaction scores

At baseline, 50% of the participants in both the control and intervention arm had adequate overall patient satisfaction with the doctor-patient interaction. However, the post-test evaluation demonstrated a considerable reduction in the proportion of satisfied participants in both arms.

The duration between base-line and end-line tests among patients can have implications for the outcomes observed (22) and may have contributed to this reduction in satisfaction scores. The duration between the pre-test and post-test evaluation for both the control and treatment arm was 10 days. As such, without an appropriate decay period between the pre-test and post-test administration, the outcome of the post-test results can be influenced by the administration of the pre-test due to the possible instructional effect of the pre-test, particularly if the participants remembered and reflected on the questions (23). This instructional effect can contribute to a response shift with a change of the participants' standards of evaluation of satisfaction with their interaction with the healthcare providers through reevaluation of the standards of determining adequate satisfaction, adjustment in the values placed on various aspects of the interaction and redefinition of the adequate satisfaction (18, 24).

Patient-centered communication in this study worsened the participants' satisfaction scores. Autonomy is a key consideration in patient-centered communication that allows the patients to receive information about their clinical condition that allows them to participate in shared decision making to varied degrees as determined by the patient (5, 25). However, there is some cultural difference in healthcare communication, particularly in patients with chronic life limiting or terminal medical conditions. Mcgrath et al. (26) demonstrated that open communication about chronic illness may be found 'frightening' in some cultures and a more indirect communication style may be preferred. In-fact, in particular cultural and social situations, a direct approach in communication with patients could be disadvantageous (27) and paternalistic or a mix between paternalistic and patient-centered communication may be ideal for some societies (28, 29) particularly in patients with insufficient health literacy.

In the next sections, we postulate various factors that may contribute to the reduction in patient satisfaction under the main subsections of the MISS 21 questionnaire.

Communication skills sub-section

Under this subsection, the participants in the intervention arm were more likely to report inadequate satisfaction on the explanation on the cause of their illness ($p < 0.001$) and felt the health-care teams were not interested in the individual and were more focused on the illness ($p < 0.001$). This was an interesting and unexpected finding from this study; the focus of the intervention was to explain the participants' chronic illness, particularly on the diagnosis and the available test results, in a way that would allow the participant to understand; we also provided an opportunity to answer any questions that arose. We also endeavored to individualize the discussions and to discuss the non-medical needs of the participants.

It has been noted that patients report being discontent with communication from healthcare providers even when the providers rate their interaction with the patient highly (30). Even when the correct terminology and appropriate information are given, the majority of patients do not identify the issues that were discussed (31). It is therefore imperative for healthcare providers to continue to assess and evaluate the communication to ensure that both parties have the same understanding.

Information provision subsection

Regional and local studies report that information provision is a key element in improving patient satisfaction with the healthcare provided (17, 21). However, in this study, participants who received patient-centered communication focused on information provision were more likely to report dissatisfaction with the information about their diagnosis, test results, ongoing management plans and advice on self-care and reported the information provided did not meet their expectations with a p-value of <0.001 in all the questions.

Majority of the participants had low education levels with 58.8% of participants with either no or incomplete primary school education compared to only 19% of participants with completed secondary and tertiary education. Patients with low education levels have low health literacy levels and therefore lower ability to access and understand healthcare related information (32). Accordingly, patients who struggle to understand healthcare information do not interact effectively with the healthcare providers and this influences their satisfaction. It is worth noting that despite efforts by the research team to provide information in a manner understandable and relatable to the participants, the explanation of information particularly relating to the medical diagnosis, the investigations and the management plan is not available in 'conversational Kiswahili' and the local languages. This presented a challenge of making sure that the information conveyed was understandable to the participants, the majority of whom had lower educational levels and were not comfortable holding conversations in English. This challenge is not unique to this study. Many African populations use native languages, however English is the main language of instruction in medical education (33). As such, healthcare providers need to translate clinical and technical information and do code-switching between standard English, vernacular English, spoken Kiswahili and native languages during conversation with non-English speaking patients (34). The lack of medical information in native languages influences how health related information is conveyed and received by patients. It is therefore probable that this and low health literacy levels among our study participants affected their reception of the information.

Another important aspect to consider is the role of illness perception that influences the reception and interpretation of any health-associated information. Illness perceptions are cognitive beliefs or views that people have that help them cope with their illness. They include the illness identity (the name and symptoms of the illness), the causal component (the individual understanding of the cause of illness) and the consequence component (the consequence of the illness to the individual and family and the control that the individual has on the illness) (35). Illness perceptions in sub-Saharan Africa are negative in nature due to the physical, psychological, emotional, spiritual and economic consequences that they bear (36). Though the effect is varied, patients with negative illness perceptions are generally less receptive to information that is contrary to their beliefs (35). Reflectively, understanding that one has a chronic life-limiting illness may raise concerns of anticipated increased dependency on caregivers, concerns of potential actual and perceived stigma as well as thoughts of 'unfinished business' that needs to be addressed and this may cause anxiety for some patients and make them less receptive to the information provided.

Consideration should also be given to the possibility of the effect of information overload, which can be thought of as 'too much' information, not only in the amount but also in the intensity and complexity of the information, that makes it difficult to understand the issues(s) being discussed (37). The conversations with the participants in the intervention arm was done over a period of two sessions and the discussions can be considered loaded in nature in both the amount and the complexity of information particularly when discussed with laypersons. It is conceivable that, although the information provided and issues discussed were beneficial, these conversations may have resulted in an information overload with the result that the information became an obstacle rather than helpful as intended by the research team.

Patient's confidence subsection

Under this subsection, the participants in the intervention arm were less likely to feel comfortable when discussing personal or private issues with a p-value of 0.004. The lack of ease during discussions of personal matters is an indication of a poor interpersonal connection between the patient and the healthcare provider. Some patient factors may contribute to the acceptability of the formation of interpersonal connections and interpersonal connections may not be as highly valued in some cultures. In their study, Waweru et al. (38) found that interpersonal components of the patient-healthcare provider were not expected and a large number of the study's participants did not expect to, nor openly discuss personal issues with their healthcare providers, as this was a role ascribed to closer social contacts such as family and elders. Additionally, the young age and the female gender of the primary investigator and research assistant who were involved in the administration of the intervention may have been a limitation in establishing a good interpersonal connection with the participants. Although this represents the current trend in healthcare providers in Kenya with a predominant young work force (39), we acknowledge that some participants particularly older and male participants may have been uncomfortable discussing some topics with younger and female healthcare providers. This is a limitation in this study and an area of improvement and a topic for future studies.

Adequacy of the time spent with participants

Several studies, including a study from sub-Saharan Africa, show that patients with longer consultations and who spend longer communicating with healthcare practitioners report having higher satisfaction scores and that most patients report having shorter than ideal consultations time (16, 40). Although there is no established standard duration of consultations, longer durations of consultations are associated with more elaborate healthcare discussions and evaluation of psychosocial aspects of care (40).

On average, the intervention took 65–90 min for the first session and the follow-up session 25–35 min; this is considered a longer duration than most standard healthcare consultations. Despite this, participants in the intervention arm were more likely to report inadequate time with healthcare providers compared to the control arm. In their study, Ogden et al. (41) postulated that the perception of inadequate time with healthcare providers was associated with unmet needs particularly emotional needs rather than information giving. It appears that despite spending additional time with the participants in the intervention group, the time spent did not meet the needs of the participants and was thus not considered meaningful time.

Conclusion

This study provides useful insight on possible impact of patient-centered communication on patient satisfaction in patients admitted with chronic life-limiting illnesses.

Surprisingly, in this study, provision of a patient-centered communication strategy did not result in improved patient satisfaction scores among patients with chronic life-limiting illnesses; the result was negative with lower patient satisfaction scores for the participants in the intervention group. The immediate effect of patient-centered communication strategies on patient satisfaction may not be linear in the Kenyan setting. Future studies ought to evaluate factors affecting and explaining this relationship. We ought to assess intermediate and long-term effects of provision of a patient-centered communication in diverse global contexts.

Strengths and limitation

A strength of this study is its design that included intentional training of the field team to ensure a full understanding of the study and to enhance their communication skills. Due to the nature of the study and the structure of the study site, a public hospital general ward, we recruited participants from both arms from the same location and this could have resulted in contamination among participants. Furthermore, the intervention sessions were not audio recorded and were therefore not objectively assessed to check whether the content provided and processes of the discussions were adequate. These are potential areas of improvement in further studies.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by MTRH/MU-Institutional Research and Ethics Committee (IREC). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

BS: Writing – review & editing, Writing – original draft, Visualization, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. VN: Writing – review & editing, Validation, Supervision, Conceptualization. PK: Writing – review & editing, Validation, Supervision, Conceptualization. DL: Writing – review & editing, Supervision.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fmed.2024.1290907/full#supplementary-material

References

1. Ahmad I, Nawaz A, Khan S, Khan H, Rashid MA, Khan MH. Predictors of patient satisfaction. *Gomal J Med Sci.* (2011) 9. Available at: https://api.semanticscholar.org/CorpusID:36569128

2. Anhang Price R, Elliott MN, Zaslavsky AM, Hays RD, Lehrman WG, Rybowski L, et al. Examining the role of patient experience surveys in measuring health care quality. *Med Care Res Rev.* (2014) 71:522–54. doi: 10.1177/1077558714541480

3. Shah PP. In patient satisfaction survey-how does it help our health care delivery system (the patient, the health care giver and the organization)? *Int Surg J.* (2017) 4:3280–7. doi: 10.18203/2349-2902.isj20174140

4. Epstein RM, Street RL. The values and value of patient-centered care. *Ann Fam Med.* (2011) 9:100–3. doi: 10.1370/afm.1239

5. Naik AD. On the road to patient centeredness: comment on: "communication and medication refill adherence." *JAMA Intern Med.* (2013) 173:218–9. doi: 10.1001/jamainternmed.2013.1229

6. Biglu MH, Nateq F, Ghojazadeh M, Asgharzadeh A. Communication skills of physicians and patients' satisfaction. *Mater Sociomedica.* (2017) 29:192–5. doi: 10.5455/msm.2017.29.192-195

7. Chandra S, Ward P, Mohammadnezhad M. Factors associated with patient satisfaction in outpatient department of Suva sub-divisional Health Center, Fiji, 2018: a mixed method study. *Front Public Health.* (2019) 7:183. doi: 10.3389/fpubh.2019.00183

8. Mwanga DM. *Factors affecting patient satisfaction at Kenyatta national hospital.* Kenya: A Case of Cancer Outpatient Clinic (2013).

9. Turner RE, Archer E. Patient-centered care: the patients' perspective-a mixed-methods pilot study. *Afr J Prim Health Care Fam Med.* (2020) 12:1–8. doi: 10.4102/phcfm.v12i1.2390

10. Camara BS, Belaid L, Manet H, Kolie D, Guillard E, Bigirimana T, et al. What do we know about patient-provider interactions in sub-Saharan

Africa? A scoping review. *Pan Afr Med J*. (2020) 37:88. doi: 10.11604/pamj.2020.37.88.24009

11. Dunlay SM, Strand JJ. How to discuss goals of care with patients. *Trends Cardiovasc Med*. (2016) 26:36–43. doi: 10.1016/j.tcm.2015.03.018

12. Svarovsky T. Having difficult conversations: the advanced practitioner's role. *J Adv Pract Oncol*. (2013) 4:47–52.

13. Jacobsen J, Whitlock SN, Lee H, Lindvall C, Jackson V. Teaching colleagues how to discuss prognosis as part of a hospital-wide quality improvement project: the positive impact of a 90-minute workshop. *J Pain Symptom Manag*. (2015) 49:960–3. doi: 10.1016/j.jpainsymman.2014.11.301

14. LeBlanc TW, Tulsky J. (2018). *Discussing goals of care*. Available at: https://www.uptodate.com/contents/discussing-goals-of-care (Accessed July 12, 2022).

15. Beattie M, Murphy DJ, Atherton I, Lauder W. Instruments to measure patient experience of healthcare quality in hospitals: a systematic review. *Syst Rev*. (2015) 4:1–21. doi: 10.1186/s13643-015-0089-0

16. Kabatooro A, Ndoboli F, Namatovu J. Patient satisfaction with medical consultations among adults attending Mulago hospital assessment center. *South Afr Fam Pract*. (2016) 58:87–93. doi: 10.1080/20786190.2016.1177977

17. Abioye Kuteyi E, Bello IS, Olaleye T, Ayeni I, Amedi M. Determinants of patient satisfaction with physician interaction: a cross-sectional survey at the Obafemi Awolowo university health center, Ile-Ife, Nigeria. *South Afr Fam Pract*. (2010) 52:557–62. doi: 10.1080/20786204.2010.10874047

18. Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Soc Sci Med*. (1999) 48:1507–15. doi: 10.1016/S0277-9536(99)00045-3

19. Kimani KN, Murray SA, Grant L. Multidimensional needs of patients living and dying with heart failure in Kenya: a serial interview study. *BMC Palliat Care*. (2018) 17:1–8. doi: 10.1186/s12904-018-0284-6

20. Namukwaya E, Grant L, Downing J, Leng M, Murray SA. Improving care for people with heart failure in Uganda: serial in-depth interviews with patients' and their health care professionals. *BMC Res Notes*. (2017) 10:1–13. doi: 10.1186/s13104-017-2505-0

21. Selman L, Higginson IJ, Agupio G, Dinat N, Downing J, Gwyther L, et al. Meeting information needs of patients with incurable progressive disease and their families in South Africa and Uganda: multicentre qualitative study. *BMJ*. (2009) 22:b1326. doi: 10.1136/bmj.b1326

22. Brown G, Irving S, Keegan P. *An introduction to educational assessment, measurement, and evaluation: improving the quality of teacher-based assessment*. New Zealand: Pearson Education (2008).

23. Hartley J. The effect of pre-testing on post-test performance. *Instr Sci*. (1973) 2:193–214. doi: 10.1007/BF00139871

24. Visser MR, Smets EM, Sprangers MA, de Haes HJ. How response shift may affect the measurement of change in fatigue. *J Pain Symptom Manag*. (2000) 20:12–8. doi: 10.1016/S0885-3924(00)00148-2

25. Childress JF, Childress MD. What does the evolution from informed consent to shared decision making teach us about authority in health care? *AMA J Ethics*. (2020) 22:E423–9. doi: 10.1001/amajethics.2020.423

26. McGrath P, Vun M, McLeod L. Needs and experiences of non-English-speaking hospice patients and families in an English-speaking country. *Am J Hosp Palliat Med*. (2001) 18:305–12. doi: 10.1177/104990910101800505

27. Avci E. Should physicians tell the truth without taking social complications into account? A striking case. *Med Health Care Philos*. (2018) 21:23–30. doi: 10.1007/s11019-017-9779-9

28. Norman I. Blind trust in the care-giver: is paternalism essential to the health-seeking behavior of patients in sub-Saharan Africa? *Adv Appl Sociol*. (2015) 5:94–104. doi: 10.4236/aasoci.2015.52008

29. Thompson GA, Segura J, Cruz D, Arnita C, Whiffen LH. Cultural differences in patients' preferences for paternalism: comparing Mexican and American patients' preferences for and experiences with physician paternalism and patient autonomy. *Int J Environ Res Public Health*. (2022) 19:10663. doi: 10.3390/ijerph191710663

30. Tongue JR, Epps HR, Forese LL. Communication skills for patient-centered care: research-based, easily learned techniques for medical interviews that benefit orthopaedic surgeons and their patients. *JBJS*. (2005) 87:652–8. doi: 10.2106/00004623-200503000-00027

31. Koul PA. Effective communication, the heart of the art of medicine. *Lung India*. (2017) 34:95–6. doi: 10.4103/0970-2113.197122

32. Yim CK, Shumate L, Barnett SH, Leitman MI. Health literacy assessment and patient satisfaction in surgical practice. *Ann Med Surg*. (2018) 35:25–8. doi: 10.1016/j.amsu.2018.08.022

33. Hamad A. Decolonization of medical education: a global screening of instructional languages and mother tongue dependence. *J Med Surg Public Health*. (2023) 1:100007. doi: 10.1016/j.glmedi.2023.100007

34. Madzimbamuto FD. Developing anatomical terms in an African language: issues in medicine. *S Afr Med J*. (2012) 102:132–5. doi: 10.7196/SAMJ.5025

35. Petrie KJ, Jago LA, Devcich DA. The role of illness perceptions in patients with medical conditions. *Curr Opin Psychiatry*. (2007) 20:163–7. doi: 10.1097/YCO.0b013e328014a871

36. de-Graft Aikins A, Unwin N, Agyemang C, Allotey P, Campbell C, Arhinful D. Tackling Africa's chronic disease burden: from the local to the global. Glob. *Health*. (2010) 6:5–7. doi: 10.1186/1744-8603-6-5

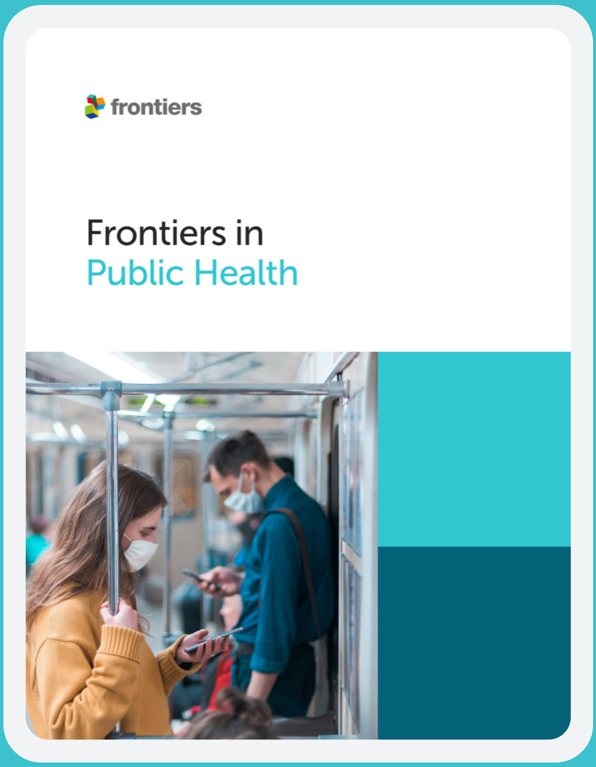
37. Hall A, Walton G. Information overload within the health care system: a literature review. *Health Inf Libr J*. (2004) 21:102–8. doi: 10.1111/j.1471-1842.2004.00506.x

38. Waweru E, Smekens T, Orne-Gliemann J, Ssengooba F, Broerse J, Criel B. Patient perspectives on interpersonal aspects of healthcare and patient-centeredness at primary health facilities: a mixed methods study in rural eastern Uganda. *PLoS One*. (2020) 15:e0236524. doi: 10.1371/journal.pone.0236524

39. Okoroafor SC, Kwesiga B, Ogato J, Gura Z, Gondi J, Jumba N, et al. Investing in the health workforce in Kenya: trends in size, composition and distribution from a descriptive health labour market analysis. *BMJ Glob Health*. (2022) 7:e009748. doi: 10.1136/bmjgh-2022-009748

40. Surbakti EF, Sari K. The relationship between consultation length and patient satisfaction: a systematic review. *Life Sci*. (2018) 4:41–9. doi: 10.18502/kls.v4i9.3556

41. Ogden J, Bavalia K, Bull M, Frankum S, Goldie C, Gosslau M, et al. "I want more time with my doctor": a quantitative study of time and the consultation. *Fam Pract*. (2004) 21:479–83. doi: 10.1093/fampra/cmh502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