

supported with blood transfusions every other day, to pace with family members to come to acceptance. Eventually they were agreeable with the medical recommendation to discontinue further blood transfusions and he was discharged back home with home hospice support.

Discussion This case raises the ethical dilemma of blood transfusions despite medical futility, while balancing the family's maintenance of hope. The Jonsen's Four Box Method (figure 1)¹ enables physicians to navigate a holistic approach.

In Mr W's case, it was recommended that repeated blood transfusions be withheld. There were no alternative curative interventions for his active bleeding that could be taken upon safely, and the low chances of a spontaneous recovery weighed significantly less against the increasing harm of worsening fluid overload. He remained comfortable and symptom-derived benefits from transfusions were negligible; fatigue and reduced activity are nonspecific symptoms and are often considered insufficient reasons for transfusion. In addition, the presence of his life-limiting metastatic CRPC, ongoing functional decline, and infective complications already portends a poor prognosis. Further prolongation of hospitalisation with repeated intravenous cannulation was not in keeping with quality of life to him. Offering a trial of therapy, with clearly defined end-points, to demonstrate medical futility facilitates acceptance of the circumstance and aligns eventual goals of care. It is imperative that physicians provide families with accurate, current, and frequent prognostic estimates throughout the course of the illness. There is a need to address the emotional needs of the family to understand the problems from the family's perspective by being available, approachable, and compassionate.

REFERENCE

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END-OF-LIFE CARE QUALITY FOR VULNERABLE POPULATIONS IN AUSTRALIA: THE COMMUNITY PERSPECTIVE

Jessica Vereker, Catriona Parker, Peter Poon. *Monash University, Clayton, Australia*

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Background Vulnerable populations are highlighted across Australian national palliative care (PC) and end-of-life care (EOLC) documents to increase care equity and inclusivity; however, there are disparities in listed populations across these documents, and justification of inclusion is limited. This narrative review aims to describe current literature about the EOLC experiences of the vulnerable populations listed across these care-influencing documents from the community perspective (comprising the perspectives of decedents, family members and caregivers).

Methods Separate literature searches were conducted for the fifteen vulnerable populations identified across three key national EOLC documents (Palliative Care Standards 2018, the Australian Government Department of Health's 'Exploratory Analysis of Barriers to Palliative Care' and the National Consensus Statement on 'Essential Elements for Safe and High-Quality End-of-Life Care'). Eight vulnerable populations were included for discussion as their searches returned one or more relevant articles. As the literature was almost entirely descriptive, a concept-based approach was used to describe the

EOLC experiences of included populations. Concepts were synthesised from key and recurring topics throughout the literature.

Results Agency and communication were critical areas for improvement amongst all included vulnerable populations. Concepts identified for the eight vulnerable groups included were as follows: for people living in rural and remote settings, concepts included EOLC designed for metropolitan settings, limitations of local services and interventions in rural communities; for people with dementia concepts included comfort of people with dementia, carer experiences and access to PC; for people with culturally and linguistically diverse backgrounds concepts included culture and decision-making, balancing death taboo and advance care planning discussions and trust in the healthcare system; for people living in residential aged care facilities (RACFs) concepts included advanced care planning in RACFs, place of death preference vs reality and inclusivity of RACFs; for Aboriginal and Torres Strait Islander Peoples concepts included fear of relocation to receive EOLC, culturally competent communication and resources and access to services in the community; for people who identify as lesbian, gay, bisexual or transgender (LGBT) concepts included expressing sexuality and gender identity, social isolation of people who identify as LGBT and substitute decision-makers and legal rights for people who identify as LGBT; for people living with disabilities concepts included access to disability-inclusive services, discrimination by healthcare professionals and disability support workforce and family limitations; for people experiencing incarceration concepts included balancing risk vs humanity and entitlements and inaccessible agency.

Implications Although enablers were identified throughout the literature, there was a predominant focus on barriers and negative experiences, perhaps speaking to the cumulative narrative for vulnerable populations. Evidence describing the experiences of the community was limited, with many studies conducted over twenty years ago, which illustrates a significant literature gap. Further research describing community experiences of EOLC across a broader range of settings for all identified populations is needed to inform future EOLC initiatives and standards and may assist in determining an accepted set of vulnerable populations across guidelines.

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QUALITATIVE EXPLORATION OF GYNAECOLOGY ONCOLOGISTS' VIEWS AND UNDERSTANDING OF PALLIATIVE CARE

¹Carolyn Wicks, ²Heidi Gregory, ¹Farwa Rizvi, ³Adam Pendlebury. ¹St Vincent's Hospital Melbourne, Fitzroy, Australia; ²Austin Health, Heidelberg, Australia; ³Mercy Hospital for Women, Heidelberg, Australia

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Background Patients with advanced gynaecological cancers have high symptom burden and supportive care needs and have traditionally had little and delayed involvement with specialist palliative care.

Aim This qualitative study explores the views and experiences of consultant gynaecological-oncologists and their trainees in managing advanced gynaecological cancers, providing generalist palliative care (with a specific focus on symptom profile and end of life care), as well as reflecting on their interactions with palliative care services in an Australian healthcare setting.

Methodology All gynaecological-oncology specialists and fellows working and training in the state of Victoria, Australia

between November 2022 and July 2023 were approached to participate in semi-structured, face-to-face interviews. A reflexive thematic analysis approach guided the data analysis.

Results Fifteen clinicians participated in the study. Four themes were derived from the qualitative data set – the evolution of the role of gynaecological-oncologist in advanced cancer from a more ‘holistic’ care provider to being ‘the surgical person or assessment decision maker’; the challenges of symptom management; the importance and challenges of difficult communication tasks, and how different models of care influenced the involvement of palliative care services.

Conclusion Both gynaecological-oncology specialists and fellows described a role for palliative care involvement in symptom management. They highlighted personal and institutional preferences for the management of all patients approaching end of life to be undertaken by specialist palliative care teams. Participants discussed the many communication tasks they undertook and how specific training could improve their skill-set in this area. Palliative care integration with gynaecological-oncology care is service dependent, which has implications for future service planning.

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PATIENT AND CAREGIVER PERSPECTIVES OF AN INTEGRATED SCLERODERMA AND PALLIATIVE CARE SERVICE: A QUALITATIVE STUDY

Carolyn Wicks, Julie McDonald, Laura Ross. *St Vincent's Hospital Melbourne, Fitzroy, Australia*

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Background St Vincent's Hospital Melbourne cares for the largest cohort of patients with scleroderma (also referred to as systemic sclerosis) in Australia, and physicians recognised potential unmet supportive and palliative care needs of patients and their caregivers. In response, a pilot integrated palliative care outpatient clinic (the Scleroderma Supportive Care Service (SSCS)) was commenced, collocated within the usual rheumatologist-run Scleroderma Clinic.

Aim This qualitative study explored patient and caregiver satisfaction of the SSCS. It aimed to identify what interventions were perceived as helpful and if further modification of the pilot clinic was needed.

Methodology Patients and their caregivers who attended at least one SSCS appointment were contacted post attendance and invited to participate in a semi-structured interview conducted via telephone. Interviews were audio recorded, transcribed and analysed. A reflexive thematic analysis approach guided the data analysis.

Results Twelve interviews were completed.

Five major themes described the data set:

1. **Communication Style.** Patients reported the palliative care physician was supportive, encouraging and empathetic. Difficult conversations were approached gently and respectfully and if requested, discontinued. The time and opportunity to explain their unique experiences and those of the caregiver was highly valued.
2. **Coping with scleroderma.** Many patients spoke of their resilience in the face of chronic disease and future uncertainty. Loss of function, loss of social agency and increasing dependency were spoken about with mixed feelings: patients described appreciation of the caregiver, finding joy in each day, and acceptance of a new normal.

Denial, sadness and grief associated with living with scleroderma were frequently expressed.

3. **Caregiving Role.** Caregivers reflected on their responsibility to provide practical care, medication and symptom management, and coordination of care. They described their desire to be involved in clinical discussions and highlighted the impact of the unpredictability of this chronic disease.
4. **Role of the SSCS.** Some patients and caregivers were confronted by the ‘palliative care’ label, yet this was balanced by the value gained from symptom management, disease explanation and future care discussions. Patients valued coordinated and specialist care from the inter-disciplinary clinic team who they voiced understood the complexity of their rare condition.
5. **Serious Illness Conversations.** There were diverging views regarding acceptance of discussions relating to the seriousness of the disease, prognosis, advance care planning and future care supports. Patients and caregivers varied from pragmatic acceptance, and being well prepared, to fearful denial of any future care discussion and a strong preference to avoid any discussion about any future, increased care needs.

Discussion This integrated inter-disciplinary palliative care clinic was found to be both acceptable and valued by patients and caregivers. Those interviewed emphasized they appreciated time to describe their experience, discuss their disease and explore symptom management. Future palliative care engagement should be sensitive to the diversity of responses to serious illness conversations, and further explore patient and caregiver perceptions of palliative care.

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CHALLENGES OF ACUTE TRANSITIONS FROM HOSPITAL TO HOME FOR END-OF-LIFE CARE (EOLC): LESSONS LEARNT FROM A COLLABORATIVE SPECIALIST PALLIATIVE CARE AND HOSPITAL-IN-THE-HOME (HITH) SERVICE PILOT

¹Angela Zeng, ^{2,3,4}Aaron Bak Ong Wong, ^{3,4}Seok Ming Lim. ¹Department of Geriatric Medicine, Royal Melbourne Hospital, Australia; ²Parkville Integrated Palliative Care Service, Royal Melbourne Hospital and Peter MacCallum Cancer Centre, Australia; ³Department of Medicine, University of Melbourne, Australia; ⁴RMH@Home Acute, Royal Melbourne Hospital, Australia

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Institution

Royal Melbourne Hospital – Parkville, Victoria, Australia

Background Although population surveys suggest that 60–70% of Australians would prefer to die at home, only 14% of them achieve this. This is comparatively low compared to other developed countries. Home-based palliative care programs increase the chance of patients dying at home through models of care providing multidisciplinary support for a complex range of care needs at the end of life.¹

Aim To support more patients transitioning home for EOLC through the delivery of a specialist palliative care and HITH hybrid model.

Methods The collaborative program included a team of HITH doctors and nurses; palliative care physicians and clinical nurse consultants; and allied health practitioners including an occupational therapist, physiotherapist and social worker. Referral criteria encompass patients admitted to the inpatient palliative care ward at the Royal Melbourne Hospital who express a preference for home-based palliative care and have an