Palliative Paramedicine:

Broadening the Role of Paramedics Delivering Palliative and End-of-Life Care in Australian Communities

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BPSci MPH

A thesis submitted in fulfillment of the requirements

for the degree of Doctor of Philosophy (Medicine)

Northern Clinical School

Faculty of Medicine and Health

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Statement of Originality

This is to certify that, to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes. I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

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Authors contribution

The work presented in this thesis has been carried out by the author under the supervision of Professor Josephine Clayton, Northern Clinical School, Faculty of Medicine and Health, The University of Sydney, Australia; and Emeritus Professor Phyllis Butow, School of Psychology, Faculty of Science, The University of Sydney, Australia.

The author planned the research, designed the studies, obtained ethics approval, collected, managed and analysed the data, interpreted the results, drafted and revised the manuscripts for submission to peer-reviewed journals, and wrote and compiled this thesis.

As Primary Supervisor for the candidature upon which this thesis is based, I can confirm the Statement of Originality is correct.

Professor Josephine Clayton

Date: 21/12/2023

Ethical clearance

The study presented in Chapter 5 was approved by the Human Research Ethics Committee (HREC) at the University of Sydney (2021/607 and 2021/608 – see appendices A and B).

The study presented in Chapter 6 was approved by the HREC at the University of Sydney (2021/607 and 2021/608 – see appendices A and B).

The study presented in Chapter 7 was approved by the HREC at the University of Sydney (2022/914 – see appendix C).

All participants gave written informed consent for participation in the respective studies.

Abstract

Background

As Australians live longer, with more chronic diseases and growing preferences to die at home, the typical treat and transport model of ambulance services is being challenged. These shifts in community demographics and preferences have resulted in an increasing global demand for paramedics to provide primary, palliative and end-of-life healthcare within our communities, in addition to conveyance to hospital for more definitive care where appropriate. It is well established that palliative care patients do not require solely specialist care and support, nor will all patients who could benefit from a palliative approach have the opportunity to engage with specialist palliative care services throughout their illness trajectory. Generalist palliative care can also be delivered by non-specialist clinicians, including paramedics, when supported with adequate knowledge, resources and clinical back-up. Paramedics are in a unique position to provide this type of care to patients in the community, particularly out-of-hours when other palliative care providers and general practitioners may not be available. Given the evolving nature of palliative paramedicine, there is a growing literature base examining this topic. However, gaps still remain in this area of research, particularly regarding how to better incorporate paramedics into palliative care policies, systems and practice for more sustainable and integrated models of care. This research responds to these gaps by exploring palliative paramedicine in community-based settings, laying foundations for the development of a whole-of-sector approach to standardising the role of paramedics delivering palliative and end-of-life care in Australian communities.

Objectives

The aims of this PhD were: (1) to investigate the current role of paramedics delivering palliative and end-of-life care, exploring how their scope of practice could be broadened to improve patients', family carers, paramedics' and other clinicians' experiences, preferences and outcomes in community-based settings; and (2) to develop a palliative paramedicine framework suitable for national implementation in Australia.

Methods

To achieve the aims of the research, both qualitative and quantitative methods, situated within a social constructivism epistemology, were employed. Predominately qualitative methods were chosen to adopt an explorative approach and prioritise the stories and perspectives of paramedics, other healthcare professionals, and family carers with lived experience of palliative paramedicine, which shaped the development of the resulting framework via consensus methods. Four phases of research were conducted:

1.) In Phase 1, a systematic integrative review of the literature describing the role, barriers and enablers of paramedics delivering palliative and end-of-life care was performed.
2.) In Phase 2, a collaborative qualitative analysis was undertaken, comparing the quality and content of existing Australian palliative paramedicine guidelines with a sample of guidelines from comparable Anglo-American ambulance services.
3.) In Phase 3, a qualitative interview study was conducted to elicit paramedics', palliative care doctors and nurses', general practitioners', residential aged care nurses' and bereaved families and carers' experiences, perspectives and attitudes on the role, barriers, enablers and opportunities for improving the practice of paramedics delivering palliative and end-of-life care in community-based settings.
4.) In Phase 4, data collected from the preceding phases were integrated to inform the development of an initial palliative paramedicine framework, to be refined for national implementation using consensus methods. A Delphi study was conducted with an international expert panel to determine the components of the framework considered most essential for improving the role of paramedics delivering palliative and end-of-life care in Australian communities.

Findings

The review of the literature in Phase 1 highlighted that paramedics can play an important role in providing emergency support to patients approaching end-of-life, help facilitate home-based deaths, and reduce avoidable hospital admissions where this is the patient's preference. The resulting publication, published in Palliative Medicine and titled '*Paramedics delivering palliative and end-of-life care in community-based*

settings: A systematic integrative review with thematic synthesis' identified untimely access to documented wishes, family discordance and the medico-legal ambiguity associated with palliative paramedicine as key barriers preventing paramedics from adopting a palliative approach to care. Key enablers acknowledged within the review included strengthening communication and support channels with multidisciplinary teams, targeted palliative care training for paramedics, partnering in care with families, and palliative care specific clinical practice guidelines to broaden the current scope of practice. This review underscored the opportunities for health services to consider paramedic involvement in integrated models of community palliative care delivery, especially as an adjunct support in palliative emergencies in collaboration with other services.

In Phase 2, a comparative quality appraisal and content analysis of the five existing Australian and three international palliative paramedicine guidelines revealed ambulance guidelines are shifting away from protocol driven paramedic practice to broader clinical models, calling on the discretion and decision-making skills of paramedics instead of fixed algorithms. The arising publication, published in Palliative Medicine and titled '*Palliative paramedicine: Comparing clinical practice through guideline quality appraisal and qualitative content analysis'* identified the prevalence of clinical back-up pathways across all the included guidelines, recognising the developing nature of palliative paramedicine and need for multidisciplinary approaches to care. The overall lack of content related to communication skills and care after death highlighted a significant gap in current clinical practice. This study identified opportunities to employ more robust methodological approaches to developing future best practice palliative paramedicine guidelines and shape future practice within integrated models of care. The findings also emphasised future research could investigate broader stakeholders' perspectives to better inform paramedicine practice and translate the palliative care skills of specialist paramedics across to the generalist paramedic workforce.

During Phase 3, two manuscripts addressed the paucity of palliative paramedicine research from diverse family carer and clinician lived experiences and perspectives. The first publication in Palliative Medicine, titled "'*It breaks a narrative of paramedics, that we're lifesavers': A qualitative study of health professionals', bereaved family members' and carers' perspectives and experiences of palliative paramedicine',* explored the role, barriers and

enablers of palliative paramedicine. The findings identified that paramedics have a revered public identity, shaped by a perceived ability to fix a crisis. However, a dichotomy exists regarding their roles as lifesaver and community responder. While mostly supportive of palliative paramedicine, paramedics and other generalist palliative care providers expressed vulnerabilities when taking this approach, and a need for support to move beyond conventional models of curative care. Participants described inconsistencies in ambulance services' governance, training and interdisciplinary approaches pertaining to palliative and end-of-life care. They suggested balancing competing priorities of what might be the appropriate goals of care for a person who appears to be dying, acknowledged that the family's expectations can be difficult, and suggested paramedic access to electronic medical records as one potential enabler of practice.

The opportunities for improving palliative paramedicine in Australia were described in the second manuscript from this phase of research (under peer review in the Medical Journal of Australia), '*Health professionals' and caregivers' perspectives on improving paramedics' provision in Australian communities: A qualitative study*.' All participants suggested paramedics play an important adjunct role in the provision of palliative and end-of-life care in home-based settings and three levels of opportunities for improvement were identified: macro (policy and frameworks; funding and education; accessing medical records; and a widening scope); meso-level (service-level training; interprofessional understanding and communities of practice; and community expectations); and micro-level (palliative care subspecialty; debriefing and selfcare; and partnering with families). To enhance paramedic capacity to provide palliative care support, participants recommended the inclusion of paramedicine in interdisciplinary palliative care, and greater investment in both the generalist and specialist palliative paramedicine workforce.

Finally, Phase 4 gained consensus from an international multidisciplinary expert panel on 32 macro-, meso- and micro-level components of a draft palliative paramedicine framework, suitable for implementation to standardise best practice at a national level. The manuscript from Phase 4 (under peer review in Palliative Medicine Journal), titled '*Development of a palliative paramedicine framework to standardise best practice: A Delphi study'* suggested paramedics should be supported to make complex clinical decisions specific to palliative care contexts with confidence, and navigate holistic care pathways that prioritise

referral functions available to other community-based clinicians. The expert panel called for stronger inclusion of bi-directional training and multidisciplinary debriefing opportunities between ambulance services and other palliative care providers. The authors concluded future research should engage a multidisciplinary team to create an implementation strategy, which would reflect any perceived barriers, facilitators and challenges for applying the framework into policy and practice. Furthermore, in developing the implementation strategy, endorsement of relevant professional associations should be sought, a theory applied to guide the next steps, and the time and resources required to standardise palliative paramedicine practice across Australia acknowledged. Findings from testing the strategy could have resonance for palliative care providers and ambulance services worldwide.

Conclusion

As the first in-depth exploration of palliative paramedicine from an Anglo-American lens, this research highlighted the significant opportunities available for broadening the role of paramedics delivering palliative and end-of-life care in Australian communities. A multifactorial framework that addresses the system, service, community and individual components relevant to improving palliative paramedicine in Australia is required to standardise best practice nationally. By engaging a multidisciplinary team of stakeholders to build capacity and engagement with key stakeholders, a comprehensive implementation strategy can be formulated for translating our developed framework into policy and practice. Future opportunities also exist to demonstrate international thought leadership in this emerging field, building a global community of palliative paramedicine practice and extending our framework into other healthcare systems.

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Throughout my candidature, I've had the privilege of interacting with a myriad of people reflecting many walks of life: from highly regarded professionals in the fields of palliative care and paramedicine, to newly graduated clinicians full of hope and ambition, and bereaved family members and carers generously sharing their lived experience, as well as policy experts offering thought provoking ideas and solutions. I would like to extend my sincere gratitude to the many individuals and organisations I have encountered along the way. No two stories have been the same; each unique insight helping shape the ultimate trajectory of this research.

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blueprint for how meaningful interdisciplinary partnerships between ambulance and palliative care services can be. Paul, you are a paramedicine wizard, relentlessly championing the professionalisation and growth of this discipline. I look forward to seeking many more collaborations with you both in the future.

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List of Abbreviations

Advisory Group (AG)

Australasian College of Paramedicine (ACP)

Australian Capital Territory (ACT)

Australian Institute of Health and Welfare (AIHW)

Emergency Department (ED)

Electronic Medical Records (EMR)

End-of-Life Care (EOLC)

Extended Care Paramedic (ECP)

General Practitioner (GP)

Human Research Ethics Committee (HREC)

National Health and Medical Research Council (NHMRC)

New South Wales (NSW)

New Zealand (NZ)

Northern Territory (NT)

Palliative Care (PC)

Palliative Care Australia (PCA)

Queensland (QLD)

South Australia (SA)

United Kingdom (UK)

United States (US)

Western Australia (WA)

World Health Organization (WHO)

Publications arising from this thesis

This thesis is presented for examination as a thesis containing published work. Three of the chapters presented have been published in peer-reviewed journals and two are currently being considered for publication by peer reviewed journals. The candidate is the principal author of all listed papers.

Chapter 3

Juhrmann, M. L., Vandersman, P., Butow, P. N., & Clayton, J. M. (2022). Paramedics delivering palliative and end-of-life care in community-based settings: A systematic integrative review with thematic synthesis. *Palliative Medicine*, *36*(3), 405–421. https://doi.org/10.1177/02692163211059342

Chapter 4

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Chapter 5

Juhrmann, M. L., Butow, P. N., Platts, C. M., Simpson, P., Boughey, M., & Clayton, J. M. (2023). "It breaks a narrative of paramedics, that we're lifesavers': A qualitative study of health professionals', bereaved family members' and carers' perceptions and experiences of palliative paramedicine. *Palliative Medicine*, 2692163231186451–2692163231186451. https://doi.org/10.1177/02692163231186451

Chapter 6

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Chapter 7

Juhrmann, M. L., Butow, P. N., Simpson, P., Boughey, M., Makeham, M., & Clayton, J. M. (2023). Development of a palliative paramedicine framework to standardise best practice: A Delphi study. Submitted to *Palliative Medicine* September 2023.

Conference proceedings arising from this thesis

2023

Juhrmann, M. L., Butow, P. N., & Clayton, J. M. Challenging perceptions, building paramedic capacity and embracing integrated models of care: Findings from a mixed-methods PhD exploring the role of paramedics delivering palliative and end-of-life care in Australian communities. Presented at the Oceanic Palliative Care Conference 13-15 September 2023, Sydney, Australia.

2022

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Juhrmann, M. L., Grindrod, A. E., & Gage, C. H. Emergency medical services: the next linking asset for public health approaches to palliative care? Presented at the Public Health Palliative Care International Conference 20-23 September 2022, Bruges, Belgium.

2021

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Juhrmann, M. L., Anderson, N. E., Boughey, M., McConnell, D. S., Bailey, P., Parker, L. E., Noble, A., Hultink, A. H., Butow, P. N., & Clayton, J. M. Palliative paramedicine: Comparing clinical practice through guideline quality appraisal and qualitative content analysis. Presented at the Sydney Partners Cancer Research Network Postgraduate and Early Career Researcher Symposium 9 September 2021, Virtual.

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Juhrmann, M. L., Butow, P. N., & Clayton, J. M. Plenary Presentation: Broadening the role of paramedics delivering palliative and end-of-life care in Australian communities. Presented at the Rural, Outback and Remote Australasian Paramedicine Conference 27-28 May 2021, Virtual.

2020

Juhrmann, M. L., Butow, P. N., & Clayton, J. M. Palliative Paramedicine: Broadening the role of paramedics delivering palliative and end-of-life care in Australian communities. Presented at the Sydney Vital Translational Cancer Research North Shore Research Showcase 30 November 2020, Sydney, Australia.

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Publications during candidature not included in this thesis

Juhrmann, M. L., Grindrod, A. E., & Gage, C. H. (2023). Emergency medical services: the next linking asset for public health approaches to palliative care? *Palliative Care and Social Practice*, *17*, 26323524231163195–26323524231163195. https://doi.org/10.1177/26323524231163195

Juhrmann, M. L., San Martin, A., Jaure, A., Polous, C. J., & Clayton, J. M. (2023). Staff perspectives on end-of-life care for people living with dementia in residential aged care homes: qualitative study. *Frontiers in Psychiatry*, *14*, 1137970–1137970. https://doi.org/10.3389/fpsyt.2023.1137970

Sansom-Daly, U. M., Lobb, E. A., Evans, H. E., Breen, L. J., Ugalde, A., Best, M., Zomerdijk, N., Beasley, E. A., Taylor, K. L., Clayton, J., Sharpe, L., Bartula, I., Olver, I., Bauld, C., Beesley, V., Blackburn, P., Bradford, N., Clasquin, B., Clover, K., Collins, A., Egan, R., Foo, B., Hetherington, K., Heynemann, S., Hilson, M., **Juhrmann, M.**, Kiely, B., King, M., Largey, G., Maccallum, F., Mason, C., McCaffrey, N., McGowan, N., McGrath, N., Michael, N., Obery, J., Olsson, C., Pearce, K., Penhale, J., Przezdziecki, A., Richardson, G., Rosenberg, J., Roydhouse, J., Scott, M., Service, B., Sherwell, S., Spelten, E., Stafford, L., Turner, J., Turner, J., Haydon, H. (2021). To be mortal is human: professional consensus around the need for more psychology in palliative care. *BMJ Supportive & Palliative Care*, *11*(4), 401–403. https://doi.org/10.1136/bmjspcare-2021-002884

Other media and presentations arising from this thesis

2023

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National Palliative Care Project Palliative Care Curriculum for Undergraduates Webinar on the Paramedic Learning Guide, Invited Presenter, 18 April 2023, Virtual.

2022

Government of Victoria Safer Care Victoria Initiative 'We are Ambulance Victoria (WAVE)' Webinar, Invited Presenter, 15 September 2022, Virtual.

National Palliative Care Project Palliative Care Curriculum for Undergraduates (PCC4U) Webinar on the Paramedic Learning Guide, Invited Presenter, 16 August 2022, Virtual.

Australasian Council of Paramedicine Deans Palliative and End-of-Life Care Webinar, Invited Presenter, 8 August 2022, Virtual.

CAA FIRST Magazine, 'Palliative care breaks a narrative for paramedics… that we are lifesavers', Invited Contributor, Winter 2022, Issue 09, pp. 104-109, access: https://issuu.com/firstbycaa/docs/caa4049_i09_first_magazine_winter_2022_aw_congress

Australian Capital Territory Ambulance Service Program of Experience in the Palliative Approach (PEPA) Education Seminar, Invited Presenter, 28 June 2022, Canberra, Australia.

2021

Community Care Review Article, 'Paramedics could fill a gap in palliative care: research', 15 December 2021, access: https://communitycarereview.com.au/2021/12/15/paramedics-could-fill-gap-in-palliative-care-research/

Palliative Care Australia National Register of Palliative Care Consumers and Carers Forum, Invited Presenter, 8 December 2021, Virtual.

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Inside Ageing Article, 'How ambos could help palliative care patients fulfill their wish to die at home', 27 January 2021, access: https://insideageing.com.au/how-ambos-could-help-palliative-care-patients-fulfill-their-wish-to-die-at-home/

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Chapter 1: Introduction

1.1 Overview

"Paramedics are uniquely placed to support patients with urgent and acute non-life-threatening conditions before they need to access emergency ambulance or hospital services, resulting in fewer unnecessary emergency department presentations and a commensurate reduction in ambulance ramping."

Dr John Bruning, CEO of the Australasian College of Paramedicine, responding to the 2022 Federal Budget opening the door to broadening the scope of paramedic practice

This thesis is presented as a series of papers exploring the potential and appetite for, and barriers and facilitators to, broadening the role of paramedics delivering palliative care (PC) and end-of-life care (EOLC) in Australian communities. In this chapter, I will provide an overview of paramedicine, then describe PC, before summarising the emerging field of palliative paramedicine. I will then examine current gaps in the literature and practice, provide a justification for this research, and outline the aims of each study.

1.2 Paramedicine

Paramedicine is a health discipline that was established in the mid-twentieth century to retrieve victims of sudden illness or injury, arising from earlier models of emergency care developed during World War 1.[1] Paramedics traditionally worked for ambulance services in limited vocational roles, responding to emergencies in the community and transporting patients to hospital for definitive medical care.[1] However, as paramedics' roles have diversified over time, so too has their nomenclature depending on the country and jurisdiction of practice, as illustrated in table 1 below:

Table 1: Terms used in the international literature to describe paramedics and ambulance services Adapted from Williams et al [2]

Terms utilised to identify ambulance services	Terms utilised to identify paramedics
Advanced life support services	Advanced care technician
Aeromedical retrieval	Advanced EMT
Air ambulance services	Ambulance driver
Basic life support services	Ambulance attendant
Community paramedicine service	Ambulance care technician
Critical care transportation services	Ambulance care assistant
Emergency ambulance services	Ambulance worker
Emergency medical services (EMS)	Cardiac rescue technician
Emergency rescue	Community paramedic
Emergency services	Critical care transport paramedic
Helicopter Emergency Medical Service (HEMS)	Emergency care practitioner
Medical rescue services	Emergency medical responder
Medical transportation services	Emergency nurse
Military medicine	Emergency practitioner
Mobile health care services	Emergency technician
Mobile integrated health care services	EMSer
Mobile intensive care services	EMS worker
Out of hospital emergency services	EMT (emergency medical technician)
Prehospital emergency medicine	EMT- Intermediate
Prehospital emergency services	EMT- Paramedic
Prehospital retrieval medicine	Extended care paramedic
Specialty care transportation services	Extended care practitioner
9---1---1 ambulance services	First responder
	Flight nurse
	Flight paramedic
	Intensive care paramedic
	Mobile intensive care nurse
	Mobile intensive care paramedic
	Out of hospital emergency clinician
	Paramedic assistant
	Paramedic clinician
	Paramedic practitioner
	Physician assistant
	Prehospital emergency clinician
	Rescue worker

1.2.1 Anglo-American and Franco-German models of care

During the 1960s, paramedicine diverged into two clear models: Franco-German services and Anglo-American services.[1] As the name implies, the Franco-German model describes the traditional French and German ambulance services' *delay and treat* approach, which aims to bring the hospital to the patient and now predominates in continental Europe.[3] This model of care is delivered by an emergency physician, supported by a paramedic or nurse with vocational training and limited scope of practice, allowing for

complex clinical treatment on scene and less transportation to hospital.[3] In cases where a patient is conveyed to hospital, they often bypass the emergency department.[3]

Comparatively, the Anglo-American model, which arose in English-speaking nations, works on a *treat and transport* approach.[1] In this model, two trained paramedics provide emergency care with medical oversight, and rapidly bring patients to the Emergency Department (ED) of a tertiary hospital via an ambulance.[3] The Anglo-American model is prevalent in Australia, Canada, New Zealand (NZ), the United Kingdom (UK) and the United States (US), and will be the key focus of this thesis. A comparison of both models is provided below in Table 2.

Table 2: Comparison between Franco-German model and Anglo-American models of ambulance services
Adapted from Al-Shaqsi [3]

Model	Franco-German model	Anglo-American model
Number of patients	More treated on scene, fewer transported to hospital	Few treated on scene, more transported to hospital
Provider of care	Emergency physicians supported by paramedics	Paramedics with medical oversight
Main motive	Brings the hospital to the patient	Brings the patient to the hospital
Destination for transported patients	Direct transport to hospital wards i.e., bypassing EDs	Direct transport to EDs
Overarching organisation	Ambulance service is part of public health organisation	Ambulance service is part of public health organisation

1.2.2 Australian paramedics and ambulance services

The Australian discipline of paramedicine, much like other Anglo-American services, is experiencing considerable professionalisation.[4, 5] Part of this continuum of change can be attributed to the introduction of mandatory tertiary-level education, professional registration and expanding occupational roles.[4, 6] Initially, Australian paramedics were trained through a vocational pathway; however, this approach was later phased out in preference for university educated clinicians.[4] To become a qualified paramedic in Australia today, an individual must complete a three-year bachelor's degree majoring in paramedic science at an accredited university.[4] During this time, students gain the clinical decision-making knowledge and skills to be a paramedic and play an integral role in the Australian health system, responding to patients with a range of health problems in diverse settings.[4] Upon graduating, paramedics have the capability to work in an ambulance service, the private paramedical industry or the defence forces.[4] Opportunities also

exist for Australian paramedics to undertake specialist post-graduate training in intensive care and extended care after some years in the profession.[4] Since 2018, Australian paramedics have also been required to register with the Paramedicine Board of Australia and meet the Australian Health Practitioner Regulation Agency registration standards.[6, 7] In 2021-22, there were 22,755 registered paramedics in Australia.[7] Most work in ambulance services, which operate in each jurisdiction, as depicted below in Table 3.

Table 3: List of Australian ambulance services

Jurisdiction	Name	Operator
Australian Capital Territory (ACT)	ACT Ambulance Service	ACT Government
New South Wales (NSW)	NSW Ambulance	NSW Government
Northern Territory (NT)	St John Ambulance (NT)	St John Ambulance contracted by NT Government
Queensland (QLD)	Queensland Ambulance Service	QLD Government
South Australia (SA)	South Australian Ambulance Service	SA Government
Tasmania	Ambulance Tasmania	Tasmanian Government
Victoria	Ambulance Victoria	Victorian Government
Western Australia (WA)	St John Ambulance (WA)	St John Ambulance contracted by WA Government

1.2.3 Shifting demographics and preferences for place of death in an ageing society

Paramedics are often the first interface of healthcare for people experiencing emergencies and life-threatening injuries, acting as gatekeepers for accessing secondary and tertiary services.[3] As new ambulance service models emerged, community health profiles also changed, placing different demands on ambulance services.[8] As a result of advancing modern medicine and living standards, global populations are also ageing.[9] The 2023 Intergenerational Report revealed Australians are living longer and using more government-funded services, including healthcare, as a result.[10] This is expected to substantially rise over the next 40 years, as life expectancy increases from 81.3 to 87 years for men and 85.2 to 89.5 years for women by 2062-63.[10] The current population aged 65 and above already account for 40 percent of total Australian health expenditure, despite constituting only 16 percent of the population.[10] The growing prevalence of chronic disease and complex multi-morbidities presenting within our society are inextricably linked to an ageing population and increasing healthcare pressures. As a result

of these demographic changes, the nature of ambulance calls has similarly changed, with fewer acute emergencies following an accident, and more complex disease exacerbations.[11]

Australian ambulance services triage emergency calls as follows:

- Emergency — immediate response required by an emergency ambulance under lights and sirens.
- Urgent — undelayed response required by an emergency ambulance without lights and sirens.
- Non-emergency — non-urgent response required by an ambulance for casualty room attendance.

According to the Australian Government Productivity Commission, in 2021-22, 42.5% of the 4.2 million incidents reported to ambulance services were prioritised as emergency incidents, followed by 31.9% prioritised as urgent and 25.6% prioritised as non-emergency.[7] This shift in demography is similarly reflected in comparable international healthcare systems. In the UK, only 8% of emergency ambulance calls are for people with life-threatening injuries or illnesses; the remaining proportion access paramedics for low acuity problems.[12]

In recent years, Australian ambulance services have struggled to sufficiently cope with the increasing number of non-urgent cases.[13] This limitation is particularly profound in regional, rural and remote areas where other healthcare services are restricted, especially out-of-hours.[14] As a result, the phenomenon of 'ramping' is increasingly occurring within Australia hospitals, whereby an ambulance and its paramedics are stalled at the holding bay of a hospital while wanting to off-load, but having to wait due to the low acuity of their patient resulting in a low-priority triage into ED.[13, 15]

Growing preferences in Australian communities for home-based deaths are also increasing pressures on the traditional treat and transport model of ambulance services. Accordingly, 70% of Australians have expressed a desire to die in their home.[16] However, during 2019, 51% of deaths occurred as an admitted in-patient; 29.5% in care homes; 14.8% at home; 1.4% other locations; and the remaining 3.4% could not be identified.[17] These shifts in community demographics and preferences for place of death have resulted in an increasing global demand for paramedics to provide primary healthcare within our communities instead of conveyance to hospital.[18-21] As a result, Anglo-American ambulance services can no longer operate on the traditional treat and transport model, assuming all calls will be responding to an emergency

and the ED is the most appropriate referral destination. Instead, modern paramedics require an identity shift toward responsible healthcare partnerships, which strive to be part of a holistic solution within the public health system.[8] In response, a renewed definition of Anglo-American paramedicine was recently developed to reflect this multidimensional role:

> "*A domain of practice and health profession that specialises across a range of settings including, but not limited to, emergency and primary care. Paramedics work in a variety of clinical settings such as emergency medical services, ambulance services, hospitals and clinics as well as non-clinical roles, such as education, leadership, public health and research. Paramedics possess complex knowledge and skills, a broad scope of practice and are an essential part of the healthcare system. Depending on location, paramedics may practice under medical direction or independently, often in unscheduled, unpredictable or dynamic settings."* [2]

1.2.4 The emergence of community paramedicine

Growing professionalisation of paramedicine within Anglo-American ambulance services and a broadening scope of practice, has led to a shift in focus beyond high acuity care to community-focussed approaches.[2, 22, 23] Community paramedicine is a model of practice that serves the needs of patients and other healthcare providers, bridging a gap in community-based primary healthcare, particularly after-hours.[22, 23] The global definition of a community paramedic is:

> *"Providing person-centred care in a diverse range of settings that address the needs of the community. Their practice may include provision of primary health care, health promotion, disease management, clinical assessment and needs based interventions. They should be integrated with interdisciplinary health care teams which aim to improve patient outcomes through education, advocacy, and health system navigation."* [23]

Examples of community paramedicine programmes include ED diversion to alternate referral destinations, primary care delivery for non-urgent patients with chronic diseases, and partnered care delivery with Indigenous-led healthcare services in First Nations communities.[22] Within Australia and NZ, community paramedicine is an emerging scope of practice, but often relegated to specialist roles such as

an Extended Care Paramedic (ECP), with limited practicing hours and geographical reach.[23, 24] However, community paramedics are more embedded into comparable ambulance service systems in Canada, the UK and the US.[12, 22, 24] In Oregon, US, community paramedicine has offered a promising model to reduce avoidable ED admissions in patients with a history of chronic disease and high hospital usage, saving 2.3 visits for every 100 people.[25] In the UK, opportunities exist for community paramedics to work outside of traditional ambulance services in alternative primary care settings such as general practice and urgent care centres.[12] Expanding pathways for paramedics to transition into other specialist primary care roles will certainly broaden career development opportunities for the discipline, and help alleviate some universal healthcare pressures, particularly in the arena of PC.

1.3 Palliative care

PC is an essential component of healthcare, defined by the WHO as:

> "*An approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illnesses. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.*"[26]

The discipline of PC originated from the hospice movement and pioneering efforts of Dame Cicely Saunders in the mid-twentieth century, which traditionally focussed on the alleviation of suffering during a person's end of life.[27] As a result, PC and EOLC are often conflated terms and used interchangeably amongst non-specialists.[28] To differentiate, the Australian Commission on Safety and Quality in Healthcare defines EOLC as:

> *"When people are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with: advanced, progressive, incurable conditions; general frailty and co-existing conditions that mean that they are expected to die within 12 months; existing conditions, if they are at risk of dying from a sudden acute crisis in their condition; and life-threatening acute conditions caused by sudden catastrophic events."*[29]

1.3.1 The interdisciplinary team

PC is a holistic and person-centred discipline that can be delivered by a wide range of professionals, at any stage of illness and accompany curative treatments. As populations continue to age, demand for PC is expected to rise substantially across low, middle and high-income countries alike, and will require a multidisciplinary approach to satisfy need.[26, 30] During the 67th World Health Assembly, the congregation's resolutions and decisions acknowledged the urgent need to recognise PC across the continuum of care, especially at the primary care level, highlighting that inadequate integration into health and social care systems was a major contributing factor to inequitable PC access:

> *"Recognising the existence of diverse cost-effective and efficient palliative care models, acknowledging that palliative care uses an interdisciplinary approach to address the needs of patients and their families, and noting that the delivery of quality palliative care is most likely to be realised where strong networks exist between professional palliative care providers, support care providers (including spiritual support and counselling, as needed), volunteers and affected families, as well as between the community and providers of care for acute illness and the elderly."* [31]

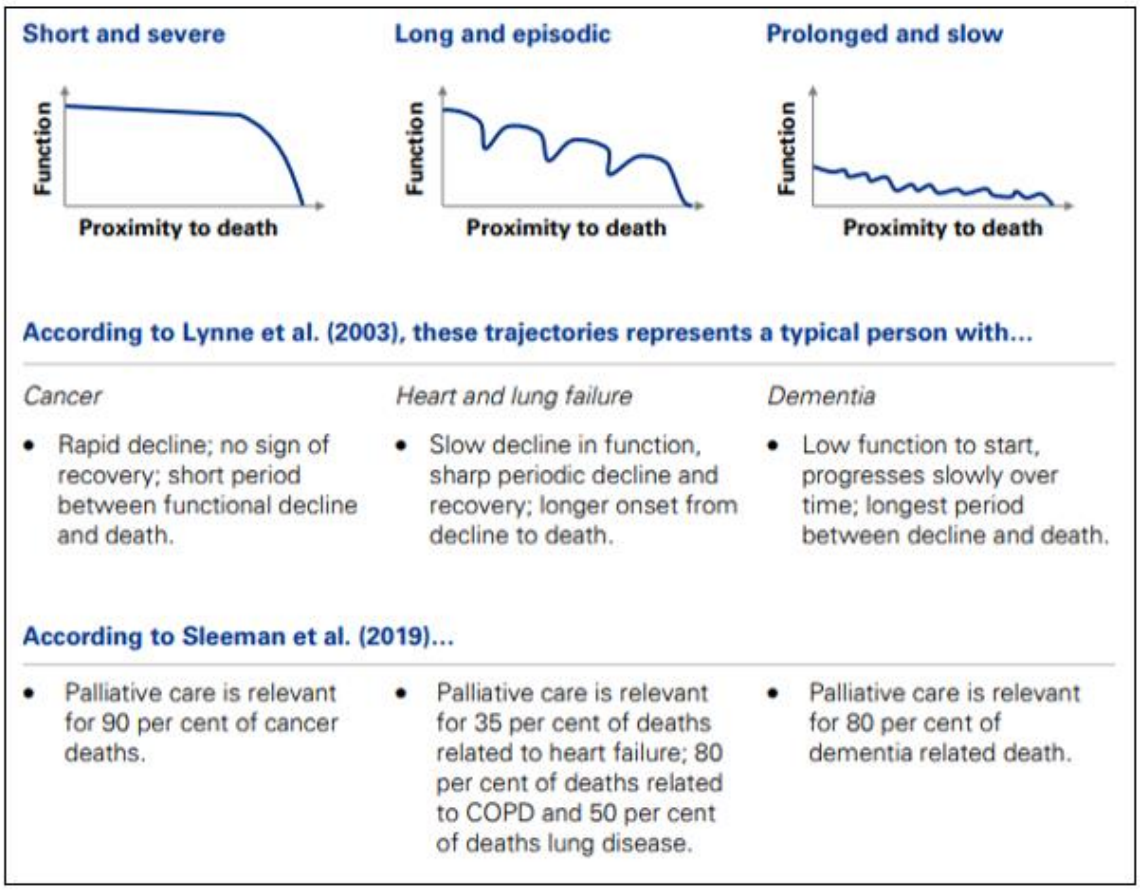
In countries with developed healthcare systems like Australia, the specialist PC team is a group of interdisciplinary clinicians and personnel consisting of a core team of PC physicians and nurses, and extended team of PC social workers, psychologists, physiotherapists, occupational therapists, dieticians, spiritual care workers and volunteers.[32] As patients are at the centre of PC, interventions must be administered with their consent and in accordance with their wishes; therefore, patients must also be considered members of the extended team, in addition to their family and carers.[32] Multidisciplinary PC team meetings are a key function of the specialist approach, ensuring genuine collaboration across the professions to facilitate comprehensive and holistic treatment pathways.[33] Specialist PC services work across a range of settings, caring for people in specialist in-patient PC units and hospices, and providing outreach community-based care in residential aged care facilities (care homes), domestic homes and acute hospitals.[32]

1.3.2 Common palliative care conditions, symptoms and disorders

Although PC's origins lie in the treatment of terminal cancer patients, its efficacy extends beyond malignant diseases, including, but not limited to, advanced heart disease, dementia, end-stage kidney disease, advanced chronic obstructive pulmonary disease, human immunodeficiency virus/acquired immunodeficiency syndrome, diabetes and other advanced neurological disorders.[27, 28, 34]

Pain and respiratory problems are the two most common and serious symptoms experienced by patients in need of PC.[26, 34] Other symptoms and disorders experienced include: constipation, nausea, vomiting, fatigue, delirium, anxiety and depression.[32] Importantly, the trajectory of a palliative patient is varied and often unpredictable, especially when multimorbidity is contributing to disease progression, as illustrated below in Figure 1.[30, 35] As such, the provision of PC services can differ along the way.[30]

Figure 1: Pathways to death associated with chronic disease [35]



1.3.3 Palliative care emergencies and hospitalisations

PC emergencies refer to an unforeseen or sudden occurrence of danger that, if left untreated, will seriously threaten the quality of life remaining for the patient.[34, 36] Examples of such emergencies include airway obstruction or severe shortness of breath, obstruction of the superior vena cava, spinal cord compression, pathological bone fractures, severe electrolyte imbalance, seizures and breakthrough pain crises. [34, 36] Most of these PC emergencies are appropriate to manage in hospital rather than at home by a community-based team. However, the important factor for a PC patient is determining their goals of care, and deciding whether it is appropriate and/or desired by the patient to have active intervention in the hospital setting. It is important to note a PC patient, their family and carers may change their preferences over time, particularly as the person approaches the last days to weeks of life. According to one Australian study, in the last week of life preferences for home care fell from 90 to 52 percent, mostly attributed to symptom management and control.[37] In such cases, patients and families may benefit from professional help to better enable them care for the patient at home, where that is desired.

The important role of PC in the ED and intensive care unit has been well recognised.[32, 34, 38] The ED often serves as a safety net for patients with a life-limiting illness: emergency specialists regularly manage the dying process for unexpected deaths, but also routinely care for seriously ill patients with chronic underlying diseases.[39] The number of patients with life limiting illnesses presenting to ED during crisis events is expected to rise. According to the Australian Institute of Health and Welfare (AIHW), between 2015-16 and 2020-21 there was a 23% increase in the number of PC-related hospitalisations.[40] This increase was at a steeper rate than for all hospitalisations (12% increase) over the same period: 45% of these hospitalisations were for EOLC in a non-PC specialist setting, of which 40% of the patients died in hospital.[40] In regional, rural and remote areas of Australia the ED utilisation for PC patients is even more profound, and likely contributed to by decreased availability of community-based PC services out-of-hours.[41]

1.3.4 Generalist palliative care provision

As death is a universal experience, the need for PC services is high, but current specialist services cannot keep up with demand. However, it is well established that PC patients do not require solely specialist care

and support, especially if their complexity of care needs are low, and not all patients who could benefit from a palliative approach have the opportunity to engage with specialist PC services throughout their illness trajectory. [26, 30, 42, 43] Generalist PC can also be delivered by non-specialist hospital clinicians, general practioners (GPs), aged care staff and community-based clinicians, when supported with adequate knowledge, resources and clinical back-up.[32, 34, 43]

1.4 Palliative paramedicine

The evolution of paramedicine seeks to better serve the needs and preferences of the community, including the evolving paradigm of PC and EOLC.[44, 45] Paramedics are remarkably well placed to provide this type of care to the community as they are dynamic and adaptable clinicians, working 24 hours a day, seven days a week across all locations.[44] This flexibility allows paramedics to help support specialist PC providers in a generalist capacity in the community, especially after hours when other services and the GP may not be available.[45] In Australia, a retrospective cohort study documented reasons for paramedic attendance to 4207 PC patients in Victoria over the course of one year, highlighting the considerable variety of PC presentations, as listed below in table 4.[46]

However, despite paramedics already playing a role in PC, and the advancements made in interdisciplinary PC over the years, paramedicine is too often under recognised as an important asset in international and domestic PC policies, planning and service delivery.[47, 48] Adding to this, the entrenched paramedic identity of treating patients to save lives is harshly juxtaposed against the more holistic goals of PC, causing tension for a profession traditionally associated with emergency response.[49] Furthermore, relegating PC and EOLC functions to specialist roles alone, as has been the case historically for most Anglo-American ambulance services, can reinforce this culture and limit palliative approaches to the availability of community paramedics.[50] Nevertheless, significant opportunities exist to sustainably engage the paramedic workforce as an adjunct provider of PC and EOLC in Australian communities. In doing so, then potentially out-of-hours PC and EOLC could be enhanced;[45] avoidable hospital admissions may be reduced, as has already been demonstrated in the US;[51] more home-based deaths may be facilitated;[48] and, most importantly, this may result in EOLC for people with life-limiting illnesses being improved.[45, 49]

Table 4: Final paramedic assessment of primary health problem of palliative care patient[46]

Final assessment	Number of patients	Percentage
Respiratory problem	845	20.1
Pain	666	15.8
Deceased	334	7.9
Weakness/collapse	316	7.5
Altered consciousness	238	5.7
Nausea/vomiting/gastrointestinal issue	237	5.6
Cardiac issue	226	5.4
General decline in health	212	5.0
Mental health issue	162	3.8
Hypo/hyperthermia	159	3.8
Other medical	144	3.4
Infection	128	3.0
No problem identified	120	2.8
Seizures/stroke	119	2.8
Trauma	112	2.7
Dizziness/headaches	96	2.3
Urinary issue	91	2.2
Cardiac arrest, no death	2	0.05
Total	**4207**	**100**

1.5 Summary of the literature

Given the evolving nature of palliative paramedicine, there is a growing base of literature examining this topic. This is described in detail in Chapter 3, which reports a systematic review on this topic. Early Canadian studies investigated the efficacy of PC specific training programmes for community paramedics,[52] identifying significant barriers and enablers of implementing such models into practice. Studies arising from the UK have also demonstrated the need for paramedics to have immediate access to information and resources to support EOLC.[53] In one study, a review of ambulance service medications to palliate symptoms of severe COVID-19 infection and advanced and terminal illness was undertaken.[54] Twelve months of data indicated increasing paramedics' scope to carry these medications on ambulances is a safe, cost-effective and patient-centred practice.[54] New Zealand-based researchers have explored paramedic care of the dying, deceased and bereaved, highlighting gaps in the current care after death

approaches of paramedics.[55] Within an Australian context, studies have been conducted to describe the incidence and nature of PC cases attended by paramedics,[46] and identified paramedics' strong willingness to use a specialist PC telehealth service.[56] Evidently, gaps still remain in this area of research, particularly regarding the development of a comprehensive whole-of-system approach to palliative paramedicine.

1.6 Aims of the research

This thesis is comprised of two stages, addressing the overall aims of this study:

a.) To investigate the current role of paramedics delivering palliative and end-our-life care, exploring how their scope of practice could be broadened to improve patient's, family carers', paramedics' and other clinicians' outcomes in community-based settings (Chapters 3, 4, 5 and 6); and

b.) To develop a palliative paramedicine framework suitable for national implementation in Australia (Chapters 7 and 8).

The specific aims of each chapter are as follows:

1.) To review and synthesise the international empirical evidence regarding paramedics delivering palliative and EOLC in community-based settings (Chapter 3).

2.) To examine the quality and content of existing Australian palliative paramedicine guidelines with a sample of guidelines from comparable Anglo-American ambulance services (Chapter 4).

3.) To elicit paramedics', PC doctors and nurses', general practitioners', residential aged care nurses' and bereaved families and carers' experiences, perspectives, and attitudes on the role, barriers and enablers of paramedics delivering palliative and EOLC in community-based settings (Chapter 5).

4.) To elicit paramedics', PC doctors' and nurses', general practitioners', residential aged care nurses' and bereaved families and carers' attitudes and perspectives on how palliative paramedicine can be improved to better suit the needs of community-based patients, their families and carers, and the clinicians involved in delivering the care (Chapter 6).

5.) To develop a palliative paramedicine framework suitable for national implementation, by determining the components considered most essential for improving the role of paramedics delivering palliative and EOLC in Australian communities (Chapter 7).

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Chapter 2: Philosophical approach and outline of the thesis

Understanding the factors shaping current paramedic approaches to PC in Australia and abroad is fundamental to developing future models of best practice. This PhD aimed 1) investigate the current role of paramedics delivering palliative and EOLC, exploring how their scope of practice could be broadened to improve patient's, family carers', paramedics' and other clinicians' outcomes in community-based settings; and 2) develop a palliative paramedicine framework suitable for national implementation in Australia. The following chapter provides a rationale for, and description of the methodological considerations made to address each of the research aims.

2.1 Research paradigm

As a non-clinical researcher conducting health services research in paramedicine and PC, it is important to explicitly acknowledge my background, worldview and standpoint as a researcher. These factors shaped the adoption of certain philosophical underpinnings of the PhD, and subsequent approaches to methodology.

2.1.1 Reflexivity, positionality and motivation for this study

I decided to embark on this PhD after significant personal reflection, arising from lengthy discussions with Australian and international paramedicine and PC experts regarding my earlier experience working as a student paramedic. During these formative years, I witnessed firsthand the limitations I, and paramedic peers – many well advanced in their career – felt when caring for patients with life-limiting illnesses in the community. Despite coming across ageing and dying patients each shift, I had not received any curriculum pertaining to PC throughout my undergraduate degree and felt completely ill-equipped responding to end-of-life frailty and expected death callouts in the community. I feared the unknown in caring for these types of patients, instead feeling more competent responding to typical prehospital *emergencies*, such as cardiac arrests and motor vehicle accidents. Initially, I considered this limited scope of practice a phenomenon of Australian paramedic practice that a junior clinician should come to expect.

However, upon later completing an international paramedic placement with Costa Rica's Red Cross, I experienced the same unmet need for palliative paramedicine in a middle-income country, leading me to realise inadequate PC and EOLC capabilities transcend our ambulance service design and demography to other contexts. Acknowledging this restricted scope of practice, coupled with the collective experiences and perspectives of other generalist palliative care providers I had listened to and come to admire, I became motivated to address this gap in Australia. Consequently, I ceased my clinical aspirations as a paramedic and undertook postgraduate studies in public health, before embarking on a career in palliative care policy and research.

Any researcher focussing on a health profession they no longer practice in must balance idealism and pragmatism when advocating for service reform.[1] Throughout this PhD, I have held the positionality of a researcher with lived experience as a paramedic. However, I have remained aware of my limited understanding of contemporary paramedic practice in Australia since leaving the clinical space. As a result, I have welcomed diverse and contrasting perspectives from clinicians on the front-line regarding the role paramedics ought to play delivering PC and EOLC in community-based settings, recognising my personal beliefs should never skew the anecdotes or suggestions of others. I have also aimed to maintain impartiality when interpreting and reporting results that do not align with my personal beliefs, recognising that challenging one's preconceptions only strengthens the research process.[2]

In summary, driven by my earlier experiences, from the outset of this PhD I wanted to generate practical improvements in the field of palliative paramedicine. As a result, I established key goals to inform the direction of my research, including (1) engaging the subjective insights and endorsement of paramedics and other key health professionals currently working in palliative paramedicine to shape the outcomes of my research; and (2) translating the findings into practical outcomes in real time. My background in public health has also influenced this research approach, as I hold strong beliefs that broader social and structural determinants influence health outcomes pertaining to palliative paramedicine in Australian communities; in turn, driving my research focus beyond clinician-level mediation of challenges, towards a multisectoral solution.[3]

2.1.2 Underlying implementation approach

I adopted an implementation focus from the outset of this PhD, incorporating aspects of the Consolidated Framework for Implementation Research (CFIR) into my overall PhD approach.[4] As described later in this chapter, I carefully involved stakeholders from the thesis inception. I also reported the outcomes of the research to key organisations, including the Australasian College of Paramedicine (ACP) and Palliative Care Australia (PCA), throughout the duration of my candidature, maintaining a constant eye for facilitating the future translation of my findings into routine policy and practice.

2.1.3 Ontology, epistemology and theoretical perspective

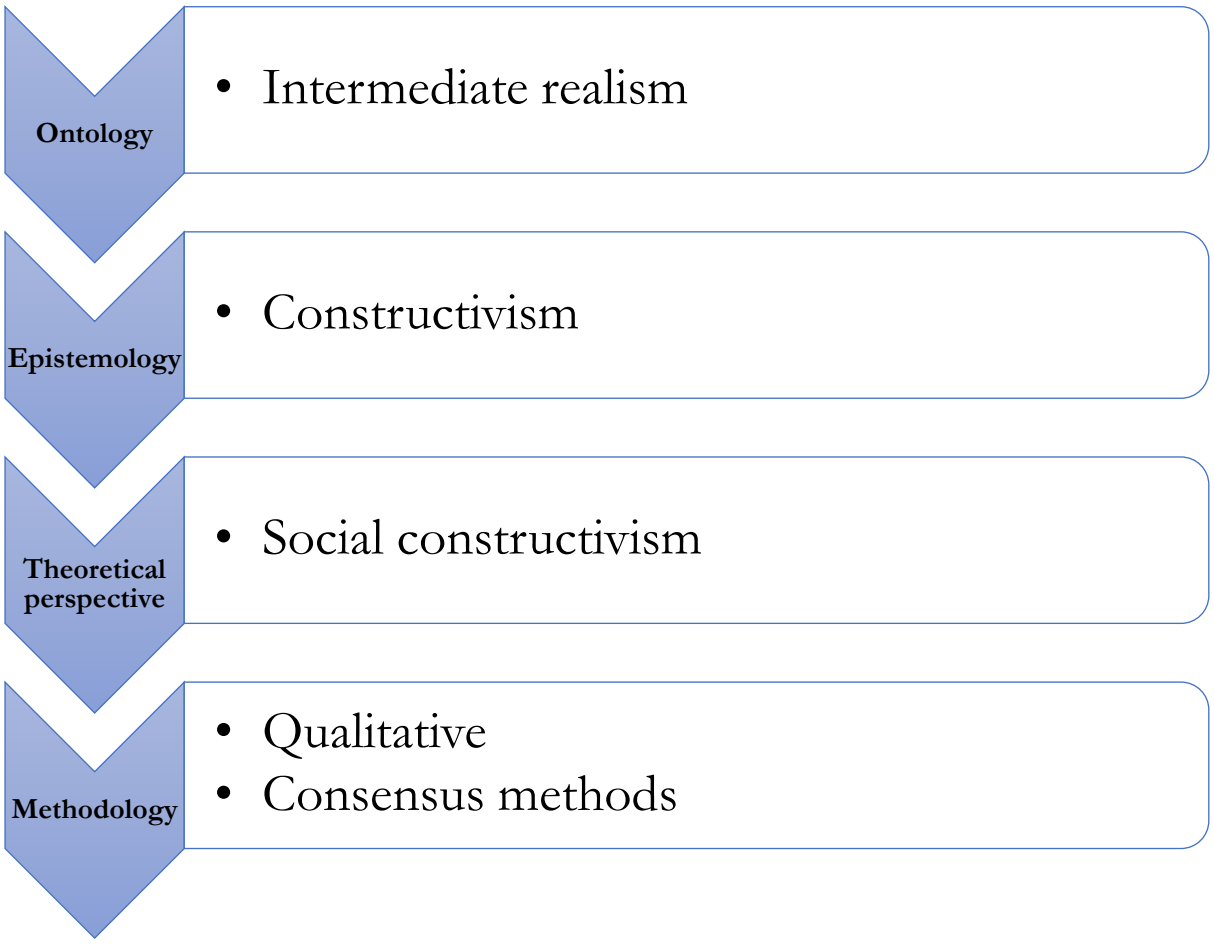
The approaches taken to understanding and exploring experiences of PC and paramedicine will differ according to the research's underlying paradigm. Throughout the course of this PhD, each study was grounded in a consistent ontology, epistemology and theoretical perspective to reflect my values and beliefs as a researcher (Figure 2). I employed an intermediate realism ontology (study of being), which purports objective answers do exist, but lack sufficient detail to fully reflect the depth of reality, instead providing "conceptual truths rather than the furniture of the world".[5] By adopting an intermediate position, one explores both subjectivist viewpoints (where multiple realities co-exist at once) through qualitative research methodology, and objectivist viewpoints (where understanding is independent of human beliefs) through quantitative research methodology, to develop a comprehensive ontological understanding of the social phenomenon being studied.[6]

Epistemology provides a philosophical grounding for deciding what constitutes knowledge, how it can be acquired or produced, and the extent to which it can be transferred.[6] I employed a constructivist epistemology in all my studies, which rejects the notion of pure objective truth.[6] Instead, this epistemology contends truth also arises through engagement with the realities of the world i.e., an individual constructs their own meaning through life experience.[6] Constructivist research is useful for generating a contextual understanding of a defined topic or problem.[7]

Paramedicine research has traditionally been conducted with a positivist lens, focussing on the physiology, pathology and management of symptoms arising from medical and traumatic emergencies in a prehospital setting.[8] This research approach is congruent with a biomedical definition of healthcare and an historical

approach to paramedic practice. Comparatively, the discipline of PC pioneered holistic medicine,[7, 9] supported by decades of sociological research that acknowledges common PC symptoms, such as pain, are often difficult to objectively measure and describe.[7] By adopting a social constructivist theoretical perspective throughout each of my studies, and employing more subjective and interpretive methodological approaches, I viewed experiences and perspectives as personally and socially constructed phenomena, closely associated with meaning and influences arising from an individual's socio-cultural context.[6, 7]

Figure 2: Research ontology, epistemology, theoretical perspective and methodologies



2.2 Ethical considerations

When conducting ethical research in paramedicine and PC, one should be particularly vigilant of the vulnerable status of participants living with a life limiting illness, and their family carers. As a researcher, I had to carefully manage my exploration with sensitivity and discretion, remaining mindful that these

participants, particularly patients at end-of-life, are unlikely to benefit from my research.[10] Keeping this in mind, I wanted to meaningfully engage end users throughout the process of this PhD, ensuring their voices were heard and helped shape the outcomes of the research. Australia's National Health and Medical Research Centre (NHMRC) supports involving consumers – including patients, family carers and/or clinicians – in the development of guidelines and frameworks, attesting "consumers are best placed to ensure that recommendations made for them or about them are consistent with their values and preferences—this is done by sharing their lived experience with developers."[11] Consumer involvement in doctoral research has also been shown to promote nuanced perspectives on experiences of a phenomenon, provide unanticipated richness to data analysis, build trust with integral stakeholders and lead to in-depth consumer engagement.[12]

2.2.1 Capacity building in the sector

To build capacity within the palliative paramedicine sector, I established a Palliative Paramedicine Advisory Group (AG). I leveraged existing paramedicine contacts and approached all ambulance services in Australia and New Zealand, seeking their interest to take part in an Oceanic community of practice. Gaining substantial buy in, all jurisdictions willingly participated and elected a suitable senior clinical manager to represent their service throughout the duration of my PhD. I also invited select PC thought leaders with paramedicine expertise from both countries to become members. As outlined in the AG Terms of Reference (Appendix D), the purpose of this group was to: strengthen and promote collaboration between ambulance services on matters related to palliative paramedicine; and advise on current operational barriers and developments specific to the provision of palliative and end-of-life care within each respective services. I invited AG members to co-author and/or participate in the PhD studies, facilitating research experience for clinician-only AG members and driving the translation of our findings into practice in real time. The AG met annually via video conference throughout the course of the PhD, and their contributions were acknowledged in all lay and academic presentations and publications arising from the research.

2.2.2 Community participation

PCA is the national peak body for PC. In 2018, it established a National Register of Palliative Care Consumers and Carers (National Register) to "give a voice to those living with a life-limiting illnesses,

people who are receiving PC, their family, carers and the PC volunteers who support them."[13] I engaged with PCA at the beginning of my research, and they assisted me in gaining access to bereaved family members and carers with lived experience of palliative paramedicine through the National Register. I made a presentation during an annual online National Register meeting, outlining the aims and methodology of my research, and invited members with suitable experience, willingness and capacity to participate in my studies on a voluntary basis. The contributions made by National Register members were acknowledged in all lay and academic presentations and publications arising from the research.

2.3 Methods

To achieve the aims of the research, both qualitative and consensus methods, situated within a social constructivism epistemology, were employed. Predominately qualitative methods were chosen to adopt an explorative approach and prioritise the stories and perspectives of paramedics, other healthcare professionals, and family carers with lived experience of palliative paramedicine, [6] which shaped the development of the resulting framework via consensus methods. The methods for each respective study are described in more detail in each chapter.

2.3.1 Phases of research

Four phases of research were conducted in this PhD: Phase 1 included a systematic integrative review with thematic synthesis (Chapter 3); Phase 2 involved a content analysis and quality appraisal of palliative paramedicine guidelines (Chapter 4); In Phase 3 qualitative interviews were conducted to explore the roles, barriers, enablers and opportunities for improving practice (Chapters 5 and 6); and Phase 4 included a Delphi study to develop a national framework to standardise palliative paramedicine. Figure 3 provides an outline of the phases, methods, outputs and outcomes of my research.

2.3.2 Qualitative methods

Qualitative healthcare research focusses on the social world, gathering subjective experiences and perspectives of participants to create descriptive accounts of a specific phenomenon.[6, 14] Qualitative methods are often pursued when they better address the research question at hand. Within my PhD, qualitative methods were selected as highly appropriate given I aimed to generate evidence about an emerging scope of practice, and develop solutions to the current limitations in paramedic practice.[6]

First, a systematic review of the empirical literature was performed to understand and describe the role, barriers and enablers of paramedics delivering palliative and EOLC in community-based settings. Given the integrative nature of this review, quantitative, qualitative and mixed-methods studies were included, and a qualitative thematic analysis was undertaken to synthesise the data,[15] as described in more detail in Chapter 3.

Next, I engaged an international and multidisciplinary group of paramedicine and PC clinicians, including members of the AG, to conduct a collaborative qualitative analysis of palliative paramedicine guidelines. We compared the quality and content of existing Australian palliative paramedicine guidelines with a sample of guidelines from comparable Anglo-American ambulance services. We used the Appraisal of Guidelines for Research and Evaluation (AGREE) II instrument[16] to methodologically assess the quality of each guideline, and employed a collaborative qualitative content analysis approach[17] to compare and contrast the content of each guideline, as specified in Chapter 4.

Semi-structured interviews were then conducted to elicit paramedics', palliative care doctors' and nurses', general practitioners', residential aged care nurses' and bereaved families and carers' experiences, perspectives and attitudes on the role, barriers, enablers and opportunities for improving the practice of paramedics delivering palliative and EOLC in community-based settings. Some of the participants included members of the AG and National Register. The findings from this study were separated into two manuscripts. The first employed reflexive thematic analysis methodology[18] to synthesise the role, barriers and enablers of practice. Further details on the methodology are included in Chapter 5.

The second manuscript focussed on the study data related to improving palliative paramedicine practice in Australian communities. It is well established that healthcare consists of many interdependent influences, relationships and factors that together shape a whole complex system; one widely recognised public health approach to researching these interconnections is by distinguishing individual considerations at macro (structural-based), meso (systems-based) and micro (individual clinician and consumer-based) levels.[19] In this manuscript, reflexive thematic analysis was again employed to synthesis the suggested improvements into these aforementioned levels, as explained in more detail in Chapter 6.

2.3.3 Consensus methods

In the final study, I used consensus methods to develop a palliative paramedicine framework to standardise best practice across Australia. To create professional frameworks, traditional quantitative methods such as randomised control trials and observational studies are usually considered the highest quality methodological approach. However, palliative care research often precludes these study types due to ethical, economic and/or practical reasons.[20] The Delphi technique is a suitable mixed-methods alternative that systematically collates expert consensus for the development of guidance, and is constructivist in nature, therefore strongly aligning with my research paradigm and objectives.[21] There are four key methodological features of a Delphi: (1) a group of experts participates on a panel and are questioned about the issue of interest; (2) the process remains anonymous to avoid conformity to a dominant view; (3) the procedure is iterative, comprising repeated rounds of enquiry and; (4) the design of subsequent rounds is informed by the summary of group responses from Round 1.[20, 21]

Data collected from the preceding phases of research were integrated to inform the development of an initial palliative paramedicine framework, which was refined for national implementation via a Delphi study. I engaged an international expert panel, including members of the AG and select previous participants of the interview study, to gain consensus on the components of the framework considered most essential for improving the role of paramedics delivering palliative and EOLC in Australian communities. Comprehensive detail of the Delphi process is included in Chapter 7.

2.4 Summary and discussion

In the concluding Chapter of this thesis, the key findings from each study are integrated and considered holistically. I then compare the outcomes of my research with existing literature, discussing the strengths and weaknesses of each study. I consider implications for policy and clinical practice, summarising the recommendations arising from this PhD and make concluding remarks on the future directions of palliative paramedicine in Australia and abroad.

TIMELINE →				
PHASE	**PHASE 1**	**PHASE 2**	**PHASE 3**	**PHASE 4**
STUDY TYPE	Literature review	Study 1 – Qualitative	Study 2 – Qualitative	Study 3 – Consensus methods
STUDY & RESEARCH METHODS	Systematic integrative review with thematic synthesis of empirical studies exploring the topic (N= 22)	Content analysis and quality appraisal of Australian and comparable Anglo-American palliative paramedicine clinical guidelines to understand current practice (N=8)	Qualitative interview study to explore experiences and perspectives of family carers and health professionals (N=50)	Delphi study with international expert panel to determine components of national framework (N=68)
OUTPUTS	Published manuscript -> Systematic integrative review	Published manuscript -> Comparative guideline study of Australian, New Zealand, Canadian and United Kingdom palliative paramedicine practice	Published manuscript -> Lived experience of roles, barriers and enablers Submitted manuscript -> Opportunities to improve practice from diverse participant perspectives	Submitted manuscript -> Macro, meso and micro-level palliative paramedicine framework suitable for national implementation
OUTCOMES	- Highlighted palliative paramedicine as an emerging field and identified gaps in the literature warranting further research.	- Summarised the quality and content of palliative paramedicine guidelines, recognising current limitations in practice. - Engaged members of the Palliative Paramedicine AG, plus additional palliative paramedicine international colleagues, to co-author the study.	- Provided a thematic schema of the role, barriers, enablers and opportunities for improving palliative paramedicine in Australia. - Engaged members of the Palliative Paramedicine AG, plus additional personnel with palliative paramedicine lived experience, to participants in the study.	- Gained consensus on a comprehensive palliative paramedicine framework to standardise best practice in Australia and offer a template for internationally comparable models. - Engaged members of the Palliative Paramedicine AG, plus additional palliative paramedicine international colleagues, to participate in the study. Acknowledged willing experts in the manuscript.

Figure 3: Summary of PhD phases, methods, outputs and outcome

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Chapter 3: Paramedics delivering palliative and end-of-life care in community-based settings: A systematic integrative review with thematic synthesis

The following chapter contains a systematic integrative review of paramedics delivering palliative and end-of-life care in community-based settings. It was published in Palliative Medicine Journal in 2021.

3.1 Citation

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PALLIATIVE MEDICINE

Review Article

Paramedics delivering palliative and end-of-life care in community-based settings: A systematic integrative review with thematic synthesis

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Abstract

Background: There is a growing demand for community palliative care and home-based deaths worldwide. However, gaps remain in this service provision, particularly after-hours. Paramedicine may help to bridge that gap and avoid unwanted hospital admissions, but a systematic overview of paramedics' potential role in palliative and end-of-life care is lacking.

Aim: To review and synthesise the empirical evidence regarding paramedics delivering palliative and end-of-life care in community-based settings.

Design: A systematic integrative review with a thematic synthesis was undertaken in accordance with Whittemore and Knafl's methodology. Prospero: CRD4202119851.

Data sources: MEDLINE, CINAHL, PsycINFO and Scopus databases were searched in August 2020 for primary research articles published in English, with no date limits applied. Articles were screened and reviewed independently by two researchers, and quality appraisal was conducted following the Mixed-Methods Appraisal Tool (2018).

Results: The search retrieved 5985 articles; 23 articles satisfied eligibility criteria, consisting of mixed-methods (n = 5), qualitative (n = 7), quantitative descriptive (n = 8) and quantitative non-randomised studies (n = 3). Through data analysis, three key themes were identified: (1) Broadening the traditional role, (2) Understanding patient wishes and (3) Supporting families.

Conclusions: Paramedics are a highly skilled workforce capable of helping to deliver palliative and end-of-life care to people in their homes and reducing avoidable hospital admissions, particularly for palliative emergencies. Future research should focus on investigating the efficacy of palliative care clinical practice guideline implementation for paramedics, understanding other healthcare professionals' perspectives, and undertaking health economic evaluations of targeted interventions.

Keywords

Palliative care, terminal care, emergency medical services, ambulances, patient transfer, review

What is already known about the topic?

- Global demand for palliative care is increasing and the reliance on exclusively specialist hospital-based care is becoming unsustainable. Community preferences also favour home-based deaths.
- Paramedics are in a unique position to help deliver palliative and end-of-life care in the home, especially after-hours for palliative care emergencies. However, their role is traditionally limited to providing life-sustaining interventions for acute emergencies and conveyance to hospital.
- No overview of the role paramedics play in delivering palliative and end-of-life care in community-based settings currently exists.

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What this paper adds?

- The findings of the review suggest paramedics can play an important role in providing emergency support to patients approaching end-of-life, help facilitate home-based deaths, and reduce avoidable hospital admissions where this is the patient's preference.
- The review identified untimely access to documented wishes, family discordance and the medico-legal ambiguity associated with palliative paramedicine as key barriers preventing paramedics from adopting a palliative approach to care.
- Key enablers highlighted within the review include strengthening communication and support channels with multidisciplinary teams, targeted palliative care training for paramedics, partnering in care with families and palliative care specific clinical practice guidelines to broaden the current scope of practice.

Implications for practice, theory or policy

- This review underscores the opportunities for health services to consider paramedic involvement in integrated models of community palliative care delivery, especially as an adjunct support in palliative emergencies in collaboration with other services.
- Further research developing and evaluating systems to enable paramedics better access to patients documented palliative care plans, targeted palliative care training programmes and palliative care specific clinical practice guidelines is needed.

Introduction

Rationale

Global demand for palliative care is increasing due to an ageing population and the growing prevalence of chronic non-communicable disease, amongst other factors. According to the World Health Organization, approximately 40 million people require palliative care each year.[1] Within Australia, tertiary health services saw a 16.9% increase in palliative care hospitalisations between 2013/14 and 2017/18.[2] However, palliative and end-of-life care being provided exclusively by specialists in hospital settings poses unsustainable costs to health services worldwide.[3] Further, international literature suggests approximately two thirds of people want to die at home.[4]

In order to meet the growing need for palliative care, reduce avoidable hospital admissions and better facilitate community preferences, early delivery and a multidisciplinary approach to palliative care service provision is required.[1] One interface capable of facilitating more home-based deaths is paramedicine. Paramedics are a unique workforce, attending to patients in the community 24-h a day 7 days a week, in the case of an emergency. However, their scope of practice has traditionally been limited to providing life-sustaining interventions for acute emergencies and conveyance to hospital.[5–7] For patients who have a progressive life-limiting condition, an acute hospital admission may not be desired or the best setting in which to deliver appropriate palliative care.

Fortunately, global ambulance services are evolving in response to the growing prevalence of palliative care patients, although through different approaches and at varying speeds. Traditionally within Franco-German ambulance models[8] emergency medicine physicians provide the majority of prehospital care and are supported by paramedics, allowing for the development of specialist prehospital medical palliative care teams in countries such as Germany.[9] In contrast, Anglo-American ambulance models rely on paramedics providing care to patients with medical oversight. However, there is not a strict dichotomy between these two models. Specialised community paramedic roles are emerging in countries following a paramedic-led ambulance approach to facilitate holistic home-based palliative care,[6] and ambulance services world-wide are adopting clinical protocols to guide end-of-life care,[10] albeit in a variable manner. Other researchers have reviewed the attitudes and perceptions of paramedics delivering palliative care in community-based settings,[11] and provided practical strategies to integrate palliative care into prehospital models of care.[12] However, to our knowledge, no attempt has yet been made to review the evidence of palliative paramedicine in community-based settings. Consequently, a systematic integrative review was conducted, including diverse methodologies, to present a wide variety of perspectives on this aspect of care and contribute to future evidence-based practice of palliative paramedicine.[13]

Objectives

This review aimed to systematically synthesise the empirical evidence of palliative paramedicine in community-based settings, answering the following research questions: what (1) is the known scope of practice of paramedics delivering palliative and end-of-life care, (2) are the perspectives of relevant stakeholders involved in paramedics delivering palliative and end-of-life care and (3) are the barriers and enablers experienced by relevant

Table 1. MEDLINE search strategy.

Search term	
#1	emergency medical services/ or emergency medical dispatch/ or 'transportation of patients'/ or ambulance diversion/ or ambulances/
#2	Emergency Medical Technicians/
#3	Patient Transfer/
#4	paramedic*.mp.
#5	ambulance*.mp.
#6	(prehospital or pre-hospital).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
#7	1 or 2 or 3 or 4 or 5 or 6
#8	exp Terminal Care/
#9	Hospices/
#10	Legislation, Medical/
#11	advance care planning/ or advance directives/ or living wills/
#12	Attitude to Death/
#13	bereavement/ or grief/ or disenfranchised grief/
#14	life support care/ or advanced cardiac life support/ or advanced trauma life support care/
#15	Terminally Ill/
#16	(palliative or palliation).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
#17	SPCS.mp.
#18	((advance* or terminal) adj1 (illness* or care or directive*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
#19	(end adj2 life).mp.
#20	(therapeutic* adj1 limit*).mp.
#21	(document* adj2 wish*).mp.
#22	8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
#23	7 and 22

stakeholders when paramedics are delivering palliative and end-of-life care.

Methods

We conducted a systematic integrative review, allowing for inclusion of experimental and non-experimental studies, in accordance with Whittemore and Knafl's[13] methodology. This type of review was chosen to gain a more comprehensive understanding of the role of paramedics delivering palliative and end-of-life care in community-based settings. The review protocol is registered with Prospero (registration number: CRD42021198518) and we adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines.[14]

Search strategy

The preliminary search strategy was defined in June 2020 by one author (MJ), with assistance from a specialist librarian. Refinements were made by the broader research team and the systematic search was performed in August 2020, exploring the phenomenon of paramedics delivering palliative and end-of-life care in community-based settings.

Database searches

Systematic searches of primary research articles published solely in English due to funding constraints were performed in MEDLINE, CINAHL, PsycINFO and Scopus. No publication date range limits were applied in anticipation of the search deriving a small number of articles, given the novel nature of the topic.

The Medline search strategy was performed first, as illustrated in Table 1, and the search profile was adapted for subsequent databases.

References and citations of included papers were additionally checked to ensure no relevant literature was missed.

Eligibility criteria

As illustrated in Table 2, articles were included if they presented empirical studies about paramedics delivering palliative and end-of-life care in community-based settings.

Table 2. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
• English language and earliest records to present • Empirical studies in peer reviewed literature • Full-text available • Participants of any age or gender • Participants include patients, families and health professionals involved in the care provided and stakeholder experience of paramedics delivering palliative and end-of-life care • Palliative and end of life care delivered by paramedics in a prehospital community-based environment for example, home or residential aged care facility	• Languages other than English • Non-empirical studies, editorials, opinion pieces and grey literature • Focus on health professionals other than paramedics delivering palliative and end-of-life care • Palliative and end-of-life care delivered outside of a prehospital community-based environment for example, hospital or hospice • Full-text not available

Study selection

Upon excluding duplicate articles, two members of the research team (MJ and PV) independently screened the remaining titles and abstracts using the Covidence systematic review management software.[15] Full-text articles ($n = 114$) were independently assessed against the inclusion and exclusion criteria by the same team members, with a total of 23 articles identified for data extraction and quality appraisal.

Data extraction, analysis and synthesis

Data analysis and thematic synthesis were conducted by MJ, cross-checked by PV, and finalised by the broader research team. Whittemore and Knafl's[13] methodology was adopted throughout, including (1) data reduction, (2) data display, (3) data comparison and (4) conclusion drawing. Firstly, data were reduced by dividing the studies into sub-groups according to type: qualitative; mixed-methods; quantitative non-randomised; and quantitative descriptive. A study-designed data extraction table was created to simplify data into a manageable framework. The table was piloted on five articles by one author; its rigor was then discussed amongst the broader research team and minor modifications were made to the table.[16] Data were extracted into the table on Excel for the remaining articles by one author, with 20% cross-checked by a second author and 100% interrater agreement achieved. The table displayed information on the author, country, study design, participants, setting, study aims, measures, study outcomes and results, and strengths and weaknesses (Table 3).

As data from quantitative, qualitative and mixed-methods studies were entered into the extraction table, a descriptive summary for data synthesis was necessary.[13] Primary quantitative studies did not meet the assumptions required for meta-analysis and therefore could not be combined statistically.[45] A thematic analysis was undertaken on the qualitative data and a constant data comparison method was employed across the data of all study types. Initially, data from the qualitative studies were coded and compared systematically through an iterative process to identify patterns, themes and relationships between the studies' findings. This coding framework was then applied to the qualitative data of the mixed-methods studies. Themes were compared and contrasted, and higher-order themes were identified that incorporated sub-themes due to interrelated data. Finally, relevant quantitative findings were integrated into the themes in adherence with an integrative synthesis approach,[13] and conclusions were drawn across the entire data set.

Quality appraisal

All 23 studies were appraised for methodological quality by one team member, with 20% cross-checked by a second author and 100% interrater agreement achieved. The Mixed-Methods Quality Appraisal Tool (MMAT) was used to assess the quality of the articles given the integrative nature of the review: qualitative, quantitative and mixed-methods studies could all be appraised using the one tool.[46] Furthermore, a number of mixed-method reviews in the field of palliative care have recently used this tool to assess for quality,[16,47,48] allowing comparability. The MMAT includes two general yes/no questions, followed by five study-specific yes/no questions, resulting in a maximum score of 7. The included studies had scores ranging between 3 and 7, with the majority scoring 6 or 7, thus indicating the inclusion of predominately high-quality studies.

Results

Study characteristics

A total of 23 studies were included in the review, as illustrated in Figure 1 (PRISMA flowchart). The studies derived from Australia ($n = 5$),[25,26,28,32,37] Canada ($n = 2$),[17,21] Finland ($n = 1$),[36] Germany ($n = 4$),[24,38,43,44] the United Kingdom ($n = 5$)[20,22,29,30,31] and the United States ($n = 6$)[27,34,39,40,41,42] between 2009 and 2020. Study methodologies varied and included qualitative ($n = 7$),[17,20,26,29,30,39,42] quantitative non-randomised ($n = 3$),[25,36,44] quantitative descriptive ($n = 8$)[22,24,28,34,38,40,41] and mixed-methods studies

Table 3. Data extraction.

Author (country)	Study design	Participants	Setting	Study aims	Measures	Study outcomes/results	Quality appraisal score	Strengths and weaknesses
Carter et al.[17] (Canada)	Mixed methods study (QUAN + QUAL + QUAN) Evaluating patient, family and paramedic satisfaction of a paramedic capacity building programme, including: – A new palliative care specific clinical practice guideline – An updated database system – Training in palliative care and end-of-life care.	Part A: Patients and families with paramedic palliative and end-of-life care encounters: Patient enrolment survey ($n = 67$) Patient interview ($n = 18$); Age ($X = 78.4$) Part B: Ambulance staff: Pre-intervention ($n = 235$) Post-intervention ($n = 267$)	Two Canadian provincial ambulance services.	To determine the impact of the programme in two parts: Part A: Patient and family satisfaction Part B: Paramedic comfort and confidence with the delivery of palliative care support.	Part A: Study-developed postal surveys and validated semi-structured interview guide modified for the ambulance context.[18] Part B: Validated pre versus post-intervention surveys using Likert scales.[19]	Quantitative: Comfort with providing palliative care without transport improved post intervention ($p \leqslant 0.001$) as well as confidence in palliative care without transport ($p \leqslant 0.001$). Participants strongly agreed that all paramedics should be able to provide basic palliative care. Qualitative: Main themes include: – Fulfilling care wishes – Family/caregiver peace of mind – Feeling prepared for emergencies – Professionalism and compassion of paramedics – 24/7 availability – Relief of symptoms – A plea for programme continuation	6	Strengths: In-depth exploration of multiple key stakeholders' perspectives on the impact of the programme; data saturation achieved. Weaknesses: Small sample size with early divergence of thematic saturation; time lapse between encounter and interview; low-moderate response rate to enrolment survey.
Hoare et al.[20] (UK)	Qualitative interviews ($n = 6$) of ambulance staff involved in the transfer of patients (case-patients) aged more than 65 years to hospital who died within 3 days of admission with either cancer, chronic obstructive pulmonary disease or dementia.	Ambulance staff: Paramedics ($n = 2$) Student paramedics ($n = 3$) Emergency care assistants ($n = 1$)	Large English hospital.	To understand the role of ambulance staff in the admission to hospital of patients close to the end-of-life.	Semi-structured interviews using a study-developed interview guide.	Main themes include: – Limited availability and accessibility of additional care and support in the community – Ambulance staff having limited access to information on the patient and their condition – Perceived ambulance service emphasis on hospital care	7	Strengths: Detailed analysis on the role of ambulance staff transporting patients nearing end-of-life to hospital; case-patient sample reflective of national trends. Weaknesses: Small ambulance staff sample size affecting likelihood of saturation of themes.
Jensen et al.[21] (Canada)	Qualitative focus group interviews ($n = 4$) investigating ambulance staff perspectives of a paramedic capacity-building programme for Extended Care Paramedics, including: – Specialised training in geriatric assessments and management, end-of-life care, primary wound closure techniques and point of care testing – Medical oversight from a dedicated ambulance service online medical physician – Established offline clinical guidelines.	Ambulance staff: ($n = 21$); Age ($X = 41$, SD = 6.93) Extended care paramedics (6) Extended care paramedic oversight physicians (3) Decision makers (5) Paramedics (6) Communication officers (1)	One Canadian provincial ambulance service.	To learn of the experiences of those directly involved in various aspects of the programme: 1. What insights have been gained and lessons learned from the implementation and operation of the programme? 2. What are the experiences of Extended Care Paramedics in particular clinical situations, specifically end of life cases?	Focus groups using a study-developed semi-structured interview guide.	Main themes include: – Programme implementation – Extended Care Paramedic process of care – Communications – End-of-life care	7	Strengths: Focus groups provided exploratory inquiry with interaction among the participants and facilitator. Weaknesses: Small sample size, although representative; potential for sensitive topics to be avoided by individuals in focus group settings.
Kirk et al.[22] (UK)	Quantitative descriptive survey distributed to paramedics across a large geographical area.	Ambulance staff: ($n = 182$); Age ($X = 41$) Entry-level paramedic (93) Senior/specialist paramedic (65) Advanced paramedic (24)	One English ambulance service.	To investigate whether paramedics view end-of-life care as a key part of their role, their confidence in managing this aspect of clinical practice, and the underlying concerns of paramedics when managing end-of-life care.	Validated online survey tool including closed, Likert scale and multiple-choice questions.[23]	The majority of participants agree that end-of-life care is a key part of their role as a paramedic ($n = 141$, 78%). Many feel they need more education and poorly rate current training ($n = 92$, 51%). The majority of paramedics have medium to high confidence when dealing with end-of-life in clinical practice, with length of service and end of life experience being a key contributor. Significant concerns about documentation, litigation and perceived lack of communication between different healthcare services were expressed.	6	Strengths: Comprehensive sample size reflected varied demographics, allowing for analysis variance; piloted instrument. Weaknesses: Observational studies and interviews would gain more in-depth perspectives; non-random sampling; intervariability in staff categories; self-reported data.

(Continued)

Table 3. (Continued)

Author (country)	Study design	Participants	Setting	Study aims	Measures	Study outcomes/results	Quality appraisal score	Strengths and weaknesses
Leibold et al.[24] (Germany)	Quantitative descriptive survey of paramedics across the country.	Ambulance staff: (n = 429); Age (X = 31)	All German ambulance services.	To determine whether a paramedic's decision-making in end-of-life situations is influenced by their religious beliefs, how they decide given the current judicial framework, and how they would decide were there legal certainty.	Study-developed and validated online questionnaire including yes/no interrogatives, Likert scale and open questions.	Religious paramedics would rather hospitalise a patient holding an advance directive than leave them at home (p = 0.036) and think death is less a part of life than the non-religious (p = 0.001).	7	Strengths: Literature review informed questionnaire; pilot phase of questionnaire ensured readability and appropriateness of content. Weaknesses: Reliability and validity were not applied; voluntary participation subject to bias; accurate response rate unknown; self-reported data.
Lord et al.[25] (Australia)	Retrospective cohort study of adult palliative and end-of-life patients receiving treatment from one ambulance service.	Adult patients attended by paramedics: (n = 4348); Age (X = 74)	One Australian state ambulance service.	To describe the incidence and nature of cases attended by paramedics and the care provided where the reason for attendance was associated with a history of palliative care.	Electronic patient care records.	The most common paramedic assessments were 'respiratory' (20.1%), 'pain' (15.8%) and 'deceased' (7.9%); 74.4% were transported, with the most common destination being a hospital (99.5%). Of those with pain as the primary impression, 53.9% received an analgesic and 99.2% were transported following analgesic administration. Resuscitation was attempted in 29.1% of the 337 cases coded as cardiac arrest. Among non-transported cases, paramedics re-attended the patient within 24 h of the previous attendance for 9.6% of the cases.	6	Strengths: State-wide study allowing for broad representation; study design reduces sampling and recall bias; causality can be inferred. Weaknesses: Retrospective data; non-experimental design.
Lord et al.[26] (Australia)	Qualitative focus groups and interviews (n = 32) of paramedics employed by two ambulance services in Australia.	Ambulance staff: (n = 32)	Two Australian state ambulance services	To identify paramedics' knowledge, beliefs and attitudes related to the care of patients requiring palliative care in community settings.	Focus groups and interviews using a study-developed semi-structured interview guide.	Main themes include: – Conflict in care goals – Legal issues – Access to information – Organisational policy and clinical practice guidelines	6	Strengths: Detailed analysis on the perspectives and experiences of paramedics delivering palliative and end-of-life care in the community. Weaknesses: Convenience sampling less optimal because it may have failed to capture important perspectives from difficult to reach paramedics.
McGinley et al.[27] (US)	Mixed methods study (QUAN + QUAL) applying a critical discourse analysis framework.	Ambulance staff: *Survey participants* (n = 239); Age (X = 35) *Interview participants* (n = 48); Age (X = 38)	Five American ambulance services within one state.	To describe how medical orders inform ambulance services' decision-making during emergencies involving people with intellectual disabilities who are nearing end-of-life.	Quantitative data collected through a study-developed cross-sectional survey. Qualitative interviews conducted utilising a study-developed demographic questionnaire and semi-structured interview guide.	Quantitative: 62.7% of participants had treated a person with intellectual disability who had medical orders directing end-of-life care. Qualitative: Main themes include: – Provider familiarity – Organisational processes – Sociocultural context	6	Strengths: Exploratory-descriptive study design employing iterative enquiry from three focal lengths; large sample size. Weaknesses: Purposive sampling open to subject bias; state-based laws not generalisable to an (inter)national context; study does not include the perspectives of people with intellectual disabilities or their caregivers.

(Continued)

Table 3. (Continued)

Author (country)	Study design	Participants	Setting	Study aims	Measures	Study outcomes/results	Quality appraisal score	Strengths and weaknesses
Mott et al.[28] (Australia)	Quantitative descriptive survey of ambulance officers known to have had an interaction with one of the last 50 paediatric palliative care referrals.	Ambulance staff: ($n = 22$)	One Australian state ambulance service.	To explore the experiences and attitudes of ambulance officers in managing paediatric patients with palliative care needs.	Study-developed questionnaire including yes/no interrogatives, option selections, Likert scale and free-text questions.	Many participants felt these cases were challenging, confidence levels varied, and staff counselling services were felt to be relevant by 50%. Ambulance officers were most likely to use correspondence provided by the family from their usual team as a guide for emergency management. 50% of the participants felt patients receiving paediatric palliative care should have a 'not for resuscitation' order. Respondents suggested officer support could be improved through increased patient documentation and promotion of existing officer supports.	3	Strengths: State-wide study allowing for broad representation. Weaknesses: Purposive sampling open to subject and recall bias; small sample size due to low completion rate; self-reported data.
Murphy-Jones and Timmons[29] (UK)	Qualitative interviews ($n = 6$) of active paramedics unknown to the primary author.	Ambulance staff: ($n = 6$)	One English ambulance service.	To explore how paramedics make decisions when asked to transport nursing home residents nearing end-of-life.	Semi-structured interviews using study-developed questions and photo elicitation.	Main themes include: – Challenges in understanding patients' wishes – Evaluating patients' best interests – The influence of others on decision making	7	Strengths: Interviews included photo elicitation, prompting deeper and more insightful reflection; review of recorded data analysis decisions to enhance confirmability and dependability. Weaknesses: Small purposive sample size open to subject and recall bias; recruited from one site limiting transferability.
Patterson et al.[30] (UK)	Qualitative interviews ($n = 10$) of paramedics, extracted from a broader study exploring health and social care professionals' experiences of data recording and sharing practices in end-of-life care.	Ambulance staff: ($n = 10$)	One English ambulance service.	To explore how access and quality of patient information affects the care paramedics provide to patients nearing end-of-life, and their views on a shared electronic record as a means of accessing up-to-date patient information.	Semi-structured interviews informed by a topic guide and revised after each interview to incorporate emerging lines of enquiry.	Main themes include: – Access to information on patients nearing end-of-life – Views on the proposed Electronic Palliative Care Coordination System	7	Strengths: In-depth exploration as part of a larger study considering multiple stakeholders' experiences and perceptions. Weaknesses: Opportunistic sampling strategy; small sample size.
Pease et al.[31] (UK)	Mixed methods study (QUAN+QUAL+QUAN) evaluating paramedics' perceived roles and challenges post-implementation of teaching sessions on: – Serious illness conversation/ communication skills – Symptom control at end-of-life – Shared decision making.	Ambulance staff: Paramedics ($n = 218$) Final year paramedic students ($n = 150$)	Welsh national ambulance service.	To describe the delivery, outcomes and potential impact of a Serious Illness Conversation project on ambulance staff.	Qualitative data collected through participant statements. Quantitative data collected through a study-developed pre- and post-intervention questionnaire using a Likert scale assessing self-confidence, and review of patient care records relating to end-of-life care.	Quantitative: All six communication domains indicate statistically significant improvements in self-assessed confidence in communication domains post-training compared to pre-training ($p < 0.001$). Qualitative: Main themes include: – Ambulance staff role includes communication, support and practical medical care – Difficulty discussing death and dying and managing expectation.	4	Strengths: Exploratory three-stage study design; comprehensive sample size. Weaknesses: Self-rated measures surrogate indicators of outcome; sequential review of patient care records not specific to participants of the training.

(Continued)

Table 3. (Continued)

Author (country)	Study design	Participants	Setting	Study aims	Measures	Study outcomes/results	Quality appraisal score	Strengths and weaknesses
Rogers et al.[32] (Australia)	Mixed methods study (QUAN + QUAL) identifying and measuring paramedics' perspectives.	Ambulance staff: (n = 29); Age (X = 38)	One Australian state ambulance service.	To identify paramedics' perspectives and educational needs regarding palliative care provision; and investigate paramedics' views about death and dying, their awareness of common causes of death in Australia, and opinions as to those for which a palliative approach is appropriate.	Piloted and validated qualitative and quantitative survey tool using Likert scales.[33]	Participants considered palliative care to be strongly focussed on end-of-life care, symptom control and holistic care. Educational needs identified were ethical issues, end-of-life communication and the use of structured patient care pathways. Cancer diagnoses were overrepresented as conditions considered most suitable for palliative care, compared with their frequency as a cause of death. Conditions often experienced in ambulance practice, including heart failure, trauma and cardiac arrhythmias were overestimated in their frequency as causes of death.	7	Strengths: Piloted and validated survey tool. Weaknesses: Low response rate; small sample size; self-reported data.
Stone et al.[34] (US)	Quantitative descriptive survey of paramedics across two states.	Ambulance staff: (n = 236); Age (X = 39)	Two American ambulance services from two states.	To ascertain paramedics' attitudes toward end-of-life situations and their frequency; to measure the frequency of end-of-life encounters; to compare paramedics' preparation for end-of-life care during training; and to compare the importance paramedics place on end-of-life issues.	Validated paper survey tool using multiple choice and Likert scale questions.[35]	Participants perceived end-of-life related issues to be important; however, they do not feel adequately trained in these areas. 95% agreed that prehospital providers should honour advance directives; 59% felt that ambulance staff should honour verbal wishes to limit resuscitation on scene; 95% had questioned whether specific life support interventions were appropriate for terminal patients; and 26% reported having to use their own judgement recently to withhold or end resuscitation in a terminal patient.	4	Strengths: Two-step statistical analysis process. Weaknesses: Convenience sampling strategy; low response rate; small sample size; self-reported data.
Surakka et al.[36] (Finland)	Retrospective cohort study of patients registered for an end-of-life care at home protocol.	Adult patients attended by paramedics: (n = 252) (X = 76.5)	One Finnish ambulance service.	To evaluate a protocol for end-of-life care at home including pre-planned integration of paramedics and end-of-life care wards.	Electronic patient records, paramedic case-forms and death certificates.	Symptom control (38%) and transportation (29%) were the most common reasons for paramedic attendance. Paramedics visited 43% of patients in areas with 24/7 palliative home care services, in contrast to 70% without this provision. 58% of calls were completed out of hours and 31% of cases were resolved at home. Patients were transferred to pre-planned end-of-life care wards in 48% of cases compared to the emergency department in 16% of cases. 54% of patients died in end-of-life care wards where no 24/7 palliative care home service was available, in comparison to 33% where this service was available.	6	Strengths: Province-wide study allowing for broad representation; study design reduces sampling and recall bias; causality can be inferred. Weaknesses: Broader stakeholder opinions and alleviation of symptoms not evaluated.
Swetenham et al.[37] (Australia)	Mixed methods study (QUAN + QUAL) evaluating patient, carer and clinician perspectives of a pilot 24/7 emergency palliative care service programme managed by: – Expert phone advice from the specialist palliative care service; and – Face-to-face assessment and management carried out by Extended Care Paramedics.	Patients attended by Extended Care Paramedics: (n = 40) Interviews: Carers (n = 24) Patients (n = 2) Surveys: Extended Care Paramedics (n = 22)	One Australian state ambulance service and specialist palliative care service.	To explore the effectiveness of a rapid response programme working alliance between an ambulance service and specialist palliative care service, and whether it meets the expectations of patients, carers and clinicians.	Quantitative data collected through call log data, patients records and study-developed surveys. Qualitative data collected through open-ended study-developed interviews.	Quantitative: Forty Extended Care Paramedic palliative care visits were undertaken during the pilot period; 90% of patients who received an after-hours visit remained at their current site of care. Of the remaining 10%, 5% attended an emergency department and the other 5% were directly admitted to a hospice unit. Qualitative: Paramedics reported palliative care work as rewarding and contributing to job satisfaction; however, demanding and sometimes difficult to meet family expectations. Paramedics appreciated the support of the specialist palliative care service's on-call telephone support.	3	Strengths: Broad exploration considering multiple stakeholders' experiences and perceptions. Weaknesses: Data collection methodology lacking detail; qualitative data lacking thematic analysis; divergences and inconsistencies between quantitative and qualitative results not addressed.

(Continued)

Table 3. (Continued)

Author (country)	Study design	Participants	Setting	Study aims	Measures	Study outcomes/results	Quality appraisal score	Strengths and weaknesses
Taghavi et al.[38] (Germany)	Quantitative descriptive survey to ambulance staff across two cities.	Ambulance staff: Paramedic (n = 704) Paramedic in practice (n = 24)	Two German ambulance services from two cities.	To examine paramedics' attitudes towards advance directives and end-of-life care.	Study-developed and validated questionnaire including total number, yes/no interrogatives, multiple choice, open answer and Likert scale questions.	84% of participants considered cardiopulmonary resuscitation in end-of-life patients not useful, and 75% stated they would withhold if legally possible. Participants highlighted more extensive discussion of medico-legal matters concerning advance directives should be included in paramedic training programmes. Participants believed palliative crisis cards should be integrated into end-of-life care.	7	Strengths: High response rate (81%); comprehensive sample size reflected varied demographics; piloted survey tool. Weaknesses: No attempts to follow-up non-respondents.
Waldrop et al.[39] (US)	Qualitative interviews (n = 43) of ambulance staff actively working for the ambulance service who had previously completed a self-administered survey about end-of-life calls.	Ambulance staff: (n = 43); Age (X = 39) Emergency medical technician (n = 10) Paramedic (n = 33)	One American ambulance service.	To explore and describe how prehospital providers assess and manage end-of-life emergency calls.	Interviews using a study-developed interview guide.	Main themes include: – Multifocal assessment – Family responses – Conflicts – Management of the dying process	7	Strengths: Data saturation achieved; rigour maintained by observer and interdisciplinary triangulation, memos and audit trail. Weaknesses: Recruited from one site limiting transferability.
Waldrop et al.[40] (US)	Cross-sectional survey of ambulance staff from one service.	Ambulance staff: (n = 178); Age (X = 34.1) Emergency medical technician (n = 76) Paramedic (n = 102)	One American ambulance service.	To explore ambulance staff's perceptions of end-of-life calls, the signs and symptoms of dying, and medical orders for life sustaining treatment.	Study-developed and validated survey tool, including closed and open-ended questions.	Participants reported frequent calls to nursing homes, 47.8% claiming every shift, and Medical Orders for Life Sustaining Treatment forms were seen infrequently by participants. However, when present wishes about intubation (74%), resuscitation (74%), life-sustaining treatment (72%) and cardiopulmonary resuscitation (70%) were identified. The most frequently observed signs and symptoms of dying were diagnosis (76%), hospice involvement (82%), apnoea (75%), mottling (55%) and shortness of breath (48%).	7	Strengths: High response rate yielding comprehensive sample size; survey tool piloted and validated. Weaknesses: No attempts to follow-up non-respondents; convenience sampling strategy; recruited from one site limiting generalisability.
Waldrop et al.[41] (US)	Cross-sectional survey to ambulance staff in one city.	Ambulance staff: (n = 178); Age (X = 34.1) Emergency medical technician (n = 76) Paramedic (n = 102)	One American ambulance service.	To identify how ambulance staff learned about end-of-life care, their perceived confidence with and perspectives on improved preparation for such calls.	Study-developed survey, including multiple choice and open-ended questions.	Quantitative: Participants reported learning about medical orders through predominately formal means; however, experiential and self-directed learning was also recorded. 93% of participants were confident in upholding a medical order, 87% were confident in interpreting a medical order, and 87% were confident resolving conflict between differing patient and family wishes. Qualitative: Main themes include: – Prehospital provider education – Public education – Educating health care providers on scope of practice – Conflict resolution skills – Handling emotional families – Clarification of transfer protocols	7	Strengths: High response rate yielding comprehensive sample size; in-depth thematic analysis of open-ended questions. Weaknesses: No attempts to follow-up non-respondents; survey tool not piloted or validated; convenience sampling strategy; self-reported data; recruited from one site limiting generalisability.

(Continued)

Table 3. (Continued)

Author (country)	Study design	Participants	Setting	Study aims	Measures	Study outcomes/results	Quality appraisal score	Strengths and weaknesses
Waldrop et al.[42] (US)	Qualitative interviews ($n = 43$) of active ambulance staff in one service.	Ambulance staff: ($n = 43$); Age ($X = 39$) Emergency medical technician ($n = 10$) Paramedic ($n = 33$)	Two American ambulance services within one state.	To explore prehospital providers' perspectives on how the awareness of dying and documentation of end-of-life wishes influence decision-making on emergency calls near the end-of-life.	Interviews using a study-developed interview guide.	Main themes include: – *Awareness of dying wishes and documented* Families were prepared but validation and/or support was needed in the moment. – *Awareness of dying wishes, but undocumented* Ambulance staff must initiate treatment and medical control guidance was needed. – *Unaware of dying wishes and documented* Families shocked and expected ambulance staff could stop the patient from dying. – *Unaware of dying wishes and undocumented* Families were unprepared, uncertain and frantic.	7	Strengths: In-depth exploration and thematic analysis of ambulance staff perspectives; rigour maintained by observer and interdisciplinary triangulation, memos and audit trail. Weaknesses: Recruited from two services, limiting transferability; additional perspectives would validate the experiences.
Wiese et al.[43] (Germany)	Quantitative descriptive survey of ambulance staff across two cities.	Ambulance staff: ($n = 728$)	Two German ambulance services from two cities.	To determine paramedics' understanding of their role in withholding or withdrawing resuscitation and end-of-life treatment of palliative care patients when an advance directive is present.	Study-designed survey including yes/no interrogatives, multiple choice, open and closed Likert scale questions.	Treating terminally ill patients presented an ethical problem for ambulance staff: if they honour a patient's wishes they may violate juridical regulations. Participants stated that improved guidelines regarding end of life decision making and following advance directives is necessary; 46% of participants felt they required a greater level of competence concerning decisions to withhold or withdraw resuscitation in terminally ill patients with advance directives.	7	Strengths: High response rate (81%); comprehensive sample size reflected varied demographics; piloted survey tool. Weaknesses: No attempts to follow-up non-respondents.
Wiese et al.[44] (Germany)	Retrospective cohort study of all prehospital emergency physician-based resuscitations during cardiac arrest situations of out-of-hospital palliative care patients with advanced cancer where no curative therapeutic approach could be applied.	Palliative care patients in cardiac arrest attended by ambulance staff: ($n = 88$)	Four German ambulance services.	To provide information about the strategic and therapeutic approach employed by Emergency Medical Teams in outpatient palliative care patients in cardiac arrest.	Standardised emergency medical documents, including hospital records.	Of the 88 patients analysed, the Emergency Medical Team began resuscitation in 78%. 11% showed a return of spontaneous circulation; however, none survived after 48 h. Advance directives were available in 43% of the cases.	6	Strengths: Study design reduces sampling and recall bias. Weaknesses: Data not generalisable beyond the German physician-based ambulance service model of care; retrospective data; non-experimental design.

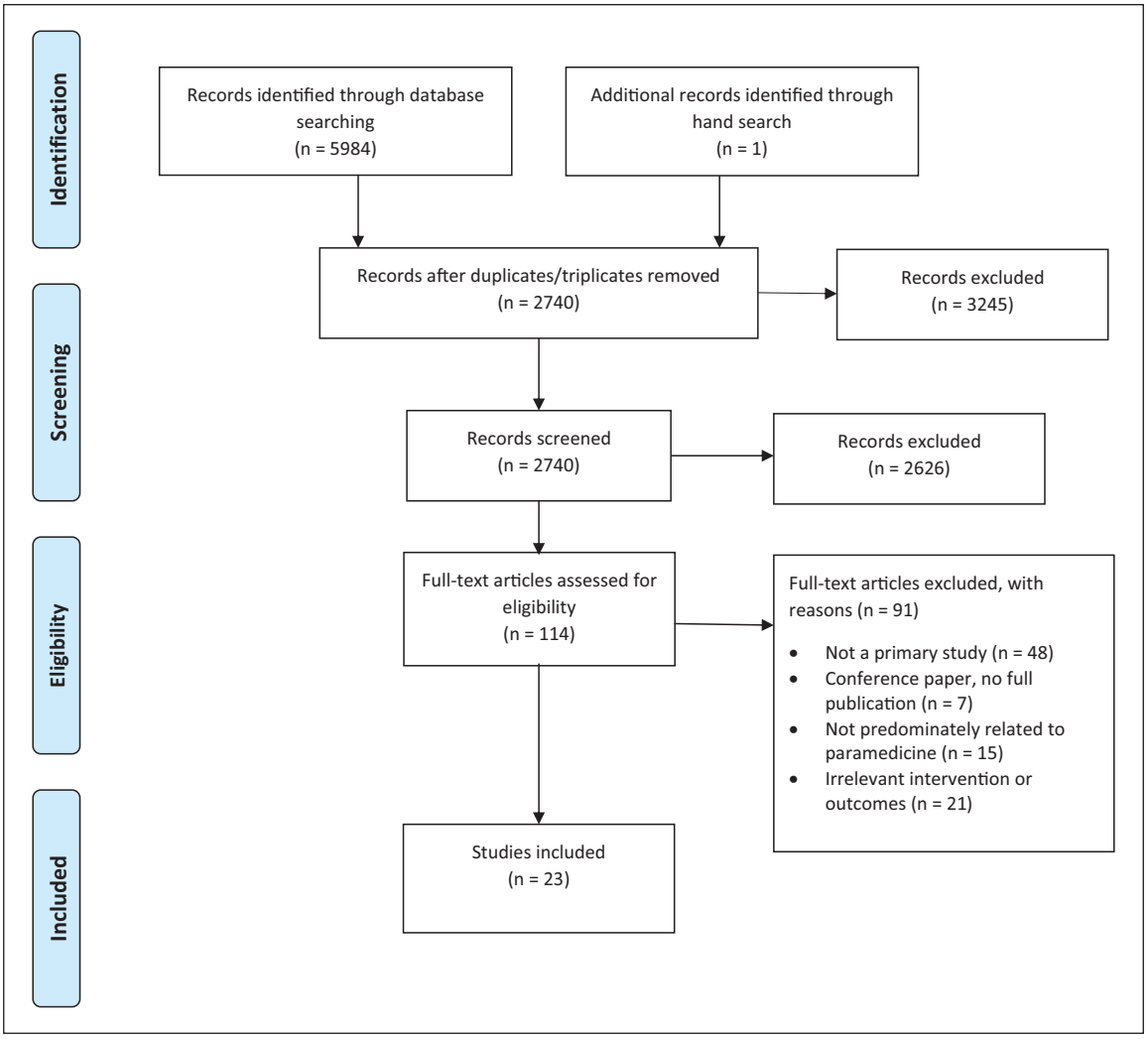

Figure 1. PRISMA flowchart.

(*n* = 5).[17,27,31,32,37] Sample sizes of the included studies were between 5 and 4348 participants; the majority of participants were ambulance staff (*n* = 20),[17,20–22,24,26–32,34,37–43] as well as patients (*n* = 4)[25,36,37,44] and family members (*n* = 2).[17,37]

Each study broadly investigated the role of paramedics delivering palliative and end-of-life care in community-based settings. Studies were performed mainly in ambulance services (*n* = 21).[17,21,22,24–32,34,36,38–44] However, one study took place in a hospital despite being focussed on community-delivery of care,[20] and another in an ambulance service partnering with a specialist palliative care service.[37] Four studies investigated the impact of palliative and end-of-life care training and education programmes,[17,21,31,37] two studies considered palliative care patient hospital admissions,[20,29] nine studies examined perceptions and attitudes towards palliative and end-of-life care,[22,24,26,28,32,34,39–41] three studies observed the nature of palliative care cases attended by paramedics[25,36,44] and five studies explored the role of medical orders and documentation on clinical decision making.[27,30,38,42,43]

Main findings and key themes

Thematic analysis of the 23 included studies resulted in the following three main themes: (1) Broadening the traditional role, (2) Understanding patient wishes and (3) Supporting families. Each main theme is supported by sub-themes, as illustrated in Figure 2. Exemplar quotes from either original study participants or authors' text were extracted to illustrate each theme.

Broadening the traditional role

All but one of the included studies explored the concept of broadening a paramedic's role beyond the traditional scope.[17,20–22,24–32,34,36–41,43,44] Seventeen recognised the

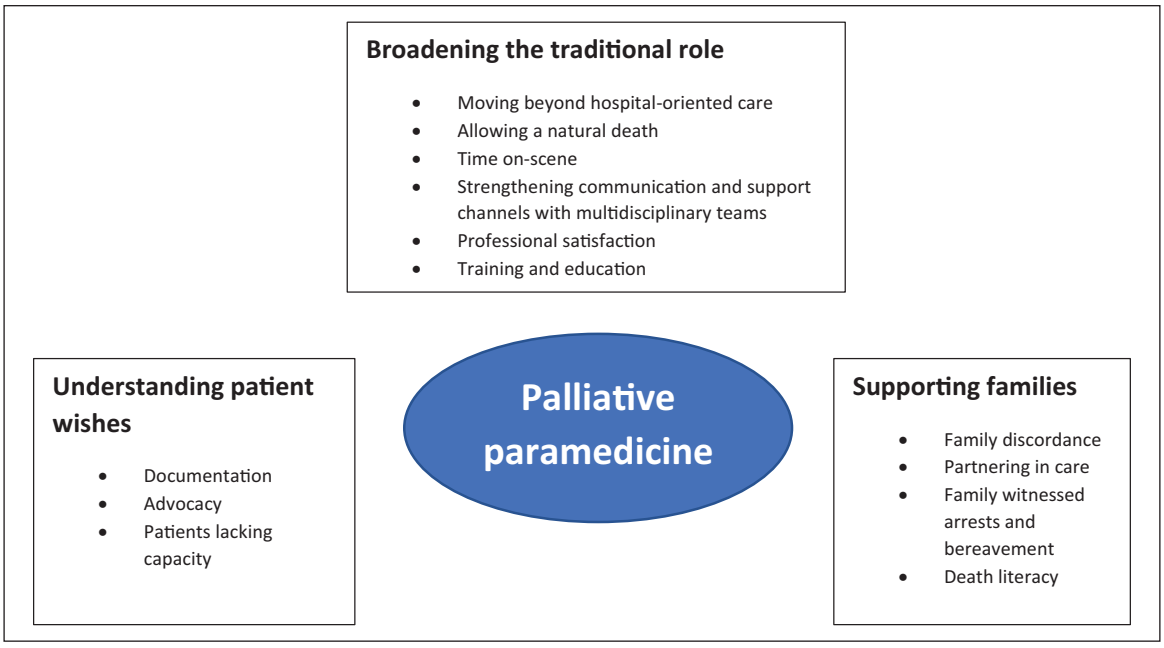

Figure 2. Palliative paramedicine.

multidimensional role paramedics play in providing care to patients nearing end-of-life, highlighting a strong desire amongst ambulance staff, family members and patients alike for paramedics to refocus their attention on holistic home-based management of palliative symptoms instead of hospital conveyance.[20–22,24–29,31,32,36–39,41,43,44] One study called for a 'change in practice, from quickly treating and transporting patients who are so acutely unwell, to remaining on-scene and supporting them through the dying process'.[21] However, another study recognised paramedics require specialised skills to successfully navigate the difficult and often uncertain circumstances associated with end-of-life care, including clinical confidence, an authoritative stance, rapid assessment, clear decision-making and strong communication skills.[41]

According to a study investigating ambulance staff's perceptions of end-of-life calls, the most frequently encountered symptoms of a dying patient include shortness of breath, dysphagia, unmanaged pain, and intractable nausea and vomiting, which are manageable for paramedics within the community.[40] These findings were supported by a retrospective cohort study evaluating paramedic attendance of patients with an end-of-life protocol.[36] However, despite many participants expressing concern over the level of suffering a palliative patient endures when undergoing life-prolonging treatment and transportation to hospital, four studies highlighted professional repercussions and fear of litigation as major barriers affecting a paramedic's ability to move beyond hospital-oriented care.[20,26,27,29] Other studies explored this further, recognising the ethical dilemma and apprehension paramedics face when resuscitating a palliative care patient – a default procedure in many clinical practice guidelines – and expressed a strong desire to facilitate natural death despite often lacking the legal latitude.[24,34,38] One participant from a study investigating paramedics' decision making during end-of-life emergencies involving people with intellectual disabilities proclaimed, 'we're doing lifesaving efforts because we're following the law instead of what is ethical [and] morally right (paramedic)'.[27] Another study quantified the poor outcomes associated with prehospital end-of-life cardiopulmonary resuscitation, acknowledging only 2% of palliative patients survived following hospital discharge.[25]

Comparatively, 21 studies highlighted enabling factors for broadening the traditional paramedic role, including increasing time on-scene,[21,26,37] strengthening communication and support channels with multidisciplinary teams,[17,20–22,24–29,31,36,37,40,41,43,44] and expanding palliative care training and education offerings to paramedics.[17,21,22,24–26,28,30–32,34,38–41] Notably, in one study hospital-based death was reported for 54% of 252 patients in areas where paramedics did not have access to 24/7 palliative home care services, in comparison to 33% in areas where these services were available.[36] Paramedic length of service and end-of-life experience appeared to be other key factors facilitating paramedic confidence to treat a palliative patient.[22]

An Australian study piloted an educational programme for extended care paramedics and connected them with a specialist palliative care service, resulting in the establishment of a collective 24/7 emergency response to palliative patients in the community.[37] This initiative fostered a strong mutual respect between the two clinical services, evidenced by ongoing collaborative training sessions and inter-professional

teamwork. As a result, 90% of patients receiving the after-hours care remained at their home, avoiding hospitalisation.[37] Other studies supported these findings, acknowledging a change in paramedic scope of practice to enable better management of end-of-life patients required focussed educational interventions,[21,22,25,26,28,31,34,38–41,43,44] improved access to equipment and anticipatory medications,[30,31] strong linkages to palliative care specialist teams,[22,24,25,27,28,31,37,39] and end-of-life care clinical practice guidelines to standardise practice.[22,26,28,36]

Lord et al.'s 2012 study reported on the limiting nature of existing clinical practice guidelines, highlighting '99% of the drugs we administer you need to take [the patient] to hospital. There is no "treat and release" (paramedic)'. Another study evaluated the use of a paramedic end-of-life protocol, which aimed to extend the role and scope of practice for paramedics managing palliative patients at home.[36] Within this study, 56% of patients required an unscheduled transfer, of whom only 14% were transported to the emergency department.[36] Comparatively, another study lacking such a protocol required an unscheduled transfer for 74% of the patients, of whom 99% went to the emergency department.[25] Equipping paramedics with the skills and resources to deliver effective palliative care also results in professional satisfaction, with participants from three studies remarking on the rewarding nature of providing good end-of-life care to patients and their families.[17,32,37]

Understanding patient wishes

Seventeen studies reported on understanding patient wishes as paramount to paramedics providing quality palliative care in community settings.[20–22,24,26,27,29–31,34,38–42] As described by one study, central to this concept is the paramedic's role as an advocate, upholding a patient's dignity, respect and goals of care at all times.[31] Legible documentation that clearly outlines a patient's preferences was highlighted as another key facilitator for paramedics.

However, a study exploring the experiences and attitudes of paramedics managing paediatric patients with palliative care needs highlighted that in participants' experience most emergency care plans for this population do not include intervention limitations, such as 'No cardiopulmonary resuscitation (No CPR) orders'.[28] This finding conflicted with the opinion of most participants: more than half expressed a view that all paediatric palliative care patients should have a 'No CPR order' in place to avoid the need for paramedics to provide distressing and potentially futile interventions to this vulnerable group. This common opinion amongst paramedics diverges from best practice family centred paediatric palliative care, whereby medical teams rarely implement a 'No CPR' order against parental wishes and highlights the need for specialist education and training for paramedics in this complex area of palliative care.

Field-based interpretation of documented wishes were cited by six studies as a source of difficulty and confusion amongst paramedics delivering palliative care.[21,22,24,26,28,41] One study acknowledged documentation is often completed before a medical crisis rather than during an end-of-life emergency.[42] These processes may precipitate irrational planning, such as a patient documenting home-based death as their preference, which the family and patient may later be unable to tolerate or facilitate. In circumstances where aggressive care plans are in place one study reported on the notion of 'flipping the plan', whereby a paramedic revaluates the care plan on-the-spot and initiates a palliative approach in consultation with the family and clinical back-up.[21]

Accessibility issues were cited by nine studies as another key barrier to fulfilling documented patient wishes.[20–22,26,27,29,30,34,39] These studies recognised the prominence of incomplete and illegible documents, including one study reporting 'nearly half of the participants have been unable to determine the authenticity of a written or verbal advance directive to withhold or withdraw interventions in the field'.[34] Four studies remarked on the large number of palliative patients without documented wishes who often encounter otherwise avoidable hospital admissions.[20,22,27,30,44]

Untimely access to documented wishes was reported as a prohibitive factor for paramedics seeking to understand patient wishes, leading many paramedics to initiate invasive treatment pathways and transportation to hospital.[20,22,26,30,39,44] However, electronic health records were investigated by one study as an effective means for paramedics to access up-to-date patient information if relevant documentation was embedded, community palliative care team details were included and remote accessibility was supported by strong WIFI or telephone signal capability.[30]

Patients lacking decision-making capacity was reported in four studies,[27,29,39,42] highlighting the importance for paramedics identifying a proxy decision maker or legally appointed guardian in these circumstances. However, one study emphasised the legal duty of paramedics to honour patients' rights to self-determination when they have capacity.[39]

Finally, religiosity was reported to influence a paramedic's interpretation of documentation and decision making. According to one study investigating this factor, paramedics considering themselves religious would rather hospitalise a patient holding a legally binding advance directive than leave them at home when compared to non-religious paramedics.[24]

Supporting families

Families were a prominent theme in fourteen of the included studies,[17,21,22,26,27,29,31,34,37,39–42] and partnering in care was often considered an integral consideration for paramedics

delivering palliative and end-of-life care.[17,21,22,27,31,34,37,40,42] One study highlighted the importance of conducting multifocal assessments that include family relations when reviewing a palliative patient, allowing paramedics to explore the influence of family dynamics on the patient's wellbeing and establish holistic pathways of care.[39] This concept was supported by five other studies, recognising families are often key decision makers in end-of-life situations and paramedics must establish a strong rapport to facilitate supported decision making.[17,21,22,27,39,42]

Interpersonal skills were highlighted as another key attribute of paramedics delivering effective palliative and end-of-life care: five studies recognised a paramedic's clear communication of care options with families could achieve better outcomes for the patient, reduce avoidable hospitalisations and prevent unwanted resuscitation where possible.[21,31,34,39,42] Another study reported the strong interrelationship between person-centred care and family guidance, noting family members felt a peace of mind when paramedics were strong communicators and could respect the patient's goals of care, supporting families at home if a palliative crisis arose.[17]

In contrast, family discordance was reported by nine studies as a significant barrier to paramedic practice of palliative and end-of-life care.[22,26,29,31,37,39–42] More than half the participants in one study raised concerns over handling conflict between patients and family members, especially when there were inconsistent expectations of outcomes.[22] This comment was supported by three other studies recounting families calling ambulance teams to stop the dying process of their loved one, despite a palliative diagnosis and pathway already existing.[31,39,42] In response to conflict, a study exploring paramedics' decision making around transporting nursing home residents nearing end-of-life emphasised, 'discord between individuals' competing interests and that of the families (was) a process of negotiation'.[29]

Family-witnessed cardiac arrests were reported as another significant challenge for paramedics responding to patients nearing end-of-life.[37,39,40,42,44] One study described the emotional intensity and volatility of a palliative patient arresting as, 'what might be considered routine in Emergency Medical Services' but 'the worst emergency in the world for the family'.[39] Four studies recognised psychosocial support as a critical component of a paramedic's role in supporting end-of-life discussions and facilitating bereavement.[37,39,41,42]

Finally, five studies reported a greater need for patient and family death literacy to better facilitate a paramedic's ability to provide palliative and end-of-life care in the community.[22,26,39,41,42] A study exploring paramedics' perspectives on how awareness of dying and documentation of end-of-life wishes influenced decision-making on emergency calls, concluded that families must be educated beyond medical decision-making to also comprehend the dying process, advance care planning and legal issues arising from documented medical orders.[42]

Discussion

This systematic integrative review presents an overview of the literature on paramedics delivering palliative and end-of-life care in community-based settings. Key themes to emerge from the synthesis of studies include broadening the traditional role, understanding patient wishes and supporting families.

From our findings, paramedics consider palliative and end-of-life care an important and increasingly prevalent component of their scope of practice. This notion is supported by the World Health Organisation, which asserts specialist palliative care alone is insufficient to fulfil the growing demand and instead, requires an integrated approach from a multitude of clinical disciplines.[1] However, certain barriers exist which hinder a paramedic's ability to provide optimal palliative care. Most notably, it has been emphasised that paramedic practice should no longer be constrained by traditional models of hospital-oriented care, and communication and support channels with multidisciplinary palliative care teams must be strengthened to improve paramedic end-of-life care capacity.

Palliative paramedicine should not replace existing specialist community palliative care teams in providing palliative care to community-based patients. Rather, the findings of this review position the role of a paramedic delivering palliative and end-of-life care as an adjunct service, especially after-hours, to existing community palliative care teams. Paramedics act as rapid responders at the patient's residence, providing appropriate care when a palliative emergency arises ideally with back-up phone support from a suitable medical practitioner or palliative care service. Patterson et al.'s[30] study piloted a programme where paramedics had access to medical oversight from a dedicated ambulance service online medical physician at all times. Establishing liaison points like this could act as a key enabler in future palliative paramedicine practice, offering paramedics greater confidence and certainty to treat palliative patients during out-of-hours calls with the reassurance of multidisciplinary back-up.

Targeted palliative care education and training for paramedics was another key enabler identified in the review for improving paramedics' capacity to deliver palliative and end-of-life care in the community. Paramedics frequently witness patients dying in their homes. However, findings from a 2021 study recognise existing education and system resources have largely failed to provide paramedics with the necessary tools to provide grief support to family members and others who are suddenly bereaved following a palliative emergency.[49] Increasing paramedics' comfort and capacity for providing grief support, in addition to other core palliative care skills, will require an array

of educational methodologies. Innovative models that focus on enabling paramedics to broaden their role as emergency clinicians providing community-based palliative and end-of-life care are already emerging. Some of these include educational partnerships with grief experts and other health professionals specialising in palliative care,[50] as well as clinical placements for health professionals in palliative care services.[51] These types of initiatives would need to be broadly integrated across ambulance service training programmes to better equip paramedics to deliver palliative and end-of-life care in the community.

Establishing a patient's goals of care is regarded as a central component of best-practice palliative care,[52] and documented wishes were identified as a key enabler for paramedics to facilitate palliative care pathways in community-based settings. However, paramedics face ongoing difficulties in accessing, interpreting and implementing medical wishes, particularly when family discordance is apparent. Electronic palliative care coordination systems were proposed by one study as a potential solution. Providing paramedics with point of care access to an integrated medical record that is used across the health system for a particular district, including documentation about a patient's palliative care plans where applicable, could significantly reduce documentation accessibility issues for paramedics. Further, such initiatives may foster stronger communication channels between ambulance services and other healthcare providers.

Overwhelmingly, participants wanted to facilitate a natural death for palliative patients and avoid aggressive pathways of care where possible. Accordingly, this requires skilled communication from paramedics to negotiate palliative approaches and alternative care trajectories with patients and their families. Fear of litigation is a major barrier preventing paramedics from pursuing a palliative pathway, especially when avoiding hospitalisation in favour of a home-based death for patients with no clear documentation. End-of-life care clinical practice guidelines were identified as a key enabler to standardising practice for paramedics, in addition to minimising the existing medico-legal ambiguity associated with paramedics' provision of palliative care. These findings are supported by broader literature highlighting the clinical protocol-driven nature of paramedic practice.[5,12,53]

Paramedic autonomy of practice was also explored within the included studies. Stone et al.'s[34] study reported 26% of paramedic participants exercised their own judgement to withhold or end resuscitation on a terminal patient in recent times. This study raises the important question: how do paramedics balance individual judgement with clinical practice guideline adherence in precarious end-of-life situations? In these circumstances clinical back-up from ambulance appointed medical physicians could again offer paramedics greater certainty to adopt a palliative approach to care.

Importantly, none of the included studies investigated the efficacy of implementing a palliative care clinical practice guideline on paramedic scope of practice or patient outcomes. Furthermore, no study quantified the economic cost of their intervention. Nor were perspectives of other health professionals on the role of paramedics delivering palliative and end-of-life care investigated in any of the included studies. Given the significant investment required to upskill paramedics to deliver best-practice palliative and end-of-life care, in addition to the need to better integrate multidisciplinary approaches to palliative paramedicine, clinical practice guideline implementation studies, broader healthcare professional perspective analysis and health economic evaluations are warranted, and this highlights a current gap in empirical research on the topic.

Strengths and limitations

A key strength of this review was its systematic approach to identifying and synthesising empirical studies. The review was rigorously carried out, including a search of four databases and a comprehensive narrative synthesis of themes. Two independent researchers conducted the screening, data extraction and quality appraisal of studies, therefore reducing subjective selection bias. Some limitations were also present. Some of the qualitative studies were based on small sample sizes, which increased the risk of sample bias and reduced the likelihood of saturation of themes. Furthermore, only non-experimental studies were retrieved, despite the integrative approach. However, most of the included studies were considered of high quality, and the risk of any studies being overlooked was minimised due to no date limitations being applied to the search strategy.

Conclusion

Integrating palliative and end-of-life care into the provision of paramedic practice has gained considerable global attention in recent years. Overall, this review demonstrates the important role paramedics can play in facilitating home-based death and reducing avoidable hospital admissions. The known scope of palliative paramedicine was established, barriers and enablers of practice identified, and the perspectives of multiple stakeholders explored to reveal three key themes: broadening the traditional role, understanding patient wishes and supporting families.

Our findings have novel implications for a multitude of stakeholders. Paramedics are a highly skilled workforce capable of filling a gap in palliative and end-of-life care provision to people in their homes, especially after-hours for palliative emergencies when other community palliative care services are unavailable. However, a multi-faceted

approach to palliative paramedicine is needed to enable optimal care. This review will be helpful to policy makers when developing models of integration between palliative care services. If they have not done so already, ambulance services should broaden their clinical practice to include palliative care specific guidelines, accompanied by education and practical training addressing the complexities and legalities of end-of-life care. Finally, palliative care researchers have scope to investigate wider health professional perspectives on the paramedic's role in palliative care, as well as the efficacy and cost-effectiveness of targeted quality improvement programmes.

Authorship contributions

The search strategy was developed by MJ, PV, JC and PB in consultation with a specialist librarian. MJ carried out the search, and together with PV, screened the articles. MJ performed the data extraction and quality appraisal, which was cross-checked by PV. MJ conducted the thematic analysis, which was cross-checked by PV, and drafted the manuscript. All authors critically revised the manuscript, making substantial contributions and approving the final version.

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Chapter 4: Palliative paramedicine: Comparing clinical practice through guideline quality appraisal and qualitative content analysis

The following chapter contains a comparative quality appraisal and content analysis of five Australian and three international palliative paramedicine clinical practice guidelines. It was published in Palliative Medicine Journal in 2022.

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Abstract

Background: Palliative care is an emerging scope of practice for paramedicine. The COVID-19 pandemic has highlighted the opportunity for emergency settings to deliver palliative and end-of-life care to patients wishing to avoid intensive life-sustaining treatment. However, a gap remains in understanding the scope and limitations of current ambulance services' approach to palliative and end-of-life care.

Aim: To examine the quality and content of existing Australian palliative paramedicine guidelines with a sample of guidelines from comparable Anglo-American ambulance services.

Design: We appraised guideline quality using the AGREE II instrument and employed a collaborative qualitative approach to analyse the content of the guidelines.

Data sources: Eight palliative care ambulance service clinical practice guidelines (five Australian; one New Zealand; one Canadian; one United Kingdom).

Results: None of the guidelines were recommended by both appraisers for use based on the outcomes of all AGREE II evaluations. Scaled individual domain percentage scores varied across the guidelines: scope and purpose (8%–92%), stakeholder involvement (14%–53%), rigour of development (0%–20%), clarity of presentation (39%–92%), applicability (2%–38%) and editorial independence (0%–38%). Six themes were developed from the content analysis: (1) audience and approach; (2) communication is key; (3) assessing and managing symptoms; (4) looking beyond pharmaceuticals; (5) seeking support; and (6) care after death.

Conclusions: It is important that ambulance services' palliative and end-of-life care guidelines are evidence-based and fit for purpose. Future research should explore the experiences and perspectives of key palliative paramedicine stakeholders. Future guidelines should consider emerging evidence and be methodologically guided by AGREE II criteria.

Keywords

Palliative care, terminal care, paramedic, emergency medical services, policy, qualitative

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What is already known about the topic?

- Palliative paramedicine is an emerging scope of practice. Community-based ambulance services are a widely unharnessed asset capable of facilitating home-based care to patients with life-limiting illnesses, particularly after-hours.
- Global ambulance services have developed specialist roles capable of delivering palliative care. However, the broader paramedic community requires the skills to take a generalist palliative approach to care where appropriate.
- Palliative care guidelines are a key enabler for standardising paramedic practice, yet a gap remains in understanding their prevailing scope and limitations.

What this paper adds?

- The findings of this study suggest ambulance guidelines are shifting away from protocol driven paramedic practice to broader clinical models, calling on the discretion and decision-making skills of paramedics instead of fixed algorithms.
- The study identified the prevalence of clinical back-up pathways across all the included guidelines, recognising the developing nature of palliative paramedicine and need for multidisciplinary approaches to care.
- The overall lack of content related to communication skills and care after death underscores a significant gap in current clinical practice.

Implications for practice, theory, or policy

- This study highlights the opportunity to employ more robust methodological approaches to developing future best practice palliative paramedicine guidelines and shape future practice on integrated models of care.
- Future research could investigate broader stakeholders' perspectives to better inform paramedicine practice related to care after death and translate the palliative care skills of specialist paramedics across to the generalist paramedic workforce.

Introduction

Palliative care is an emerging scope of practice for paramedicine, a clinical discipline traditionally associated with emergency treatment and transport of patients to tertiary facilities for further care.[1] The World Health Organization (WHO) recognises that high quality and equitable access to palliative care requires an integrated multidisciplinary approach[2] and community-based ambulance services are a widely unharnessed asset capable of facilitating home-based care to patients with life-limiting illnesses,[3] particularly after hours. The COVID-19 pandemic has highlighted the perpetual challenges global health care systems face to sustainably care for ageing populations with end-of-life needs[4–6] and the opportunity for emergency settings to deliver palliative and end-of-life care to patients wishing to avoid intensive life-sustaining treatment and transport to hospital.[7] Furthermore, international community preferences to die at home are increasing,[8,9] resulting in a greater need for paramedics to provide palliative and end-of-life care in community-based settings and deviate away from long-established assumptions of needing to transport all patients to hospital.[10,11]

Within an Australian context, evidence indicates a higher need for ambulance response at the end of a palliative care patient's life.[12] Despite this, all national, state and territory level palliative care strategies fail to address the role paramedics play in delivering palliative and end-of-life care in communities.[12,13] Globally, ambulance services have developed specialised roles capable of delivering palliative and end-of-life care, such as Extended Care Paramedics,[14] to mirror the pioneering success of Canada's community paramedicine model.[15] However, these roles will not suffice the growing demand for palliative paramedicine alone and, instead, the broader paramedic community requires the skills to take a palliative approach to care for patients with end-of-life needs.[16]

A recent systematic review identified end-of-life care Clinical Practice Guidelines (guidelines) as a key enabler to standardising palliative care practice for paramedics.[17] The WHO also recognises that palliative care guidelines vastly improve the effectiveness of palliative care service delivery at the point of care.[2] International literature suggests paramedics have expressed a strong desire to support palliative care patients in the community[18–24]; however, they lack guidelines for managing these types of patients,[20,25] particularly those wishing to remain and die at home.[26] Furthermore, although it is well established internationally that paramedics have been traditionally protocol driven,[3] in many jurisdictions there is little or no option for variation and there remains a gap in understanding the prevailing scope and limitations of ambulance services' approach to palliative care. This study aimed to examine the quality and content of existing Australian palliative paramedicine guidelines with a sample of guidelines from comparable Anglo-American ambulance services.[27]

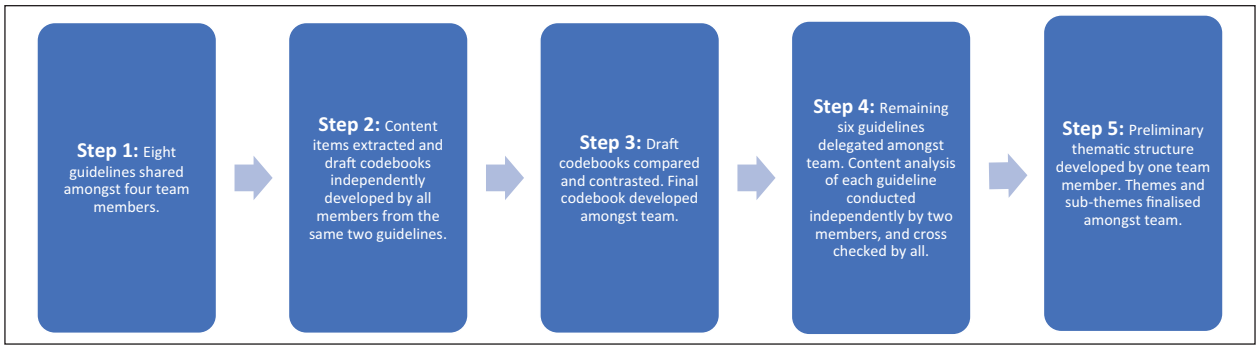

Figure 1. Content analysis process.

Methods

Design and approach

This study consisted of two components: (1) critically analysing the content of the guidelines employing a collaborative qualitative approach,[28,29] and (2) appraising their methodological quality using a validated instrument.[30] The Standards for Reporting Qualitative Research (SRQR) criteria guided the conduct and reporting of the methods and results.[31]

Data collection

Guidelines were collected in March 2021. Representatives from all eight Australian ambulance services were invited to put forward their respective palliative and/or end-of-life guidelines for inclusion in this study. In discussion with the international authorship team, a sample of guidelines were also sourced from countries with Anglo-American ambulance services[27] the team determined comparable to current Australian paramedic practice. This included New Zealand (NZ), the United Kingdom (UK) and Canada.

NZ has a single national ambulance sector collection of guidelines, including one specific to end-of-life. The UK's Joint Royal College Ambulance Liaison Committee developed a national end-of-life care guideline adapted from many locally derived protocols. One Canadian service was selected to reflect contemporary best practice derived from the findings of a recently implemented palliative paramedicine quality improvement programme.[15] However, variation in palliative paramedicine practice is apparent across Canada and it was acknowledged amongst the team this one service may not reflect all.

Data extraction and analysis

The content analysis process is outlined in Figure 1. Authors were not blinded to guideline origin, as they were already familiar with them from clinical practice. A manual collaborative content analysis using Word and Excel was conducted to identify key themes and sub-themes in the data following a four-step process: (1) establishing candidate content items, (2) developing the codebook and pilot testing, (3) undertaking collaborative coding; and (4) reviewing coding and finalising thematic analysis.[29] Four authors (MJ, paramedicine academic; MB, professor and palliative care physician; NA, emergency nurse and academic; and DM, paramedic and ambulance service clinical services manager) independently coded the same two guidelines, each constructing a draft codebook of candidate content items and sub-items and an audit trail. The codebooks were compared, with oversight from JC (professor and palliative care physician) and, upon reaching consensus, a data extraction form was devised and piloted on the same two guidelines. The remaining six guidelines were then delegated amongst MJ, MB, NA and DM and independently conducted by two members of the team, then cross checked by all four members. Each content sub-item was coded as: comprehensively addressed (yes), partially addressed (partial) or missing (no). MJ reviewed the coding for each guideline, made numerical counts for each sub-item (Table 3) and developed a preliminary thematic structure of the results through inductive coding. The team met to review and gain consensus on the thematic structure.

Quality appraisal

The methodological quality of each guideline was assessed using the validated Appraisal of Guidelines for Research and Evaluation (AGREE) II instrument, comprising six domains: scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability and editorial independence.[30] As per the manual, two authors independently conducted the appraisal: PB, an ambulance service medical director and emergency physician and LP, a critical care paramedic and ambulance service director of clinical policy. MJ coordinated the appraisal and resolved discrepancies. Both appraisers had previous experience using the AGREE II instrument for appraisal of ambulance guidelines.[32] The appraisers used the online My AGREE PLUS platform, for 23 items across the six domains employing a seven-point Likert scale to strongly

Table 1. Included guidelines.

Region, country	Ambulance service	Guideline, version, year
Victoria, Australia[34]	Ambulance Victoria	Palliative Care Clinical Practice Guideline A0712, version 1, 2016
New South Wales, Australia[33]	New South Wales Ambulance	Palliative Care Protocol S9, version 1, 2020
Queensland, Australia[35]	Queensland Ambulance Service	Other/Palliative Care Clinical Practice Guideline 0417, version 1, 2017
Northern Territory, Australia[36]	St John Ambulance Northern Territory	Palliative Care Patients Clinical Practice Guideline, version 2.3, 2013
South Australia, Australia[37]	South Australian Ambulance Service	Extended Care Paramedic Clinical Pathway Palliative Care, version 2, 2017
New Zealand[38]	St John New Zealand National Service	End of Life Care Clinical Procedure and Guideline 1.13, version 1, 2019
Ontario, Canada[40]	County of Renfrew Paramedic Service	Community Paramedic Palliative Care Booklet, version 2, 2021
United Kingdom[39]	Joint Royal Colleges Ambulance Liaison Committee	End of Life Care General Guidance, version 1, 2019

YwM: Yes with modifications.

disagree (1) or strongly agree (7) the item was met. Results were then compared and appraisers modified their score based on the discussion, in accordance with AGREE II methodology. An overall average appraisal score, scaled domain percentages and an overall percentage rating of quality were calculated for each guideline (see Table2 for methodology and results). Based on these scores, a recommendation of whether to use, use with modifications or not use each guideline was made. As AGREE II assesses the methodological quality of development processes and not content, coders additionally responded to the following statement for each guideline: 'I would recommend this guideline for use' (based on my knowledge of the clinical validity of the guideline recommendations).

Results

Guideline characteristics

A total of eight guidelines published between 2013 and 2021 were included in the study (Table 1). Five guidelines were Australian,[33–37] one NZ,[38] one from the UK[39] and one Canadian.[40]

Quality assessment

Table 2 summarises the AGREE II appraisal of included guidelines. No guideline was recommended without amendments by both appraisers for use based on AGREE II evaluations; however, Canada's guideline was recommended for use by both based on their knowledge of its clinical validity. This guideline also scored highest (83%) in the overall summary of domains 1–6. Scaled individual domain percentage scores varied significantly across the guidelines: scope and purpose (8%–92%), stakeholder involvement (14%–53%), rigour of development (0%–20%), clarity of presentation (39%–92%), applicability (2%–38%) and editorial independence (0%–38%).

Main findings and key themes

Extracted data are included in Tables 2 and 3. Six themes and sub-themes, as illustrated in Figure 2, emerged from the content analysis data: (1) audience and approach; (2) communication is key; (3) assessing and managing symptoms; (4) looking beyond pharmaceuticals; (5) seeking support; and (6) care after death.

Audience and approach

Each guideline had substantial differences in stylistic approach, which could be categorised into three general types. New South Wales (NSW),[33] South Australia (SA)[37] and Victoria's (VIC)[34] guidelines were structured as protocols, comprising prescriptive direction and often accompanied by a flow-chart.

> *"In cases where there is no person responsible and/or paramedics are unsure about the patient's treatment goals and the patient is unable to communicate, paramedics should commence treatment per specific protocol(s) until additional information becomes available".*[33]

In contrast, Queensland (QLD),[35] the Northern Territory (NT)[36] and NZ[38] guidelines adhered to a broader framework, offering guidance rather than instruction.

> *"Paramedics may administer drugs and may recommend the patient not be transported; providing this is consistent with ongoing symptom control and they make contact with the patient's palliative care team".*[36]

Table 2. Quality appraisal using the AGREE II instrument.

Guideline	Domain score (%)						Overall score, Domains 1–6 (%)	Recommendation for use based on the outcomes of all AGREE II evaluations, Domains 1–6	Recommendation for use based on knowledge of the clinical validity of the guideline recommendations
	Scope and purpose	Stakeholder involvement	Rigour of development	Clarity of presentation	Applicability	Editorial independence			
Canada	69	53	20	92	38	0	83	YwM (Reviewer 1) Yes (Reviewer 2)	Yes (Reviewer 1) Yes (Reviewer 2)
New South Wales, Australia	61	14	0	53	19	0	33	YwM (Reviewer 1) No (Reviewer 2)	Yes (Reviewer 1) YwM (Reviewer 2)
New Zealand	36	17	2	72	15	0	50	YwM (Reviewer 1) No (Reviewer 2)	YwM (Reviewer 1) YwM (Reviewer 2)
Northern Territory,Australia	42	35	3	42	2	0	25	YwM (Reviewer 1) No (Reviewer 2)	YwM (Reviewer 1) YwM (Reviewer 2)
Queensland, Australia	75	36	6	53	13	38	58	YwM (Reviewer 1) No (Reviewer 2)	YwM (Reviewer 1) Yes (Reviewer 2)
South Australia, Australia	8	17	2	39	4	0	42	YwM (Reviewer 1) No (Reviewer 2)	YwM (Reviewer 1) YwM (Reviewer 2)
United Kingdom	92	14	13	89	38	0	50	YwM (Reviewer 1) Yes (Reviewer 2)	Yes (Reviewer 1) No (Reviewer 2)
Victoria, Australia	78	14	0	69	13	0	33	YwM (Reviewer 1) No (Reviewer 2)	Yes (Reviewer 1) No (Reviewer 2)

Individual ratings across all 23 items were averaged to yield an overall average appraisal score for each guideline. To determine scaled domain percentages, both appraisers' ratings of items within each domain were added and the maximum and minimum possible domain scores were scaled before being converted into an overall percentage for the domain.

Table 3. Content analysis summary of content items and sub-items.

Content items and sub-items	Guideline								Total Yes (Y) =1 No (N) =0 Partial (P) =0.5
	Canada	New South Wales (Australia)	Northern Territory (Australia)	New Zealand	Queensland (Australia)	South Australia (Australia)	United Kingdom	Victoria (Australia)	
Content item 1: Who does this guideline apply to?									
a) Palliative care definition	Y	Y	Y	Y	Y	N	P	P	6
b) Indicators for a paramedic to apply a palliative approach	Y	Y	Y	N	N	N	Y	Y	5
c) Circumstances where an ambulance service may be required for a palliative patient	Y	N	Y	P	Y	Y	Y	Y	6.5
Content item 2: Determining the person responsible for making decisions									
a) Establishing the patient's capacity	N	N	N	N	Y	N	P	N	1.5
b) Identifying proxy-decision makers	N	P	N	P	Y	N	P	N	2.5
Content item 3: Determining the patient's wishes with respect to treatment and transport									
a) Documentation describing the patient's wishes for life sustaining treatment and hospital care	N	Y	Y	P	P	P	P	N	3
b) Medical orders to withhold CPR and/or other life sustaining treatment (goals of care)	P	Y	Y	Y	Y	N	P	P	5.5
c) Indications for transfer to hospital	N	Y	Y	P	Y	Y	Y	Y	6.5
Content item 4: Partnering in care with the family									
a) Communication approaches for establishing rapport with families	N	Y	P	P	P	Y	P	N	4
b) Cultural considerations	N	N	N	N	N	N	N	N	0
Content item 5: Recognising and responding to imminent death									
a) Signs and symptoms of approaching death	Y	Y	N	N	N	N	Y	N	3
Content item 6: Managing pain									
a) Identifying the analgesia type and dosage the patient is already receiving	Y	P	P	Y	Y	N	Y	Y	6
b) Specific drug type and dosage recommended to manage this symptom	Y	P	P	Y	N	P	P	Y	5
c) Route and location of drug administration	Y	Y	N	P	Y	P	Y	Y	6
d) Recognising drug contraindications and offering alternatives	P	N	N	N	N	N	P	Y	2
e) Non-pharmaceutical approaches	Y	Y	N	N	N	N	Y	N	3
Content item 7: Managing nausea and vomiting									
a. Identifying the antiemetic type and dosage the patient is already receiving	Y	P	P	P	Y	N	P	Y	5
b. Specific drug type and dosage recommended to manage this symptom	Y	P	N	N	P	N	P	P	3
c. Route and location of drug administration	Y	Y	N	N	N	N	N	Y	3
d. Recognising drug contraindications and offering alternatives	Y	N	N	N	N	N	N	N	1
e. Non-pharmaceutical approaches	Y	Y	N	N	Y	N	P	N	3.5

(Continued)

Table 3. (Continued)

Content items and sub-items	Guideline								Total Yes (Y) =1 No (N) =0 Partial (P) =0.5
	Canada	New South Wales (Australia)	Northern Territory (Australia)	New Zealand	Queensland (Australia)	South Australia (Australia)	United Kingdom	Victoria (Australia)	
Content item 8: Managing breathlessness									
a. Identifying the drug type and dosage the patient is already receiving	Y	P	P	Y	N	N	P	Y	4.5
b. Specific drug type and dosage recommended to manage this symptom	Y	P	P	Y	N	P	P	Y	5
c. Route and location of drug administration	Y	Y	N	P	N	P	N	Y	4
d. Recognising drug contraindications and offering alternatives	Y	N	N	N	N	N	N	N	1
e. Non-pharmaceutical approaches	Y	Y	N	N	N	N	Y	N	3
Content item 9: Managing confusion									
a. Identifying the drug type and dosage the patient is already receiving	N	N	P	P	P	N	P	N	2
b. Specific drug type and dosage recommended to manage this symptom	N	N	N	N	N	N	P	N	0.5
c. Route and location of drug administration	N	N	N	N	N	N	N	N	0
d. Recognising drug contraindications and offering alternatives	N	N	N	N	N	N	N	N	0
e. Non-pharmaceutical approaches	Y	N	N	N	N	N	P	N	1.5
Content item 10: Managing constipation									
a. Identifying the drug type and dosage the patient is already receiving	N	N	P	P	N	N	N	N	1
b. Specific drug type and dosage recommended to manage this symptom	N	N	N	N	P	N	N	N	0.5
c. Route and location of drug administration	N	N	N	N	N	N	N	N	0
d. Recognising drug contraindications and offering alternatives	N	N	N	N	N	N	N	N	0
e. Non-pharmaceutical approaches	Y	N	N	N	N	N	N	N	1
Content item 11: Managing dehydration									
a. Identifying the drug type and dosage the patient is already receiving	N	N	P	P	N	N	N	N	1
b. Specific drug type and dosage recommended to manage this symptom	N	N	N	P	P	N	N	N	1
c. Route and location of drug administration	N	N	N	N	N	N	N	N	0
d. Recognising drug contraindications and offering alternatives	N	N	N	N	N	N	N	N	0
e. Non-pharmaceutical approaches	Y	N	N	N	Y	N	N	N	2
Content item 12: Managing the patient's anxiety and agitation									
a. Identifying the drug type and dosage the patient is already receiving	Y	P	P	P	N	N	P	Y	4
b. Specific drug type and dosage recommended to manage this symptom	Y	P	P	Y	N	P	P	Y	5
c. Route and location of drug administration	Y	Y	N	P	N	P	N	Y	4
d. Recognising drug contraindications and offering alternatives	Y	N	N	N	N	N	N	Y	2
e. Non-pharmaceutical approaches	Y	Y	N	N	N	N	P	N	2.5
Content item 13: Managing respiratory secretions									
a. Identifying the drug type and dosage the patient is already receiving	Y	N	P	P	N	N	P	N	2.5
b. Specific drug type and dosage recommended to manage this symptom	Y	N	N	N	N	N	P	N	1.5
c. Route and location of drug administration	Y	N	N	N	N	N	N	N	1
d. Recognising drug contraindications and offering alternatives	Y	N	N	N	N	N	N	N	1
e. Non-pharmaceutical approaches	Y	N	N	N	N	N	Y	N	2

(Continued)

Table 3. (Continued)

Content items and sub-items	Guideline								Total Yes (Y) =1 No (N) =0 Partial (P) =0.5
	Canada	New South Wales (Australia)	Northern Territory (Australia)	New Zealand	Queensland (Australia)	South Australia (Australia)	United Kingdom	Victoria (Australia)	
Content item 14: Options for clinical back-up									
a. Generic and local sources of assistance	Y	Y	Y	Y	Y	Y	P	Y	7.5
b. Hierarchy of who to contact	N	N	N	N	N	N	N	Y	1
Content item 15: Care after death (technical skills)									
a. Verification of death	N	P	N	N	N	Y	P	N	2
b. Who to contact	N	N	P	N	N	Y	N	N	1.5
c. Identifying who will complete the death certificate and process to avoid calling police when the death is expected	N	N	N	N	N	Y	N	N	1
Content item 16: Care after death (soft skills)									
a. Breaking bad news	N	N	N	N	N	N	N	N	0
b. Bereavement support for the family	N	N	N	N	P	N	P	N	1
c. Cultural considerations	N	N	N	N	N	N	N	N	0
Content item 17: Documentation									
a. What is needed to be recorded by the paramedic	Y	Y	Y	Y	N	P	P	Y	6
Content item 18: Additional items included in the guideline									
b. Any additional and imperative information which is included in this guideline but is not already covered by an existing content item	Y	N	N	Y	Y	N	Y	Y	5

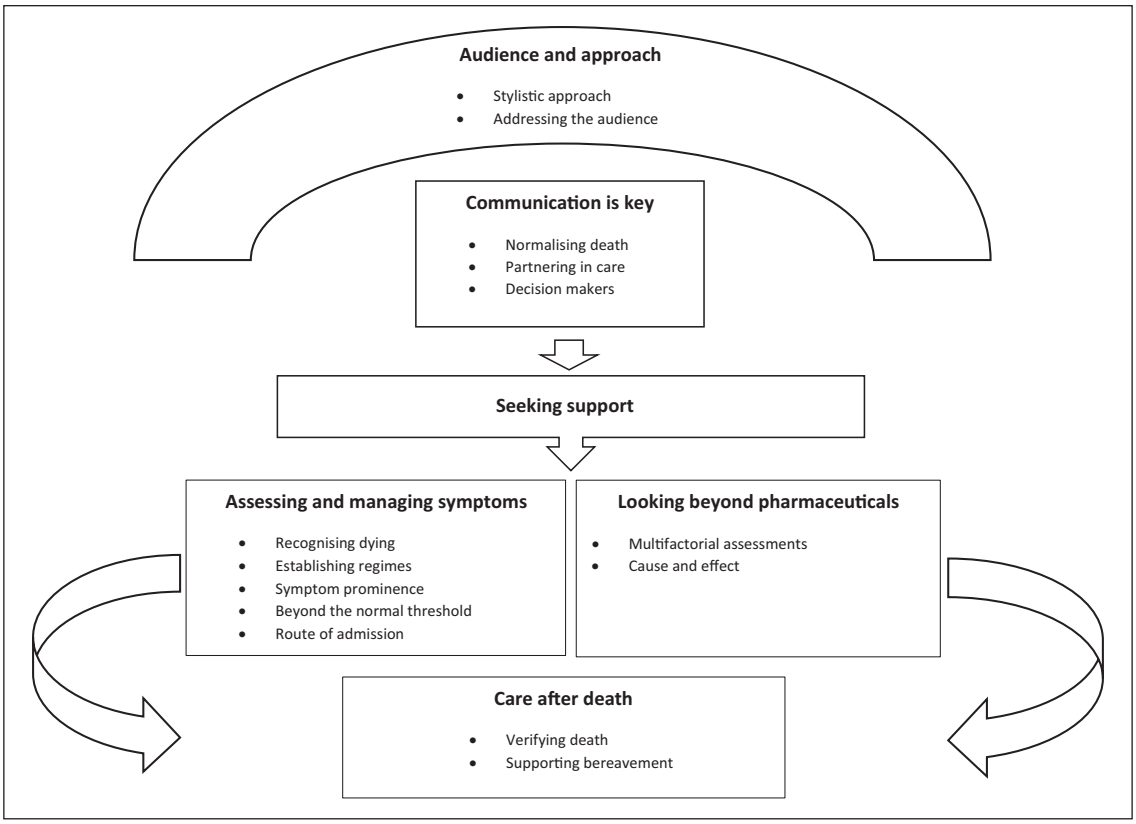

Figure 2. Thematic summary of content analysis.

The Canadian[40] and UK[39] guidelines were comprehensive booklets, detailing many aspects of care and integrating both a prescriptive and guiding approach.

> *"Patient-centred care is the cornerstone of all medical directives. Should the patient already have a symptom management kit in the home, prescribed by their primary care provider for the management of palliative care, the paramedics may provide symptom assist to the patient and/or family for the patient's prescribed medications in accordance with the prescription. This may include, but is not limited to, drawing up medications as prescribed, aiding in the administration of prescribed medications and assisting the family with mediation administration and/or education".*[40]

Variations in the audience addressed were also apparent across guidelines. Two were written exclusively for specialist community-based paramedics,[37,40] while the other guidelines were applicable to generalist paramedic audiences. Furthermore, four jurisdictions required the patient to be registered with a community-based palliative care service for the guideline to be applicable.[33,34,38,40]

Communication is key

All but one guideline[37] defined palliative care to varying degrees and recognised dying as a normal process of life, a key strength of the guidelines which offered paramedics clarity to communicate these principles in end-of-life emergencies. Eliciting information from the patient and bystanders is a basic task for paramedics; however, only two guidelines acknowledged the importance of partnering in care with families, addressing communication approaches for building rapport with and supporting these important stakeholders.[33,37]

> *"Families/carers may be committed to caring for the patient in the place of their choice, but at times may need support over and above that which is currently being provided or is available. Acknowledgement of the burden of this type of care and support may be all they require at this difficult time. Normalising the feelings that the family may experience will assist to minimise the family's distress".*[33]

Other key palliative care communication skills were tackled to varying degrees. Only one guideline comprehensively covered establishing patient capacity and determining proxy-decision makers,[35] while two others referred to seeking medical advice if the decision-maker was unclear.[38,39] Another two guidelines clarified what constituted valid medical directives within their jurisdictions,[33,36] equipping paramedics with the medicolegal literacy of what to request and look out for.

> *"If the patient can communicate and has the capacity to make decisions regarding treatment and transport, consult*

directly with the patients and obtain the patient's consent before any treatment and/or transport is provided".[35]

Assessing and managing symptoms

Recognising dying to initiate a palliative approach was a strong point amongst the guidelines. Three jurisdictions offered prescriptive lists of the signs and symptoms of a patient approaching death[33,39,40] and more outlined circumstances where an ambulance may be called to care for a palliative patient.[34–40] However, overwhelmingly most cited transportation to or from a hospital as the primary reason for paramedic intervention.

"A point comes when the person enters the 'dying phase'. Ambulance services are frequently called upon at this stage. This may be for planned transport, such as the rapid transfer of a person from hospital or hospice to their preferred place of death. Ambulance services are also frequently called during the dying phase because of an unexpected complication, or a sudden deterioration in condition".[39]

Seven guidelines clearly directed paramedics to establish the patient's existing medication regime before initiating management of any palliative symptoms.[33–36,38–40] Pain was most comprehensively referenced and addressed across guidelines; however, nausea and vomiting, breathlessness and agitation were also commonly considered. Other less reported symptoms included confusion, constipation, dehydration and respiratory secretions. Depending on the guideline approach, pharmaceutical symptom management details varied to include drug types,[34,38,40] pharmacokinetics,[40] contraindications[34,39,40] and dosages.[34,38,40] One guideline provided paramedics with an online application to assist with calculating dosages, reducing room for error in a high-pressure environment.

"Morphine is recommended as the mainstay treatment for palliative pain. When the palliative care service is unavailable to advise paramedics on management, the dose of subcutaneous Morphine to be administered is calculated by using the Ambulance Victoria CPG App to convert each of the patient's regular opioid analgesics to a total equivalent daily dose of oral morphine".[34]

All guidelines suitably recognised palliative care patients often have stronger pain relief requirements and recommended administering analgesia beyond the normal thresholds of an opioid-naive patient, if required, thereby permitting paramedics to work outside their traditional scope. Differences in the location and route of administration were also discussed by seven guidelines,[33–35,37–40] most preferencing the subcutaneous delivery of pharmaceuticals in the arm to speed uptake. Other technical skills addressed outside a paramedic's usual repertoire included using syringe drivers[34,37,39,40] and transdermal patches[39] for pain management. Importantly, paediatric pathways of care were only acknowledged by one guideline,[34] highlighting a potential gap in current palliative paramedicine practice.

Looking beyond pharmaceuticals

All guidelines addressed the medicinal management of symptoms to some degree; however, non-pharmaceutical approaches were not broadly adopted across guidelines. Only one guideline prescribed a multifocal approach to comprehend the holistic needs of a palliative patient, recommending paramedics undertake medical, sociological and psychological assessments before commencing treatment.[39] Another guideline offered two pages of generic information about the process of dying, albeit directed at family caregivers, which included non-pharmaceutical comfort-focussed interventions.[40] These two guidelines and another encouraged the paramedic to explore the causative root of palliative symptoms beyond superficial assumptions, highlighting opportunities for paramedics to identify when a non-pharmaceutical approach may be applied to better effect.[35,39,40]

"From a pre-hospital care perspective, as an ambulance clinician it is vital that you are mindful of the evidence which concludes that the use of a fan and low dose opiates is as effective, if not more effective, than the administration of oxygen. The disadvantages often outweigh the benefit of administering oxygen in that if a patient feels that they cannot breathe and a paramedic attends and administers oxygen, the patient may believe that they need oxygen therapy each time thereafter that they feel breathlessness. Even worse, the patient may fear that the thing they need to breathe is being taken away when you leave the house. This may result in the person feeling that they need an emergency response whenever they feel breathless."[39]

Seeking support

Options for clinical back-up was the only content item addressed by all guidelines, emphasising a requirement to identify and contact the patient's leading medical professional, usually the community palliative care service, when responding to a palliative emergency.

"Treatment should be in consultation with palliative care team, medical officer managing patient's care or South Australian Ambulance Service Extended Care Paramedic Mentor".[37]

Half of the guidelines listed contactsforsupport,[34,36,37,40] while the other half referred to options but did not stipulate specific details.[33,35,38,39] Two guidelines provided details for a 24/7 palliative care specialist specifically on call to provide support for paramedics[34,36] and another

guideline permitted paramedics to treat patients beyond their normal practice if directed by clinical supports.[38]

> *"All personnel may administer medicines outside their delegated scope of practice if instructed to do so (including over the phone) by a registered medical or nurse practitioner".*[38]

Care after death

Content items relating to care after death were underrepresented across all guidelines, including the more comprehensive guidelines of Canada and the UK. No single guideline addressed the content items breaking bad news or cultural considerations, highlighting two clear gaps in current documented clinical practice. Three guidelines referred to separate protocols covering the skills of verifying death,[33,38,39] raising the question of utility for interrelated content across multiple guidelines. One jurisdiction directed paramedics to complete a declaration of life extinct document when the death was expected and stipulated who could complete the certification, assisting paramedics in avoiding unnecessary police involvement at a time of bereavement.[37]

> *"There is no requirement for South Australian Police to attend the case provided a declaration of life extinct document is completed and a palliative care medical officer or the patient's GP can complete the certificate within the 24 hours of the death".*[37]

Finally, supporting family and carer distress and grief after the death of a loved one was only partially addressed by two guidelines,[35,39] highlighting an under-recognition of the potential for paramedics to employ vital communication skills, support early bereavement, respond to acute grief and provide culturally responsive care.

> *"Ambulance clinicians will often be on the scene at or shortly after the point of death. There may be occasions where the patient is in the final stages of dying. If all reversible causes have been considered, then supportive care for the patient and the relatives/carers may be all that is required"*[39]

Discussion

Palliative paramedicine is an evolving scope of practice: only five of Australia's ambulance services had existing guidelines suitable for inclusion in this study. The diversity of approaches reported across the included guidelines reflects the international shift away from protocol-driven paramedic practice to broader clinical models, calling on the discretion and decision-making skills of paramedics instead of fixed algorithms.[1,41–43]

Overall, the quality of guideline development was poor to moderate. Notably, Australian and Canadian ambulance guidelines are usually part of a comprehensive suite of policies and procedures, not to be used in isolation. Thus, despite succinct guidelines potentially offering greater utility for paramedics, they were rated poorly according to AGREE II criteria, as reflected in another study employing the same tool to appraise paramedic practice.[32] Looking ahead, the AGREE II instrument offers substantial methodological guidance for developing future best practice palliative paramedicine guidelines;[44] however, the instrument should not be used to determine their clinical validity.[45]

The need for community-based palliative care provision by paramedics has emerged from the recognition of ambulance and out-of-hours community palliative care service shortfalls, an increasing acuity of elderly populations living in communities and a greater need to respond to illness with preventative and rehabilitative approaches.[46] However, relegating palliative paramedicine to specialist roles alone – as was the case for only two guidelines – seems an unviable option to support the ever growing demand for community-based palliative care and increasing community preferences to die at home.[16] Future research could investigate opportunities to integrate the palliative care skills of specialist paramedics across to the generalist paramedic workforce and embed palliative and end-of-life care principles into undergraduate paramedicine curriculum.[12,47]

Constraining the provision of palliative and end-of-life care exclusively to patients already receiving specialist community palliative care services is another barrier to practice. Paramedics often encounter frail and chronically ill patients with rapidly deteriorating health, some of whom might benefit from or prefer a palliative approach to their care. Paramedics' unique position as clinicians entering patients' homes allows them to gather important information about social contexts; details that can be used for holistic palliative care needs assessments and inform immediate careplanning.[12] However, systems must be in place for this information to be shared with multidisciplinary palliative care teams in order to also influence future care planning. Broadening guidelines to allow these patients to be eligible to receive palliative care from a paramedic where appropriate, with clinical back up, would increase access and equity and entrench palliative care as a core skill of paramedicine. This would require the capability to link with specialist palliative care services at the time of need or for future follow up and assessment if time and circumstances permit.

Clinical back-up pathways were a key strength present across all eight guidelines, recognising the developing nature of palliative paramedicine and highlighting the need for multidisciplinary approaches to care. A recent study confirmed Australian paramedics have a high level of intention to use a specialist palliative care telehealth service if it were made available to them.[47] Opportunities remain to shape future ambulance service palliative care policies and practice on integrated models of care.

Finally, the overwhelming lack of content related to communication and care after death identified a significant gap in current practice. These concepts are difficult to translate into simple algorithms, which could potentially justify their exclusion in protocol-based guidelines. However, current literature also fails to address the experiences of families and paramedics responding to the death of a palliative patient.[48] Instead, we generalise practice based on in-patient and emergency department environments, which fail to recognise the nuance of prehospital settings.

Future research ought to investigate all stakeholders' perspectives to better inform practice related to care after death. Literature supports the need for soft skills communication training for paramedics to initiate advance care planning,[49] break bad news[50] and discuss end-of-life matters[48]; a gap that has only been reinforced by the broadening role of paramedics providing grief support during the COVID-19 pandemic.[51]

Findings from our study have the potential to shape future policy and practice, identifying the need to broaden palliative care beyond a specialised role, remove restrictions on prerequisite services required to apply a palliative approach, invest in integrated models of care and address care after death. Prospective research should explore the experiences and perspectives of key palliative paramedicine stakeholders to inform future guidelines; the methodological development of which ought to follow the AGREE II criteria to achieve best practice.

Strengths and limitations

To our knowledge, this is the first study to explore palliative paramedicine practice from a policy perspective. Only palliative and end-of-life care specific guidelines were included in this study, therefore excluding potentially relevant information from other guidelines within each ambulance service's suite. Furthermore, only one Canadian guideline was included, which may not reflect the variation in palliative paramedicine practice across the country. However, review of all guidelines would have been significantly more resource intensive and out of scope for this study. Further, the specific inclusion criteria allowed us to analyse the utility of each guideline.

Conclusion

Palliative care is a growing component of paramedicine and translated into practice by ambulance services' palliative and end-of-life care guidelines. This study examined both the quality and content of existing Australian palliative paramedicine guidelines with a sample of guidelines from comparable Anglo-American Ambulance services. The study highlights the variance in methodological quality, approach and content of these guidelines to reveal six key themes: audience and approach, communication is key, assessing and managing symptoms, looking beyond pharmaceuticals, seeking support and care after death.

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Ethics approval

Ethical approval was not required for this study as the research method was a quality appraisal and content analysis of publicly available material.

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Chapter 5: 'It breaks a narrative of paramedics, that we're lifesavers': A qualitative study of health professionals', bereaved family members' and carers' perceptions and experiences of palliative paramedicine

The following chapter contains a qualitative study of the perspectives and experiences of 50 health professionals and family caregivers towards the role, barriers and enablers of palliative paramedicine in Australian community-based settings. It was published in Palliative Medicine Journal in 2023.

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'It breaks a narrative of paramedics, that we're lifesavers': A qualitative study of health professionals', bereaved family members' and carers' perceptions and experiences of palliative paramedicine

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Abstract

Background: Paramedic practice is diversifying to accommodate evolving global health trends, including community paramedicine models and growing expertise in palliative and end-of-life care. However, despite palliative care specific clinical practice guidelines and existing training, paramedics still lack the skills, confidence and clinical support to provide this type of care.

Aim: To elicit paramedics', palliative care doctors and nurses', general practitioners', residential aged care nurses' and bereaved families and carers' experiences, perspectives, and attitudes on the role, barriers and enablers of paramedics delivering palliative and end-of-life care in community-based settings.

Design: A qualitative study employing reflexive thematic analysis of data collected from semi-structured online interviews was utilised.

Setting/participants: A purposive sample of 50 stakeholders from all Australian jurisdictions participated.

Results: Five themes were identified: positioning the paramedic (a dichotomy between the life saver and community responder); creating an identity (the trusted clinician in a crisis), fear and threat (feeling afraid of caring for the dying), permission to care (seeking consent to take a palliative approach) and the harsh reality (navigating the role in a limiting and siloed environment).

Conclusion: Paramedics were perceived to have a revered public identity, shaped by their ability to fix a crisis. However, paramedics and other health professionals also expressed fear and vulnerability when taking a palliative approach to care. Paramedics may require consent to move beyond a culture of curative care, yet all participant groups recognised their important adjunct role to support community-based palliative care.

Keywords

Palliative care, terminal care, emergency medical services, paramedic, ambulance, qualitative research

What is already known about the topic?

- Since its inception, paramedic practice has diversified beyond emergency care to include community paramedicine models and growing expertise in palliative and end-of-life care.
- The traditionalist orthodoxy of treatment and compulsory transfer to hospital is now being questioned.
- Palliative care clinical practice guidelines and training to support paramedics in this aspect of care have been developed in some jurisdictions.

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What this paper adds?

- Paramedics have a revered public identity, shaped by a perceived ability to fix a crisis. However, a dichotomy exists regarding their role as a lifesaver and community responder.
- While mostly supportive of palliative paramedicine, paramedics express vulnerabilities when taking this approach to care and need support to move beyond conventional models of curative care.
- Participants described inconsistencies in ambulance services' governance, training, and interdisciplinary approaches. Anecdotes of greater specialisation pathways and growing unity between ambulance and palliative care services were also articulated.

Implications for practice, theory or policy?

- Balancing competing priorities of what might be the appropriate goals of care for a person who appears to be dying, and the family's expectations, requires a high degree of clinical skill and discretion amongst paramedics, perhaps facilitated in the future by universal paramedic access to electronic medical records.
- Ambulance services ought to review current palliative care guidelines, training and interdisciplinary practice to optimise their role in this context.
- Future research could investigate strategies for overcoming prohibitive paramedicine cultural norms related to palliative and end-of-life care, potentially enabling a smoother transition for paramedics to provide high quality care for people with life-limiting illnesses, reduce avoidable hospital admissions and facilitate more home-based deaths.

Background

Since their inception, ambulance services have been responding to acute emergencies and unexpected deaths in communities worldwide.[1] However, global health trends are shifting as we live longer, with greater levels of chronic disease, and increasing preferences to live and die at home.[2,3] As a result, paramedic practice is diversifying to include community paramedicine models,[4–7]and growing expertise in palliative and end-of-life care.[8–10]

Yet, as paramedics respond to increasing numbers of palliative and end-of-life care patients in the community, the traditionalist orthodoxy of treatment and compulsory transfer to hospital is being questioned[9,10,11] Palliative paramedicine clinical practice guidelines[12] and training programmes[4] are emerging, alongside interdisciplinary palliative care teams that include paramedics,[13] to broaden scopes of practice and facilitate more home-based deaths. However, paramedics reportedly still lack the skills, confidence and clinical support to provide palliative and end-of-life care in the community.[8,14–16]

Previous studies have qualitatively explored the importance, feasibility and challenges of palliative paramedicine in one country[14]; bereaved family members' experiences of ambulance care at end-of-life[17,18]; the alignment of paramedics' identity with providing palliative care at home[19]; and the educational needs of paramedics providing this type of care.[20] However, a gap remains in understanding multidisciplinary stakeholders' perspectives of the current impediments and facilitators of palliative paramedicine practice; the findings of which could have resonance for ambulance and palliative care services worldwide. Thus, the aims of this study are to elicit paramedics', palliative care doctors and nurses', general practitioners', residential aged care nurses' and bereaved families and carers' experiences, perspectives, and attitudes on the role, barriers and enablers of paramedics delivering palliative and end-of-life care in home-based settings.

Methods

Design

This paper draws on data from a larger study exploring the experiences of palliative paramedicine in Australian communities, from the perspectives of both health professionals and bereaved family members and carers. A qualitative study design was underpinned by a social constructivist epistemology,[21] contending that experiences and perspectives are socially constructed by participants as they engage with the world, rather than reflections of objective truth. This study is reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.[22]

Setting

Each Australian State and Territory has a respective ambulance service providing emergency care 24 h a day, 7 days a week across a range of metropolitan, regional, rural and remote locations. Every ambulance service maintains an emergency call-taker centre, where emergency calls are received and, based on the information received, an ambulance is dispatched into the community. In line with other Anglo-American ambulance services, Australian ambulances are usually crewed by two registered paramedics with university-level qualifications and autonomous clinical decision-making capacity.[1] However, the scope of palliative paramedicine practice remains

heterogenous across the country: only five of eight Australian ambulance services have palliative care specific clinical practice guidelines to standardise practice, and many jurisdictions rely solely on specialist roles, such as Extended Care Paramedics (ECPs), to deliver palliative and end-of-life care in the community.[12]

Population

Health professionals and bereaved family members and carers were eligible to participate in this study if they were aged 18 years or older and were involved in the care of someone – during any period of their life and/or career – with palliative care needs who encountered paramedics towards the end of their lives in the community. Health professional sub-groups included paramedics, general practitioners (GPs), palliative care nurses, palliative care doctors and residential aged care home managers.

Sampling/recruitment

Participants were purposively sampled to ensure a range of demographics and clinical experience were represented. Health professional participants were recruited through professional organisations, and family and carer participants were recruited through a national organisation's register of palliative care consumers and carers. An advertisement about the research was published in each respective online newsletter and an email was sent to each organisation's members outlining the study and inviting them to contact the research team if they were interested in participating. An invitation was also circulated through collegial networks and sent to opinion leaders with publicly available email addresses, outlining the study, inclusion criteria and contact details of the research team. Once an interested person contacted the research team, they had the opportunity to talk to a researcher to ask questions before their participation was confirmed. The study was approved by the University of Sydney Human Research Ethics Committee (*2021/607; 2021/608*).

Data collection

Virtual semi-structured interviews were conducted via Zoom between November 2021 and April 2022. Development of separate interview guides for health professional participants and family/carer participants was informed by discussions with the study-created Australasian Palliative Paramedicine Advisory Group (a multidisciplinary community of practice comprised of jurisdictional palliative care and paramedicine representatives), a comparative policy study of Australian and Anglo-American palliative paramedicine guidelines,[12] and a systematic integrative review on the topic.[8] Interview guides were then pilot tested amongst the research team. See Supplemental Appendices 1 and 2 for finalised interview guides.

Two female health researchers (MJ and CP) unknown to participants independently conducted the interviews online. Both researchers had completed training and were experienced in qualitative research methods. Participants were informed the purpose of the interviews was to further research into improving palliative paramedicine in community-based settings. Participant recruitment ceased when no new themes became apparent within each sub-group across three consecutive interviews. With participant consent, interviews were audio-recorded and transcribed verbatim by an external company, Pacific Transcription Inc. The researchers also took field notes for reflection during data collection.

Data analysis

Drawing on Braun and Clarke's six-phase guide in reflexive thematic analysis,[23] an inductive approach was employed, coupled with the researchers' existing knowledge, to progressively refine themes based on codes identified in the data. Acknowledging the research team's personally held beliefs influencing the interpretive analysis of the data, all members approached the topic with a positive perspective of the role paramedics can play in providing palliative and end-of-life care in communities. However, we remained mindful of this and invited all participant perspectives to be captured, reporting both negative and positive cases.

MJ read all the transcripts and familiarised herself with the content, then independently identified potential codes and met with CP, JC and PB to discuss and develop the codebook, allowing for consistent interpretation and classification of the data. This codebook was then used to guide coding of the remaining transcripts by MJ. Consecutive rounds of discussions were held with MJ, JC, PB, CP, MB and PS to capture multidisciplinary perspectives and enhance the analytical framework. NVivo was used to store, organise and support analysis of the anonymised data.[24]

Results

We sought to capture the experiences, perspectives and views of various stakeholders with comprehensive detail to be confident we were representing the differing participant sub-groups. As a result, a total of 50 individual interviews were conducted between November 2021 and April 2022, including 17 paramedics, five GPs, seven palliative care doctors, eight palliative care nurses, five residential aged care nurses and eight bereaved family members and carers deriving from all states and territories of Australia. Participant characteristics are outlines in Table 1. The interviews ranged in duration between 18 and 64 min (mean 43.64 min). We identified five themes: positioning the paramedic (life savers vs community responders), creating an identity, fear and threat, permission to care and the harsh reality. A thematic diagram of the themes and

Table 1. Descriptive characteristics of participants.

All participant characteristics	Participants (*n* = 50)	%
Age		
18–30	1	2
31–65	44	88
66–75	5	10
Gender		
Male	19	38
Female	31	62
Country of birth		
Australia	31	62
United Kingdom	10	20
Other	9	18
Employment status		
Full time	37	74
Part time or causal	9	18
Not employed	4	8
State		
Australian Capital Territory	5	10
New South Wales	18	36
Northern Territory	4	8
Queensland	5	10
South Australia	6	12
Tasmania	1	2
Victoria	9	18
Western Australia	2	4
Main occupation		
Paramedic	17	34
General	9	18
Intensive care	4	8
Extended care	1	2
Intensive and extended care	2	4
Rescue	1	2
GP	5	10
Palliative care doctor	7	14
Palliative care nurse	8	16
Residential aged care nurse	5	10
Family member/carer	8	16
Health professional participant characteristics	**Participants (*n* = 42)**	**%**
Location of workplace		
Metropolitan	27	64.3
Rural	10	23.8
Remote	5	11.9
Predominant practice setting		
Ambulance service	17	40.5
On road	10	58.8
On road and PhD candidate	2	11.8
On road and leadership role	5	29.4
Palliative care	15	35.7
Community consult service	2	13.3
Inpatient palliative care unit		
Acute hospital consult service		
Mix of settings	13	86.7
General practice	3	7.1

(Continued)

Table 1. (Continued)

Residential aged care	6	14.3
Other	1	2.4
Length of work experience		
1–5 years	1	2
6–10 years	5	10
More than 10 years	36	72
Family member/carer participant characteristics	Participants (n = 8)	%
Education background		
Completed high school to year 10 equivalent	1	12.5
Completed final year of high school equivalent		
Professional certificate or vocational school	3	37.5
Undergraduate degree	1	12.5
Postgraduate degree	3	37.5
Location that the person was cared for		
Metropolitan	6	75
Rural	2	25
Remote		
Relationship with the person cared for		
Spouse	3	37.5
Parent/Guardian	4	50
Aunt/Uncle	1	12.5
Age range of person cared for		
31–65	4	50
66–75	1	12.5
76–85	1	12.5
86+	2	25
Primary medical diagnosis of person being cared for	8	100
Cancer		
Heart failure		
Chronic respiratory disease		
Dementia		
Kidney failure		
Liver failure		
Motor neuron disease		
Other		

sub-themes is illustrated in Figure 1. Below, themes are illustrated by quotes, identified by role and ID number.

1. Positioning the paramedic

The participants reported differing rationales for objecting to or endorsing palliative paramedicine within Australian communities, ultimately determining their perception of the role, barriers and enablers paramedics and other stakeholders face. These rationales fell into a dichotomy: lifesavers versus community responders.

Life savers

Participants from a range of groups considered the paramedic role ought to be rooted in responding to acute emergencies and adhere to the traditional perception of *'ambulance services really being there to save lives' (Family member ID44)*. One paramedic asserted, *'our major role is to transport a patient' (ID2)*. Another clinician affirmed paramedics' scope of practice should remain curative, *'not palliative care focussed' (residential aged care nurse, ID39)*. Family members also expressed hesitancy in calling an ambulance unless their family member wanted every active intervention possible to keep them alive. Participants suggested these were long-held perspectives about paramedics:

> *"Since I was a kid, an ambulance was always that thing where you're saving someone from a heart attack or you're saving people. . . you're saving a life." (Palliative care doctor, ID29)*

Community responders

Conversely, other participants described the role of a paramedic as evolving in response to the diverse and changing needs of populations, including an increasing demand

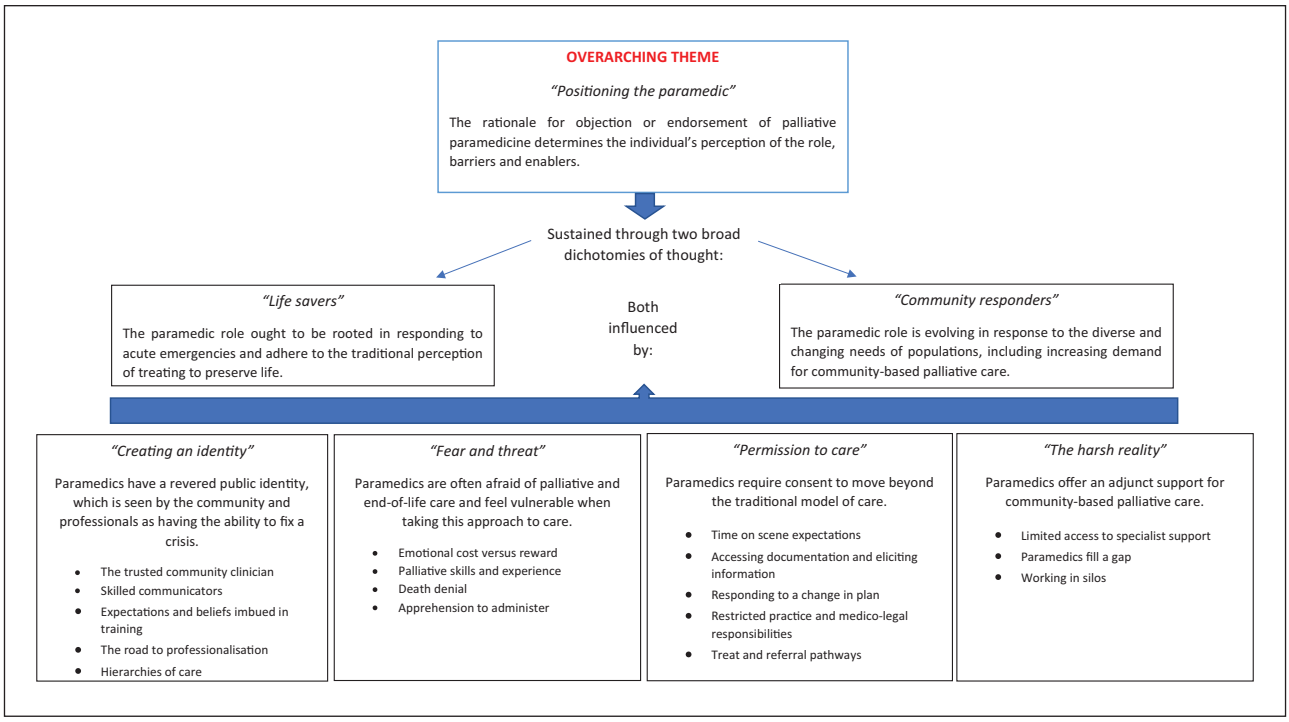

Figure 1. Thematic summary.

for community-based palliative and end-of-life care. Participants noted the importance of placing the patient firmly at the centre of care, with all health professionals, including paramedics, having an obligation to provide good end of life care when the need arises. They also noted that generalists, as well as specialists, can and should deliver that care:

> *"The whole notion of palliative care is not just about specialist palliative care, and I'm a specialist palliative care provider. I think there's a whole host of services that provide palliative care, and paramedics and ambulance services are certainly one of them. It doesn't mean that patients not known to a specialist palliative care service aren't provided with palliative care. It's about the patient at the centre and their care needs. Members of the health care services, which includes paramedics, have an obligation I think to provide good end of life care." (Palliative care doctor, ID25)*

2. Creating an identity

Participants suggested paramedics have a revered public identity, which is seen by the community and professionals as having the ability to fix a crisis:

The trusted community clinician

Family members and carers expressed significant trust towards paramedics, often calling upon them in times of a palliative care emergency. All groups noted that this trust results in paramedics often being the health professionals called upon to identify and explain end of life situations and support family and carers in taking an end-of-life approach, an often highly appreciated contribution:

> *"They certainly had a role in making my husband comfortable in his last stages of life and they had a role in how I felt towards it. They assured me everything was ok, explained what was happening and I felt completely not in any fear. I just felt calm." (Family member, ID48)*

> *"I wish we didn't need to have this support from paramedics. We should have it under control, but sometimes we need a little bit of support because the families, and sometimes the residents,. . .sadly, sometimes the respect and acceptance is not as high as when they see someone in a different uniform coming and saying there is not much we can do for you." (Residential aged care nurse, ID39)*

Conversely, participants noted this trustful identity sometimes promoted unrealistic expectations that a life could be saved, when indeed the patient was nearing the terminal phase, making it more difficult for paramedics to provide end-of-life care:

> *"I think they're pushed by families and carers to act, and they come from a place of acting." (Palliative care doctor, ID25)*

Skilled communicators

Paramedics noted that their existing skills and experience in difficult communication tasks in the acute care setting, such as breaking the news that a patient had died, can readily be transferred to the palliative setting. Other clinicians also recognised the *'advanced communication skills'* paramedics already possess, which can be *'transferred over for when a patient is actually dying' (palliative care nurse, ID33)*, as evidence of their suitability for providing end-of-life care.

However, some paramedics acknowledged that communication can be more difficult for expected deaths, where family and carers may be exhausted after a prolonged period of providing care:

> "*But being comfortable around an inevitable death and how you talk about that again is very different. I think potentially that just weighs a little harder. I think it's a much rawer or fatigued form of grief, rather than a purely emotional outburst that we see when we go to more acute cases, or people who have died by trauma or unexpectedly. It's very hard to articulate, but it looks, sounds and feels different. . ." (Paramedic, ID8)*

Participants also acknowledged that the traditional emergency response mentality instilled in junior paramedics did not match well with the more relationship-based, continuity of care approach required in palliative care:

> *"It's so ingrained in paramedics. Walk in, identify that sick patient, okay, primary survey, can someone get some monitoring on, taking over that scene control in quite often a non-emotive state. It's an efficient state and when you apply that onto a palliative care patient it's quite abrupt." (Paramedic, ID13)*

Expectations and beliefs imbued in training

Participants described an entrenched '*culture of curative care' (paramedic, ID10)* that is fostered amongst all clinical disciplines. However, paramedics noted this focus and capability is particularly emphasised in their ongoing education and maintained throughout the trajectory of their careers:

> *"We're taught about what to do in a cardiac arrest. We're taught what to do when someone's deceased, but we're never actually taught the in-between." (Paramedic, ID4)*

Others suggested paramedicine attracts a certain type of individual who seeks, is skilled in, and thrives in emergency situations. Such individuals may struggle more with the holistic aspects of palliative care:

> "*The people who go into paramedics tend to be very decisive, problem-solving, adrenaline-seeking individuals, who are not fazed being put under extreme stress. They've got to think quickly, act quickly, and the idea of stepping back and thinking more reflectively and potentially coming to a decision that you don't do anything active is often difficult for some people." (GP, ID19)*

*P*articipants suggested paramedics will need training to fill in gaps in their current education and provide the specific skills required in palliative care:

> "*Paramedics should be trained to assess all palliative patients, provide emergency symptom control, make assessments around goals of care and also consider the requirement to come to hospital*" (Palliative care doctor, ID26).

> *"We're literally there when people expire, and we don't necessarily have great tools unless you've been involved in an Extended Care Paramedic program, or something like that. . . That it's not part of general ambulance practice to give a sub-cut injection, for example, or to put a sub-cut line in, is worrying. It's a mechanical skill, but it's not something that we do generically." (Paramedic, ID13)*

The road to professionalisation

Participants highlighted traditional perceptions of paramedics as ambulance drivers had historically limited expanded conceptualisations of this role. Paramedics cited interprofessional reluctance, a lack of rigorous evidence of the feasibility and efficacy of paramedic involvement in palliative care, and limited drivers to initiate change, as hindering the movement beyond an ambulance-based model of care:

> *"I think there are some barriers to paramedics working outside of ambulance services. The health services need to be open for paramedics to work within it and see the value that paramedics provide. . . . I don't think we've had any significant change agents yet that have really proven that paramedics have capacity to work outside of an ambulance service." (Paramedic, ID12)*

However, palliative care specialists acknowledged the recent introduction of professional registration for paramedics and subsequent broadening of clinical roles were slowly challenging this stereotype:

> *"I do think legislatively things changed. But it's taken a long time for the systems to sort of catch up. But I think they've got an increasingly expanding role, and the thrust of working beyond an ambulance response is new and exciting. It's really going through that transitions that nurse practitioners went through about 10 to 12 years ago. So, they're just beginning that journey." (Palliative care doctor, 26)*

Hierarchies of care

Participants described professional and gender hierarchies within clinical disciplines, which sometimes hinder interprofessional collaboration. They noted the male-dominated paramedic profession might under-value the quieter, more considered approach required for palliative care, while other professions may be concerned about losing their palliative care patients if shared care with paramedics became the accepted model:

> *"I felt like the male paramedic dominated the women in the space and disregarded the expertise of the palliative care nurses. I felt like they had the clinical expertise in that situation, but it wasn't acknowledged." (Family member, ID47)*

> *"I think not many GPs would be willing to share all their records about the patient with other health professionals because they could become a little bit defensive about that." (GP, ID20)*

However, aged care nurses described mostly positive multidisciplinary engagements within ambulance staff:

> *"Paramedics are quite responsive and willing to partner. I see them speak with our nurses and they share the information. . ., it's always a collaboration." (Residential aged care nurse, ID39)*

3. Fear and threat

Participants suggested health professionals are often afraid of palliative and end-of-life care and feel vulnerable when taking this approach to care.

Emotional cost versus *reward*

Paramedics described palliative and end-of-life care as emotionally draining, and questioned whether they therefore tended to avoid such an approach:

> *"I wonder if maybe it's because paramedics don't want to get too touchy feely because that's where the risk is for us to become emotionally attached to the job." (Paramedic, ID17)*

Yet, they recounted fulfilment when a good death was facilitated:

> *"It's a tough job but it's one of the most rewarding. To me it's a privilege being there at the end of someone's life, and I get great satisfaction from helping a family go through that moment and just supporting them and making it a nice death. Because so many people don't get that option. So, if I can be there to make things a little bit easier then to me that's an honour to be there." (Paramedic, ID1)*

Palliative skills and experience

Participants highlighted the heterogeneity of paramedics' skills and expertise, and that a clinician's previous experience and exposure to end-of-life determines their propensity to fear palliative approaches to care:

> *"You're really relying on individual (paramedics) rather than on a process." (Palliative care nurse, ID30)*

> *"If they've been around for a while, they know what a dying person looks like and when dying is not going to be reversible. After you've been in the job for a while, you'll see where the line between potential success and inevitable failure is." (GP, ID18)*

Thus, with age and experience, a palliative care approach may become more acceptable and easier to deliver for paramedics. Yet, participants suggested some older paramedics may be more likely to reluctant change, subscribing to the traditional role and resisting shared decision making:

> *"They want to be black and white, . . . and they're just like, if this person needs to be transferred to hospital, let's transfer this person to hospital." (Residential aged care nurse, ID41)*

Death denial

Participants described a broader society lacking adequate knowledge, skills and awareness to compassionately respond to death:

> *"We've outsourced death and dying. We don't do it anymore. We don't support people. We put old people in nursing homes, so we don't see it, unless you're in a situation where it's happening to someone you care about, and then often I think it's not done very well, because people don't know what to do." (Family member, ID50)*

Some suggested that death denial amongst families can prevent planning, communication and acceptance; all of which facilitate paramedics to take a palliative approach:

> *"When someone's dying, the family may not be accepting of that. It might be cultural. It might be the care home has provided really poor care and they're blaming them and don't want their loved one in that care home anymore. They're missing the fact that their loved one is actually deteriorating and dying." (Palliative care nurse, ID30)*

Participants reported clinicians may also experience death anxiety, which can hinder communication.

They noted, clinicians *'aided and abetted the dysfunction in refusing to talk about the nature of the condition'*

(family member, ID45). One palliative care nurse suggested, *'sometimes it's because clinicians don't feel comfortable having those conversations' (ID35)*, while a GP asserted, *'one of the reasons GPs don't do death well is our own fear of death' (ID21).*

Apprehension to administer

Paramedics, GPs and aged care nurses expressed fear in administering palliative medications that they may inadvertently cause, and be held responsible for, death. Family members expressed similar apprehension when the responsibility fell on them:

> *"There would be times where I'd be scared to because what if I've just overdosed my partner?" (Family member, ID46)*

4. Permission to care

Participants suggested paramedics require consent to move beyond traditional models of curative care.

Time on scene expectations

Participants commonly expressed a belief that paramedics worked under a very time-pressured environment, which conflicted with the potentially long time it takes to manage a palliative care patient. Some paramedics referenced ambulance services setting key performance indicators which restricted them to a maximum 20 minutes on scene. Numerous participants endorsed the sentiment of this policy:

> *"When someone's dying or approaching death, in my experiences when paramedics are called, they can't spend hours with someone, unless it's trying to keep them alive or stabilise them. They're called for emergencies. Their role is an emergency role." (Family member, ID50)*

However, other participants supported *'discretion for staying on scene'* in palliative care situations *(Paramedic, 10).* Specialist roles were discussed by participants as a solution to avoiding taking an operational ambulance out of the system:

> *"I think there's always a role for Extended Care Paramedics in palliative care as well. Because I think we've got a bit more specialist training, we run around as singles; we don't have a stretcher resource, we're not tying up an emergency ambulance." (Paramedic, ID6)*

Accessing documentation and eliciting information

All participants emphasised the importance of paramedics being able to access information in a timely manner to make sound clinical decisions. Palliative care doctors recounted experiences where paramedics have called them in otherwise avoidable circumstances because they did not have sufficient information to guide care. Participants universally felt paramedics ought to have greater access to Electronic Medical Records (EMR) and standardised advance care planning documentation, given that they are a recognised part of the health system.

> *"{They phoned me because] things have not been clearly documented and a decision hasn't been made whether the patient is to return to hospital or not" (ID24), [because the ambulance service] "can't access EMR" (Palliative care doctor, ID27).*

Some clinicians suggested eliciting information about advance care planning from families and carers could sometimes be difficult as they were too stressed to remember its relevance or location:

> *"Forget about documentation during times of crisis because they're worried, they may not recognise this could be the end" (GP, ID19).*

However, family members and carers recalled more positive experiences:

> *"They suggested that he had blood poisoning. . .. They then said, well we're going to now intubate him and keep him alive, and I said, well he's got a certificate here from the doctor to say that he doesn't want to be kept alive. . .. So, I had to go and get that form which they read through very, very thoroughly. . . and then they said, yep, we completely understand, put it aside and then just explained to me how to make him comfortable." (Family member, ID48)*

Responding to a change in plan

Although patients and their families may prefer and plan for a home-based death, participants suggested paramedics facilitate the transport of a palliative patient to hospital if this option is no longer feasible due to uncontrolled symptoms or family exhaustion. Family members sometimes expressed feelings of guilt associated with changing the plan:

> *"People need permission to know that it's okay, that they haven't failed anyone if they can't be at home, or they need to go to hospital." (Family member, ID46)*

However, others noted the reassurance of knowing that transport to hospital was an option facilitated their decision to change the plan:

> *"Even though his intention was to pass away at home, it just became too much for us to handle. The nurses. . . said 'look, all it takes is a phone call and the ambulance patient transport*

will come, and we'll take him over to the hospital.'." (Family member, ID46)

Some paramedics also voiced apprehension in responding to a change of plan, but recognised the need to take family-centred approaches to palliative care:

"You've tried to advocate for what the patient's wishes were, to die at home. . . But then the family members sometimes are screaming at you to take them back to the hospital, because they don't want them to die there. There are significant emotional challenges associated with dealing with the family. . . But you've got to remember that the family are also your patients in palliative medicine as well." (Paramedic, ID15)

Restricted practice and medico-legal responsibilities

Participants reported ambulance services have inflexible policies and procedures, which often limit their scope of practice to treat a palliative patient. The recent registration of paramedicine has added further legal complexities to palliative care, making services even more fearful of being seen to do the wrong thing:

"Having rigid protocols really becomes an impediment for, I believe, paramedics to enact patient-based care that's based on the particular situation. Instead, they're following more of an algorithm associated with that". (Paramedic, ID12)

"Even if I truly believe I'm acting in the best interests of the patient. . . we're really fearful here of - and probably as an ambulance service thing in general - getting a complaint and then not being supported by the service." (Paramedic, ID7)

Treat and referral pathways

Palliative care specialists noted a shift towards paramedics wanting to keep people at home, which has led to ambulance services *'connecting with the palliative care services in a more structured way' (Palliative care doctor, ID24).* Participants described the benefits of engaging multidisciplinary teams for clinical back-up and support, which allowed paramedics to initiate palliative approaches to care where they would otherwise be uncertain:

"We were called for a palliative care patient at home who I could hear was moaning in the background with pain, but the paramedics didn't feel they could give pain relief because there was no ambulance plan in the house. I talked through what had happened with the new protocols. They called their supervisor and then came back and said, 'oh you're right, we'll give pain relief'. That patient died later that afternoon at home". (Palliative care doctor, ID27)

"*When I go to a patient with unidentified palliative care needs, because I have the number for the palliative care service, I've got the confidence to talk to them, I'm then happy to consult the patient almost as a referral." (Paramedic, ID10)*

5. The harsh reality

Despite the preferences of some participants to maintain a paramedic focus on emergency care, all participants recognised paramedics should offer an adjunct support for community-based palliative care because often they are the only health professional available.

Limited access to specialist support

All groups reported specialist palliative care services were not always available, especially out-of-hours, due to funding constraints:

"After-hours specialist support was inconsistent at best, and it was non-existent at worst." (Family member, ID46)

"Unfortunately, the resourcing for after-hours palliative care support is not enough." (Palliative care doctor, ID24)

Paramedics fill a gap

Participants highlighted the significant support paramedics offer when specialist palliative care services were unavailable, particularly in rural areas:

"We were called because of his deterioration and the family weren't sure what to do. They'd called the palliative care team, but they were an hour or two away, so we were called as a bridging service, I guess." (Paramedic, ID14)

"In regional and remote areas, it's the ambulance that gets called because that's all there is." (Palliative care doctor, ID23)

GPs also acknowledged their increasingly practice-based model of care requires ambulance services to be available for home visits in an emergency, to help fill the community in-reach gap:

"There are lots of GPs who don't have scope or interest in doing home visits anymore, and there are very few nursing services where medication can be initiated without involvement of a medical officer. . . The effective use of paramedic protocols in end-of-life care goes some way to filling that gap." (GP, ID18)

Working in silos

Participants reported accessing multidisciplinary services was often disjointed and inconsistent, relying on the knowledge and networks of individual clinicians rather than a streamlined approach. Accordingly, ambulance

services and GPs often worked alone, lacking integrated approaches with other services:

> *"Paramedics are predominantly employed and work within a centralised service for a state. But then they have to operate within all these individual health services, who aren't always all on the same page." (Paramedic, ID15)*

> *"We work in silos. We don't communicate well." (GP, ID22)*

However, specialist palliative care providers expressed a desire to collaborate more in *'shared care models'* (Palliative care doctor, ID23) with ambulance services and other healthcare providers in the future.

Discussion

Main findings/results

The broad range of perspectives and experiences captured in this study reflect a diversity of cultures within, and across, healthcare disciplines and communities. A dichotomy of thought was expressed amongst the participants. Some participants in our study described inconsistencies in ambulance services' governance, training, and interdisciplinary approaches. Conversely, anecdotes of greater specialisation pathways and growing unity between ambulance and palliative care services were also articulated.

What this study adds

The main findings of our study align with broader literature, which suggest although paramedics are increasingly attending palliative and end-of-life care patients in the community, a divergence of opinion exists within the discipline regarding their capacity to provide this type of care at the expense of other emergencies. Some argue palliative paramedicine is not for everyone, but rather for those paramedic 'champions' who have a passion for palliative care.[25,26] We agree with this sentiment, but also call for a generalist palliative care capacity for all paramedics, and specialist roles for those demonstrating interest and aptitude.

In 2018, paramedics entered the National Registration and Accreditation Scheme for Health Practitioners in Australia.[27] One study described the experience as a transition from a discipline with a disparate framework of employer-based regulation and governance, to a nationally regulated profession with self-determination over standards and practice.[28] This significant step towards paramedicine professionalisation in Australia has aligned with an increasing scope of autonomy, roles and practice relevant to the provision of community-based care internationally.[10,16,28] Registration has precipitated similar changes within the United Kingdom's paramedic workforce a decade earlier,[29] resulting in the emergence of paramedic practitioner roles, including those specialising in palliative care.[30,31] However, the Canadian paramedic workforce – a pioneering leader in community and palliative paramedicine[4,32] – remains registered provincially, rather than nationally, and trains clinicians through vocational pathways in preference to university degree programmes.[33] This raises the pertinent question: does paramedicine professionalisation drive the emerging scope of palliative and end-of-life care, or do community needs and ambulance service innovation have a greater influence? We believe both factors have an impact; the latter being most critical.

Some participants expressed strong-held beliefs of restricted time on scene and the necessity to treat and transport all patients to hospital, which are seemingly driven by individual perceptions, creating a culture of paramedicine at odds with what is reflected in clinical practice guidelines and accordingly permitted by ambulance service management.[12] Furthermore, community expectations and media responses to ambulance waiting times could be proliferating these assumptions. Future research could investigate strategies for overcoming such cultural norms, potentially enabling a smoother transition for paramedics to reduce avoidable hospital admissions and facilitate more home-based deaths.

Multidisciplinary approaches to palliative care were praised by participants and supported by literature.[34,35] The Australian and New Zealand Society of Palliative Medicine has previously called for a greater focus on expanding the practice of specialist palliative care teams to better support primary palliative care providers through consultative or consortium arrangements.[36] Despite these assertions, paramedicine is still lacking from palliative care policies,[16,37] and remains an under recognised palliative care asset within international frameworks.[38] Moreover, paramedicine has traditionally prided itself as a discipline of independence and autonomy, perhaps reinforcing hierarchies and siloes of care, and hindering opportunities for establishing communities of palliative care practice.[19,39]

However, the COVID-19 pandemic has expediated the settings in which paramedics can work, highlighting opportunities for these skilled clinicians to join multidisciplinary teams in general practice and palliative care settings.[1,40] This approach has resulted in congenial relationships across disciplines, foreshadowing opportunities for future integrated models of community-based palliative care. One study highlighted collaborative relationships with paramedics require professional acknowledgement, respect and reciprocity to strengthen their willingness to share knowledge and skills.[41] To foster sustainable networks of interdisciplinary learning and care across paramedicine, palliative care and community-based health services, a contextual awareness and understanding of operational culture, barriers and enablers will be required.

Finally, advance care planning processes can help mitigate unwanted interventions and crisis-fuelled decision

making for palliative care emergencies.[15,42] However, timely access to legible advance care planning documentation remains a key challenge for paramedics globally.[11,43–45] The previous use of paper-based standardised palliative care documentation for paramedics offered a solution for one Australian jurisdiction, while rendering significant challenges along the way.[46] Participants of our study also raised the importance for families to be able to 'change the plan' in cases of carer burnout and distress. Balancing these competing priorities in the future will require a high degree of clinical skill and discretion amongst paramedics, perhaps facilitated by universal paramedic access to electronic medical records.

Strengths and limitations of the study

This study explored participant perspectives of paramedic practice in Australia, which follows an Anglo-American ambulance system. However, we believe the findings of this study are relevant to ambulance services in many countries given the important role that paramedics may have in providing palliative and end-of-life care in home-based settings. A key strength of this study was the sizeable and varied sample of participants, coming from six important stakeholder groups and all jurisdictions of Australia, allowing for in-depth analysis and transferability of the data. Self-selection and recall bias are potential limitations of this study. Opportunities also exist to investigate the lived experience of patients with palliative care needs in the future.

Conclusion

Palliative paramedicine is an emerging scope of practice within ambulance services internationally, but findings from this study align with literature from different countries which, suggests a dichotomy of thought exists regarding what the role of a paramedic ought to be. They have a revered public identity, shaped by a perceived ability to fix a crisis. However, paramedics and other health professionals sometimes express fear and vulnerability when taking a palliative approach to care. They require consent to move beyond a culture of curative care and will offer an adjunct support for community-based palliative care. Future research could investigate strategies for overcoming prohibitive paramedicine cultural norms related to palliative and end-of-life care, and explore the practical steps required to overcome barriers and introduce facilitators addressed in future research to improve paramedic interdisciplinary practice with palliative and primary care services.

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Ethics approval

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Supplemental material

Supplemental material for this article is available online.

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Chapter 6: Health professionals' and caregivers' perspectives on improving paramedics' provision of palliative care in Australian communities: A qualitative study

The following chapter contains a qualitative study of the perspectives and experiences of 50 health professionals and family caregivers towards the opportunities for improving palliative paramedicine in Australian community-based settings. It has been submitted to the Medical Journal of Australia in August 2023, and is currently under peer review.

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Health professionals' and caregivers' perspectives on improving paramedics' provision of palliative care in Australian communities: a qualitative study

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Abstract

Objectives: Paramedics have the potential to make a substantial contribution to community-based palliative care provision. However, they are hindered by a lack of policy and institutional support, as well as targeted education and training. This study aimed to elicit paramedics', palliative care doctors' and nurses', general practitioners', residential aged care nurses' and bereaved families and carers' attitudes and perspectives on how palliative paramedicine can be improved to better suit the needs of community-based patients, their families and carers, and the clinicians involved in delivering the care.

Design, setting, participants: In this qualitative study underpinned by a social constructivist epistemology, semi-structured interviews were conducted with 50 participants with palliative paramedicine experience, from all jurisdictions of Australia. Participants were interviewed between November 2021-April 2022.

Results: All participants suggested paramedics play an important adjunct role in the provision of palliative and end-of-life care in home-based settings. Three levels of opportunities for improvement were identified: macro (policy and frameworks; funding and education; accessing medical records; and a widening scope); meso-level (service-level training; interprofessional understanding and communities of practice; and community expectations); and micro-level (palliative care subspecialty; debriefing and selfcare; and partnering with families).

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Conclusion: To enhance paramedic capacity to provide palliative care support, improvements targeting systems, services, communities and individuals should be made. This calls for stronger inclusion of paramedicine in interdisciplinary palliative care, and greater investment in both the generalist and specialist palliative paramedicine workforce.

Keywords: Palliative care, terminal care, emergency medical services, paramedic, ambulance, qualitative research

The known

Paramedics have an increasing and expected adjunct support role delivering community-based palliative and end-of-life care, especially out of hours. However, only five Australian ambulance services currently have palliative care-specific guidelines.

The new

Improvements targeting systems, services, communities and individuals should be prioritised. We call for stronger inclusion of paramedicine in interdisciplinary palliative care, equipping paramedics with generalist palliative care capability, and offering specialist pathways to those demonstrating aptitude and interest.

The implications

Gaining consensus on interventions considered most essential for improving palliative paramedicine in communities could help inform the future implementation and evaluation of a palliative paramedicine framework, to standardise best practice across Australia.

Introduction

Australia is an ageing society with a growing demand for community-based death. Yet despite approximately 70 percent of people wanting to die at home, only 14.8 percent currently get that wish granted, at least in part due to palliative care workforce shortages.[49, 50] Specialist palliative care medical and healthcare workers are insufficient, alone, to provide the entirety of this care, nor is it necessary or viable for all patients to receive solely specialist support. Instead, the World Health Organisation advocates a multidisciplinary approach to palliative and end-of-life care.[51] General practitioners (GPs) contribute substantially to the provision of community-based palliative and end-of-life care in Australia, but their round-the-clock availability and resources are limited.[50] The Royal Commission into Aged Care Quality and Safety has also underscored the significant shortfalls of generalist and specialist palliative care service provision for older Australians living in residential aged care and the community.[52] Recently it has been highlighted that paramedics may have an important role to play in delivering community-based palliative and end-of-life care as an adjunct support, especially out of hours.[53, 54]

Paramedics work predominately for state and territory-based ambulance services, providing emergency care for communities 24 hours a day, seven days a week across all locations of Australia. Palliative care emergencies are now recognised within the scope of paramedics' unique skillset, but only five Australian jurisdictions currently have palliative and end-of-life care clinical guidelines to standardise practice in this area.[55]

Previous studies have investigated the elements required for implementing a community-based palliative paramedicine programme in Canada,[56] developed a theory of change-based approach for improving English paramedic responses to patients dying at home,[57] and highlighted the top ten tips American palliative care clinicians should know about improving partnerships with ambulance services.[58] However, there remains a gap in identifying opportunities for enhancing the role of paramedics delivering palliative and end-of-life from diverse stakeholder perspectives. This study aimed to explore how palliative paramedicine can be improved to better suit the needs of community-based patients, their families and carers, and the clinicians involved in delivering that care.

Methods

Methodology

This paper draws on a sub-set of data from a larger study[59] exploring key stakeholders' experiences and perspectives of the role, barriers and enablers of palliative paramedicine in Australian communities. A qualitative study design was underpinned by a social constructivist epistemology, contending that experiences and perspectives are socially constructed by participants as they engage with the world, rather than reflections of objective truth. This study is reported following the Consolidated Criteria for Reporting Qualitative Research Guideline.[60]

Sampling strategy

Health professionals and bereaved family members and carers were eligible to participate in this study if they were aged 18 years or older and were involved in the care of someone with palliative care needs who encountered paramedics towards the end of their lives in the community. Health professional sub-groups included paramedics, GPs, palliative care nurses, palliative care doctors and residential aged care home managers.

Participants were purposively sampled to ensure a range of demographics and clinical experience were represented. We aimed to capture the perspectives of all stakeholders involved in palliative paramedicine. Health professional participants were recruited through professional organisations, and family and carer participants were recruited through a national organisation's register of palliative care consumers and carers. An advertisement about the research was published in each respective online newsletter and an email was sent to each organisation's members outlining the study and inviting them to contact the research team if they were interested in participating. An invitation was also circulated through collegial networks and sent to opinion leaders with publicly available email addresses, outlining the study, inclusion criteria and contact details of the research team. Once an interested person contacted the research team, they had the opportunity to talk to a researcher to ask questions before their participation was confirmed.

Data collection

Virtual semi-structured interviews were conducted via Zoom between November 2021 and April 2022. Interview guides (Appendix 1 and 2) were developed, and pilot tested, informed by discussions with the

Australasian Palliative Paramedicine Advisory Group and previous studies.[54, 55] Two health researchers (MJ and CP) unknown to participants independently conducted the interviews online. Both researchers were experienced in qualitative research methods. With participant consent, interviews were audio-recorded and transcribed verbatim by an external company, Pacific Transcription Inc. The researchers also took field notes for reflection during data collection. Participant recruitment ceased when no new themes became apparent across the sub-groups.

Data analysis

Supported by literature, we surmised palliative paramedicine structures exist at systems (macro), service and community (micro), and clinician and consumer (meso) levels.[61-63] Drawing on Braun and Clarke's six-phase guide in reflexive thematic analysis,[23] an inductive approach was employed, coupled with the researchers' existing knowledge, to identify interventions that contribute to the improvement of palliative paramedicine at these differing structural levels. MJ read all the transcripts and familiarised herself with the content, then independently identified potential codes for each structural level and met with CP, JC and PB to discuss and develop the codebook – a typology of macro-, meso- and micro-level interventions for improving palliative paramedicine- allowing for consistent interpretation and classification of the data. .[64, 65] This codebook was then used to guide coding of the remaining transcripts by MJ. Consecutive rounds of discussions were held with MJ, JC, PB, CP, MB and PS to capture multidisciplinary perspectives and enhance the analytical framework. NVivo was used to store, organise and support analysis of the anonymised data.[66]

Ethics approval

Ethics approval was sought from the University of Sydney Human Ethics Committee (registration number 2021/607 and 2021/608). All participants gave their written informed consent to participate.

Results

A total of 50 individual interviews were conducted between November 2021 and April 2022, including participants from all states and territories of Australia (Table 1). The interviews ranged in duration between 18-64 minutes. Themes are classified into macro-, meso- and micro-level interventions (Figure 1) and illustrated by quotes identified by role and ID (Table 2).

Overall, all participants strongly supported the important adjunct role that paramedics have in the provision of palliative and end-of-life care in home-based settings, recognising *"a substantial remit for Ambulance in the care of palliative patients" (Palliative care doctor, 23).*

Macro-level

Participants suggested numerous macro-level interventions to improve palliative paramedicine practice, which focussed on high-order aspects of the aggregate national healthcare system.

Policy and frameworks: All participant groups acknowledged the lack of paramedic inclusion in both international and domestic palliative care policies and framework, and considered this to be a top priority for improving systems, services and practice in the future:

> *"If they're recognised in policy and framing, then it's more than likely people need to then incorporate that thinking into their workload." (Palliative care doctor, 26)*

Funding and education: Interdisciplinary palliative and end-of-life care funding and competencies were also championed to encourage the *"sustainability"* of palliative care practice through *"a shared care model"* (Palliative care doctor, 22). As part of this multidisciplinary approach, participants advocated for palliative care to be embedded into undergraduate paramedicine curriculum, *"so paramedics start to see themselves as part of the palliative care continuum"* (Paramedic, 10).

Accessing medical records: Participants also expressed concern with the ongoing limitations paramedics and other clinicians face retrieving patients' medical and social histories in a timely manner, calling for universal healthcare access to electronic medical records. Paramedics emphasised a need for a *"streamlined process"* whereby everyone *"knew what to expect"* (Paramedic, 1) from a standardised document, which paramedics could then contribute to:

> *"If we could use some kind of integrated messaging system say, 'I've been to this patient, I administered this medication, I identified these issues, I recommend this'. Being able to feed that back to other clinicians would improve patient outcomes." (Paramedic, 4)*

A widening scope: Broadening a paramedic's scope of practice to verify death was also acknowledged amongst participants as an opportunity to reduce avoidable attendance from police, in cases of an expected death where a doctor or senior nurse is unable to attend the home in a timely way. Participants noted this was already available to paramedics in some jurisdictions, however they argued for a national

approach. Paramedics contended, evoking these macro-level changes will require *"a shift in our culture and identity"* (4) and flagged the growing professionalisation of the paramedic role opened doors to work *"outside of ambulance services"* (15) in the future.

Meso-level

Meso-level interventions were put forward by participants, which focussed on enhancing palliative paramedicine in healthcare services and communities.

Service-level training: Clinicians highlighted a need for ambulance services to *"build on the existing skillset of paramedics"* (GP, 20) to *"chart and have access to end-of-life medications"* (Residential aged care nurse, 42) and *"administer via sub-cuts"* (Paramedic, 2). Participants noted these changes would require *"very clear guidelines on symptom management"* (Palliative care nurse, 32) and standardised palliative care education and training, with optional specialisations for ambulance services demonstrating capacity and interest.

Interprofessional understanding and communities of practice: All participant groups remarked on the *"multidisciplinary and holistic approach"* (Palliative care nurse, 30) of palliative care, which required greater *"collaboration across agencies"* (Family carer, 45). Specialist palliative care personnel suggested *"having more structured dialogue and shared time"* between ambulance services and other palliative care providers, including GPs, to establish interprofessional understanding and communities of practice (Palliative care doctor, 27). Participants from regional, rural and remote backgrounds recognised the need for innovative solutions in their settings, where after-hours specialist palliative care support is particularly limited:

> *"We could have a programme where palliative patients are actually introduced to paramedics prior to them requiring any assistance from an ambulance." (Paramedic, 11)*

Localised referral pathways were another priority for all participants, allowing a paramedic *"to ring a palliative care service in a situation where they're really not wanting to transfer the patient, or they feel they need to get some advice fast"* (Palliative care doctor, 25). Virtual emergency departments were discussed by some participants as an emerging solution for ambulance services with limited access to specialist palliative care support.

Community expectations: Paramedics remarked on the challenges facing ambulance service dispatch systems, noting *"we over-triage as a way of protecting the system"* (9). Some participants called for improved coordination to prompt call takers to identify palliative care patients early on. Others suggested public

death literacy and ambulance service education campaigns were needed, in addition to compassionate communities' initiatives, to better educate the public about the realities of death and dying, as well as the role paramedics can play in delivering palliative care at home:

> *"Empowering people to know that this is just another part of life and one that we used to deal with in our families. A lot of it can be managed at home without acute hospital situations." (Family carer, 47)*

Micro-level

Interventions focussing on individual clinicians' and consumers' capacity and experience were also suggested by participants and classified as micro-level.

Palliative care generalist versus specialist capability: Although participants recognised not all paramedics gravitate towards non-traditional elements of paramedicine, including palliative care, they recommended every paramedic ought to have a mandatory generalist palliative care capability, with pathways to specialise in community and palliative care roles if they wish:

> *"This is one of my favourite areas of clinical practice and if they made palliative care paramedics, I'd definitely put my hand up for that." (Paramedic, 1)*

Participants emphasised, those paramedics with an aptitude and interest required opportunities to become palliative care champions within their networks to *"drive that direction to keep the palliative approach going"* (Palliative care nurse, 31).

Debriefing and selfcare: More broadly, participants reiterated the importance of paramedics of all levels receiving access to self-care and multidisciplinary debriefing services, ensuring they were not being *"exposed to too much"* death and dying without adequate peer support (Paramedic, 6).

Partnering with families: Participants highlighted the contributions family members and carers could make towards facilitating paramedics to take a palliative approach. Family carer participants suggested *"acknowledging the family are often the experts in these scenarios"* (47) and supporting them *"to be involved and included"* (45) alleviated distress and facilitated early bereavement. Participants also noted paramedics would often be called to simply provide in-home manual handling support for immobile palliative patients, and these cases could be opportune moments to refer families and carers to palliative care supportive services:

"Giving families a bit more guidance around what they should do at this point, as some families would not be prepared because maybe the GP hasn't been proactive." (GP, 20)

Finally, family-centred care after death principles were considered important by all participant groups to *"make sure the process of dying is as dignified as possible"* (Paramedic, 10).

Discussion

This study identified opportunities for improving a current gap in the provision of care for people at end-of-life, especially out-of-hours, by enhancing the existing skill base and presence of paramedics within Australian communities. All participants agreed greater paramedic involvement in palliative emergency responses would assist patients, families and carers, as well as other healthcare professionals. Our findings suggest a multifaceted approach – incorporating interventions for systems, services, communities and individuals – will be required to improve patient care and enable better access to paramedics delivering palliative and end-of-life care in conjunction with broader multidisciplinary teams. [61-65] However, integrating palliative care into paramedicine core business must strike a balance between enhancing the role of the paramedic as an adjunct provider, while preserving the broader medical emergency response function of an ambulance service in the community.[67, 68] Evoking cultural change to overcome the lifesaving orthodoxy of the paramedic role will be one associated challenge.[56, 57, 67] To support this, as a first step we recommend all undergraduate and postgraduate paramedicine degrees embed palliative and end-of-life care theory and practice throughout their curriculum.[69]

To strengthen paramedics' role within existing interdisciplinary palliative care networks, greater recognition of their capacity and skills across the healthcare sector is required.[70] A Canadian study highlighted the importance of breaking down silos between ambulance services and other palliative and primary care providers through boundary spanning roles and formal advisory groups.[56] Consensus methodology has also been used to establish multidisciplinary core competencies for health and aged care workers in Australia in recognition of the ageing population and greater need for collaboration within disciplines.[71] We suggest the findings of both studies could help inform the development of future multidisciplinary palliative care approaches to also include paramedicine

Participants remarked on the need to invest in innovative models of palliative paramedicine beyond metropolitan areas. Findings from a recent project highlight the opportunity to pilot palliative paramedicine quality improvement initiatives in regional, rural and remote areas of Australia, where greater levels of continuity of care can foster stronger relationships across sectors.[72] Prioritising these areas could also reduce the pressure other healthcare teams face providing after-hours palliative and end-of-life care.

Finally, all paramedics are in a unique position to identify patients in the community who could benefit from a palliative approach to care, potentially sharing insights of their social and structural determinants of health if a referral to GP and/or palliative care services became available.[56, 68] However, not all paramedics will have a sustained passion for working in the palliative care space. From our findings, we recommend individual paramedics ought to have a generalist scope of palliative care practice, while those expressing interest and capacity should be afforded the opportunity to specialise in this area.[59]

Limitations and implications

Our findings represent the perceptions, experiences and expertise of the health professionals and family carers we interviewed and may not be representative of all health professionals and consumers involved in palliative paramedicine across Australia. We recruited no patients with life-limiting illnesses and experience receiving palliative care from paramedics in the community. Opportunities exist to investigate these important stakeholders' perspectives in the future. Employing Delphi methodology to gain consensus from a group of multidisciplinary palliative paramedicine experts on the macro-, meso- and micro-level interventions considered most essential for improving palliative paramedicine in communities could help inform the future implementation and evaluation of a palliative paramedicine framework, to standardise best practice across Australia.

Conclusion

Paramedics play an important adjunct role in the provision of palliative and end-of-life care in home-based settings. To ensure their sustainability in this provision, improvements targeting systems, services, communities and individuals should be made. Our findings provide a preliminary framework of interventions at macro-, meso- and micro-levels that could shape future policy and practice: imploring a

broadening of cultural assumptions surrounding what it means to be a paramedic, stronger inclusion of paramedicine in interdisciplinary palliative care, and greater investment in both the generalist and specialist palliative paramedicine workforce ought to be prioritised.

Declarations

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The study design was developed by MJ, JC, PB and CP in consultation with the Advisory Group. The interviews were conducted by MJ and CP. MJ conducted the thematic analysis, which was cross-checked by JC, PB, CP, MB and PS. MJ drafted the manuscript. All authors critically revised the manuscript, making substantial contributions and approving the final version.

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Table 1 Descriptive characteristics of participants

All participant characteristics	**Participants (n = 50)**	**%**
Age		
18-30	1	2
31-65	44	88
66-75	5	10
Gender		
Male	19	38
Female	31	62
Country of birth		
Australia	31	62
United Kingdom	10	20
Other	9	18
Employment status		
Full time	37	74
Part time or causal	9	18
Not employed	4	8
State		
Australian Capital Territory	5	10
New South Wales	18	36
Northern Territory	4	8
Queensland	5	10
South Australia	6	12
Tasmania	1	2
Victoria	9	18
Western Australia	2	4
Main occupation		
Paramedic	17	34
General	9	18
Intensive care	4	8
Extended care	1	2
Intensive and extended care	2	4
Rescue	1	2
GP	5	10
Palliative care doctor	7	14
Palliative care nurse	8	16
Residential aged care nurse	5	10
Family member/carer	8	16
Health professional participant characteristics	**Participants (n=42)**	**%**
Location of workplace		
Metropolitan	27	64.3
Rural	10	23.8
Remote	5	11.9
Predominant practice setting		
Ambulance service	17	40.5
On road	10	58.8
On road and PhD candidate	2	11.8
On road and leadership role	5	29.4
Palliative care	15	35.7
Community consult service	2	13.3
Inpatient palliative care unit		
Acute hospital consult service		
Mix of settings	13	86.7

General practice	3	7.1
Residential aged care	6	14.3
Other	1	2.4
Length of work experience		
1-5 years	1	2
6-10 years	5	10
More than 10 years	36	72
Family member/carer participant characteristics	**Participants (n=8)**	**%**
Education background		
Completed high school to year 10 equivalent	1	12.5
Completed final year of high school equivalent		
Professional certificate or vocational school	3	37.5
Undergraduate degree	1	12.5
Postgraduate degree	3	37.5
Location that the person was cared for		
Metropolitan	6	75
Rural	2	25
Remote		
Relationship with the person cared for		
Spouse	3	37.5
Parent/Guardian	4	50
Aunt/Uncle	1	12.5
Age range of person cared for		
31-65	4	50
66-75	1	12.5
76-85	1	12.5
86+	2	25
Primary medical diagnosis of person being cared for		
Cancer	8	100
Heart failure		
Chronic respiratory disease		
Dementia		
Kidney failure		
Liver failure		
Motor neuron disease		
Other		

Figure 1: Thematic summary of interventions to improve palliative paramedicine practice

Policy and frameworks

- Include paramedicine in palliative and end-of-life care policies and frameworks

Funding and education

- Fund interdisciplinary palliative and end-of-life care competencies
- Embed palliative care into paramedicine curriculum

Accessing medical records

- Provide paramedics access to electronic medical records

A widening scope

- Broaden paramedic scope to verify death
- Establish specialist paramedic roles beyond ambulance settings

Macro-interventions

Palliative care subspecialty

- Palliative care generalist versus specialist capability
- Establish optional specialist palliative care capabilities and palliative care champion roles

Debriefing and selfcare

- Provide access to selfcare and peer support services

Partnering with families

- Facilitate opportunities to partner in care
- Provide in-home manual handling support
- Refer families and carers to palliative care supportive services
- Employ family-centred care after death principles

Micro-interventions

Service-level training

- Broaden palliative and end-of-life care scope of practice
- Standardise palliative care education and training, with specialist pathways

Interprofessional understanding and communities of practice

- Establish interprofessional understanding through training, debriefing and communities of practice
- Identify localised referral pathways

Community expectations

- Improve coordination of ambulance dispatch
- Establish public death literacy and ambulance service education campaigns
- Support Compassionate Communities initiatives

Meso-interventions

Table 2: Illustrative comments by participants, by theme and sub-theme

Theme/Sub-theme	Participant comments
1. Macro-level interventions	
• Include paramedicine in palliative and end-of-life care policies and frameworks	"Policy needs to acknowledge that the ambulance services can play a very important role in the palliative care of patients." (Palliative care doctor, 24)
• Fund interdisciplinary palliative and end-of-life care and competencies	"We need to stop considering ourselves as separate entities within health. Start considering ourselves as one health unit with different functions within that unit." (Paramedic, 2)
• Provide paramedics access to electronic medical records	"When we get our state-wide electronic medical record up, paramedics should have access to that. Ambulance should have access to a value-add, shared medical record. We know that the Commonwealth one hasn't been a good solution. Whatever's in my notes here for my patients, it's not visible to Ambulance, it's not visible to general practice, it's not visible to pharmacists. So, I think access to the EMR is really important." (Palliative care doctor, 23)
• Embed palliative care into paramedicine curriculum	"The shift to university-based education is broadening the scope and flavours that students are seeing throughout their undergraduate curriculum. They're starting to see that not all medicine is curative. That there is that balance. Even just being able to work with other professions throughout their undergraduate degree, I think really opens them up to the way that different people work. Therefore, they start to think about health, rather than just curing disease, and palliative medicine is a part of that." (Paramedic, 15)
• Broaden paramedic scope to verify death	"Paramedics have actually called the police and then the police have called the coroner for a palliative care patient because they thought it was an unexpected death. So, I think if that can be avoided, that's also another good thing that could happen as well. Because it just puts the family through a lot of unnecessary trauma." (Palliative care nurse, 37)
• Establish specialist paramedic roles beyond ambulance settings	"It's about the health service acknowledging what paramedicine being registered means and where the skillset of paramedics can be of a huge benefit across a number of different areas. It's starting to open those doors to appreciate the level of professionalism within our role and allowing us to see the degrees of difficulty that are being dealt with by other roles as well." (Paramedic, 8)
2. Meso-level interventions	
• Broaden palliative and end-of-life care scope of practice	**"**I think we need a way to discern, okay is that appropriate for what this patient needs today, who prescribed that, who's looking after their care and what are the risks associated with this approach. Then we can make clinical judgements around what the patient needs. So, we're a little bit more supported to work outside our scope of practice, but I think there needs to be support for us to ensure that's appropriate." (Paramedic, 5)
• Standardise palliative care education and	**"**The hardest thing about these jobs for paramedics is talking to the family or to the patient and knowing what to say. Some people have a knack for it and some people don't. But I think some training around

training, with specialist pathways	how to talk to the family about these things or you know, what you should or shouldn't be saying. I mean for me personally, it's not about what you should or shouldn't be saying, it's about reading the room and picking up on those social cues, which isn't necessarily something that everyone's always good at." (Paramedic, 1)
• Establish interprofessional understanding through training, debriefing and communities of practice	"We work in silos. We don't meet each other or know one another's services. We have to communicate in ways that are sensitive to the next clinician along the line for the interest of the patient. To try and just get that right balance of suggestion versus telling so that services work together, not against one another. We have to get past our personal service biases to work together for the patient. But it does require sensitive communication between all services and understanding what their roles should be." (GP, 22)
• Identify localised referral pathways	"We talk about integrative care, but we need the support system around us to actually integrate care. I think paramedics know pretty confidently that going to the emergency department is not the best solution for most palliative care patients. They know that they're going to have unnecessary testing done. They're probably going on a trajectory as soon as they go to the ED that isn't what the patient wants. What they want to do is often be at home and have services come to them. So, we need a way to bridge that gap, to bring the service to the patient. We can provide that initial emergency palliative care. We can spend time with family members and make sure they're supported. It can be a medical support, and psycho-social support as well. But we need to be able to refer them on, because I think that's where we end up reverting to that transport approach." (Paramedic, 4)
• Improve coordination of ambulance dispatch	"If it's palliative care, we'll have our call takers flag it to us immediately and say, this is a palliative care patient." (Paramedic, 6)
• Establish public death literacy and ambulance service education campaigns	"I feel like there needs to be a lot more education for the families about what to expect, including visual footage of somebody at the end of their life. So, that they can really see how confronting it can be." (Paramedic, 11)
• Support compassionate communities initiatives	"The people that I know who have had a very good experience with palliative care had someone within their family who was a nurse or doctor, who was able to administer or understand what's happening. Or they might be trained in aged care, knowing how to change sheets, help someone with the toilet, all of the hygiene stuff. All of that takes training, and unless people are trained or have someone within their networks that can do that, it's very difficult, and often, I think from what I've seen, it's just a handful of people who are trying to do their best, who are exhausted." (Family carer, 50)
3. Micro-interventions	
• Palliative care generalist versus specialist capability	"Most people don't become paramedics because they want to engage in end-of-life care. If they want to do that, they tend to go off and do something else in health. So, I think we've got to be mindful of the fact that many of the people in the paramedical services are paramedics because they actually want to be involved in the trauma and emergency response. So, really, it's about giving people access to a suite of skills that will help them do the work that they are going to invariably get called to,

	without necessarily making it an expectation that this is then going to become their core business. Because at the end of the day that's not what people sign up to become ambulance officers to do, in the main." (GP, 18)
• Establish optional specialist palliative care capabilities and palliative care champion roles	"Single responder paramedics could potentially specifically respond to these scenes which might not be time critical, so there's not that time urgency in general. They might have some further training in palliative care and be able to assist." (Paramedic, 14)
• Provide access to selfcare and peer support services	"Patient care of the dying is really hard on workers, on the workforce as well. Yes, there's critical incident debriefing, but just prolonged exposure to dying, to garden variety dying, can actually be challenging as well. So, I think that that's a really important part of it as well is acknowledging the impact on the workforce." (Palliative care doctor, 23)
• Facilitate opportunities to partner in care	"If they can come to the home where the person is living, provide effective symptom management and what I would call supportive counselling. They're not there to counsel, but they're there to reassure with open, direct, honest communication. Especially if the person with the life-limiting illness doesn't want to go to hospital, they can offer reassurance and help them realise that these are the strategies that you can use, this is how you can care for your loved one or your significant person." (Family carer, 45)
• Provide in-home manual handling support	"Being that physical support in helping them move patients, because obviously there's that transition of patients wanting to be in their chairs, to that point where the patients need to go into the bed. So we can be that physical help and we've got lifting equipment, we've got manual handling support." (Paramedic, 9)
• Refer families and carers to palliative care supportive services	"I think they need to, as much as possible, be aware of who they need to call if there are other services involved. Community palliative care services all have 24-hour numbers, so they should be able to organise support." (Palliative care nurse, 30)
• Employ family-centred care after death principles	"Everybody experiences death in a different way and there's not one easy way to go around it. So you need to have more than one skill to console the family that's there, because they are now your patient. Once a person has passed you now have two, three, a multitude of different people who are going to experience it in a different way." (Paramedic, 3)

Chapter 7: Development of a palliative paramedicine framework to standardise best practice: A Delphi study

The following chapter contains a Delphi study of the components considered most essential for improving the role of paramedics delivering palliative and end-of-life care in Australian communities. It has been submitted to Palliative Medicine Journal in: September 2023, and is currently under peer review.

7.1 Citation

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Development of a palliative paramedicine framework to standardise best practice: A Delphi study

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Abstract

Background: Growing global demand for palliative care services has prompted generalist clinicians to provide adjunct support to specialist teams. Paramedics are uniquely placed to respond to these patients in the community. However, embedding palliative care principles into their core business will require multifactorial interventions at structural, healthcare service and individual clinician and consumer levels.

Aim: To develop a palliative paramedicine framework suitable for national implementation, to standardise best practice in Australia.

Design: Delphi study utilising questionnaire completion; each round informed the need for, and content of, the next round. Free text comments were also sought in Round 1. Two rounds of Delphi were undertaken.

Setting/Participants: Sixty-eight participants took part in Round 1, representing six countries, and 66 in Round 2. Participants included paramedics, palliative care doctors and nurses, general practitioners, researchers and carers with lived experience and expertise in palliative paramedicine.

Results: Seventeen of the original 24 components gained consensus; six components were modified; and nine new components arose from Round 1. All modified and new components gained consensus in

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Round 2. Only one original component did not gain consensus across both rounds and was excluded from the final 32-component framework.

Conclusion: This study has developed a comprehensive national framework addressing the macro-, meso- and micro-level interventions required to standardise palliative paramedicine across Australia. Future research ought to engage a multidisciplinary team to create an implementation strategy, addressing any perceived barriers, facilitators and challenges for applying the framework into policy and practice.

Key words: palliative care, terminal care, emergency medical services, paramedic, consensus development, Delphi methods

What is already known about the topic?

- When adequately trained and supported, paramedics can enhance person-centred care, reduce avoidable hospitalisations and facilitate the fulfilment of one's preferred place of death.
- Embedding palliative and end-of-life care into paramedics' core business will require multifactorial interventions at structural, healthcare service and individual clinician and consumer levels.
- The Delphi technique is a method of systematically collating expert consultation and building consensus. It is particularly useful for establishing frameworks in complex settings such as palliative paramedicine.

What this paper adds?

- This study gained consensus from an international multidisciplinary expert panel on 32 macro-, meso- and micro-level components of a palliative paramedicine framework, suitable for implementation to standardise practice at a national level.
- The expert panel called for stronger inclusion of bi-directional training and multidisciplinary debriefing opportunities between ambulance services and other palliative care providers.

Implications for practice, theory or policy?

- Our findings suggest paramedics should be supported to make complex clinical decisions specific to palliative care contexts with confidence and navigate holistic care pathways that prioritise referral functions available to other community-based clinicians.
- Future research should engage a multidisciplinary team to create an implementation strategy, which would reflect any perceived barriers, facilitators and challenges for applying the framework into policy and practice.
- In developing the implementation strategy, endorsement of relevant professional associations should be sought, a theory applied to guide next steps, and the time and resources required to standardise palliative paramedicine practice across Australia acknowledged. Findings from testing the strategy could have resonance for palliative care providers and ambulance services worldwide.

Background

Growing global demand for palliative care services, and rising international preference for home-based deaths,[1] have prompted an increasing number of generalist clinicians to provide adjunct palliative and end-of-life care support to specialist teams.[2-4] The COVID-19 pandemic accelerated this shift towards interdisciplinary palliative care,[5] highlighting the role primary care settings can play in this context.

Paramedics are uniquely placed to respond to palliative and end-of-life care patients in the community, particularly after-hours when specialist palliative care services might be unavailable.[6] When adequately trained and supported, paramedics can enhance person-centred care, reduce avoidable hospitalisations and facilitate the fulfilment of one's preferred place of death.[1, 7] However, attitudes towards expanding paramedics' role to deliver palliative and end-of-life care in communities varies considerably within ambulance services, across health professions and throughout cultures.[8-11]

Embedding palliative and end-of-life care into paramedics' core business will require multifactorial interventions at structural, healthcare service and individual clinician and consumer levels. Previous studies have argued for greater inclusion of paramedicine in palliative care policies and frameworks;[9] discussed whether the role of palliative care ought to be relegated to specialist community paramedics;[12, 13] identified the barriers to understanding and utilising advance care planning documentation in American pre-hospital settings;[14] explored Finnish paramedics' palliative and end-of-life care clinical protocol and educational needs;[15] and investigated the essential elements to implementing a Canadian paramedic palliative model of care.[16] However, to our knowledge, no previous studies have outlined the strategies necessary to develop a comprehensive whole-of-system approach to palliative paramedicine.

The Delphi technique is a method of systematically collating expert consultation and building consensus. It is inherently constructivist in nature, and particularly useful for establishing frameworks in complex settings such as this one.[17] The aim of this study was to develop a palliative paramedicine framework suitable for national implementation, by determining the components considered most essential for

improving the role of paramedics delivering palliative and end-of-life care in Australian communities. It is hoped the findings will shape a best practice framework suitable for national implementation.

Methods

Design

We employed a Delphi methodology to build systematic consensus from a broad range of experts, underpinned by a social constructivist epistemology.[17] This approach has previously been used in palliative care research to gather international perspectives and develop best practice guidelines and frameworks, especially when clinical trials and large-scale observational research were not possible.[17-20] The study adopted the four key methodological features of a Delphi: (1) a group of experts participated on a panel and were questioned about the issue of interest; (2) the process was anonymous to avoid conformity to a dominant view; (3) the procedure was iterative, comprising repeated rounds of enquiry and; (4) the design of subsequent rounds was informed by the summary of group responses from Round 1.[17, 21] We adhered to the 'Guidance on Conducting and REporting DElphi Studies' (CREDES) to ensure robust methodology and reporting.[17]

Setting

The focus of this Delphi study was paramedics delivering palliative and end-of-life care in community-based settings. An Anglo-American lens of ambulance services, where paramedics provide care to patients with medical oversight, was adopted throughout, in contrast to the Franco-German emergency physician-led model.[22]

Population

To broaden participation and encourage a wide range of international expertise, the target population to be recruited were healthcare professionals, academics and family carers with lived experience and significant expertise in palliative paramedicine in Australia and/or abroad. The healthcare professional and academic discipline sub-groups included paramedicine, palliative care, general practice and emergency medicine.

Sampling approach

We adopted a purposive, then snowballing approach to recruit participants who would become part of an expert panel. Firstly, potential health professional and academic participants were identified through their affiliation with the Australasian Palliative Paramedicine Advisory Group. This study-developed group was comprised of medical directors and senior clinical managers from all Australian and New Zealand ambulance services, and an experienced emergency nurse/palliative paramedicine researcher. We then approached health professional collegial networks with a targeted invitation, including the Australasian College of Paramedicine, Australasian College of Paramedicine Deans, Royal Australasian College of Physicians Chapter of Palliative Medicine, Palliative Care Nurses Australia and Royal Australian College of General Practitioners. International palliative paramedicine opinion leaders with publicly available email addresses were also invited to participate in the Delphi, as well as health professional and family carer participants of our previous study – a qualitative exploration of palliative paramedicine – who demonstrated strong interest and expertise in the topic. Then using a snowballing approach, all initial recipients of the Delphi invitation were also encouraged to forward the email to colleagues and affiliates they believed would be suitable and interested to participate in the study.

Recruitment

All potential participants were initially contacted by email and provided a participant consent form and information sheet, including a background on the topic, the purpose of the study, the intended Delphi process and contact details of the research team. Participants were invited to contact MJ via email to indicate they wished to take part.

Data collection

To gain consensus on which components should be included in a Palliative Paramedicine Framework (framework), an online Delphi process was conducted using the Welphi platform,[23] incorporating subsequent rounds of feedback until consensus was reached. Materials provided to the expert panel throughout the study, including the participant information statement and round questionnaires, were carefully reviewed and piloted by the research team, to examine understandability and balance. To maintain confidentiality, each participant was assigned a unique identifier which remained consistent throughout the Delphi rounds.

Original proposed framework components

Based on analysis of broader literature and the findings of our three previous studies,[3, 6, 8, 12, 16, 24, 25] 23 original proposed framework components were created by the research team for consideration by the expert panel. These components were categorised according to systems-based macro-level interventions, service and community-based meso-level interventions, and individual clinician and consumer-based micro-level interventions.[26, 27] MJ drafted the original components and shared these with the research team for multiple rounds of discussion and refinement, before informal consensus was met and the team was satisfied to put these components to the expert panel in the round 1 questionnaire (appendix 1) .

Round 1 Delphi

A Round 1 Welphi link was sent to all registered participants via email in March 2023, and the questionnaire was open for two weeks. The participants completed a short demographic survey within this round to allow the sample to be described. The Round 1 questionnaire included 23 original components separated into three sections: macro-level; meso-level; and micro-level. Participants were asked to rate their level of agreement for each component to be included in the final framework using a 5-point Likert scale: 1 – strongly disagree, 2 – disagree, 3 – neither agree nor disagree, 4 – agree, 5 – strongly agree. Free text comment boxes were also included after each component in this round, for participants to provide specific feedback and suggest modifications for consideration in Round 2. After each section, participants also had the opportunity to highlight anything that was missing and make suggestions for new components via free text comment boxes. The Delphi Round 1 questionnaire is available in Appendix 1.

Round 2 Delphi

A Round 2 Welphi link was sent to all Round 1 respondents in April 2023, and the questionnaire was open for two weeks. The Round 2 questionnaire included 16 original, new and modified components separated into the same three sections. During this round, participants were given the opportunity to revise their responses for any original components that did not reach consensus during round 1. The collective feedback of the expert panel from Round 1 was visible to participants for these original components to help guide their decision making. Participants were also asked to rate their level of agreement for the new and modified components arising from Round 1 feedback, using the same Likert

scale. Participants were unable to provide feedback for any of the components via free text comments boxes during this round.

Data analysis

Percentages, median values and interquartile ranges (IQRs) were calculated for each component to describe the spread of answers. These values were then used to determine the level of agreement across the expert panel:[17, 19]

- Very high agreement: median = 5; percentage agreement ≥ 80%; IQR 0
- High agreement: median =4 or 5; percentage agreement ≥ 80%; IQR 1
- Moderate agreement: median ≤4; percentage agreement ≥ 60-79%; IQR ≥1
- Low agreement: median <4; percentage agreement <60%; IQR >1

An a priori criterion for consensus was defined by the research team as a component receiving 'very high agreement' or 'high agreement' from the expert panel. Those components that received these levels of agreement were retained for the framework. Those components that received 'low' agreement were removed after one round. Those components that received 'moderate' agreement were presented to participants for further rounds of rating, after which if they still didn't reach 'high' or 'very high' agreement, they would be removed from the framework.

Round 1 Delphi

Descriptive statistics were automatically generated via the Welphi platform and cross-checked by MJ using Excel. Percentages, median values and IQRs were calculated for each Round 1 component to describe the spread of answers and determine the level of agreement across the panel. MJ qualitatively analysed the free text comments for each section, employing principles of content analysis[28] to categorise feedback accordingly: 1) already addressed in existing component(s); 2) additional information constitutes a new component; and 3) could be used to modify, and thus enhance an existing component(s). One researcher read all of the free text comments, familiarised herself with their content, independently identified potential new and modified components, and met with the team to discuss and develop these components. Consecutive dialogues facilitated multidisciplinary perspectives and allowed for consistent interpretation and classification of the feedback data into Round 2 components.

Round 2 Delphi

Percentages, median values and IQRs were again calculated for each Round 2 component to describe the spread of answers and determine the level of agreement across the panel. The a priori criterion for conducting a subsequent round was not met and, therefore, no further rounds were conducted.

Results

Participation

Of the 87 invited experts, 19 declined to participate due to too many other commitments and/or a self-perceived lack of expertise in the area to contribute meaningfully to the Delphi. Sixty-eight participants took part in Round 1, representing six countries and all jurisdictions of Australia, while 66 participants took part in Round 2, representing the same six countries. Table 1 shows demographic and professional characteristics of participants across the two rounds of the Delphi. In Round 1 and 2, 37% and 38% of the expert panel were aged between 45-54 respectively, 65% and 62% were female respectively, 44% had a palliative care background, and 59% had more than 20 years' experience in their profession.

Round 1 Delphi

Seventeen of the original components from Round 1 gained consensus: and were included in the final Framework, as depicted in Figure 1 and Table 3. Six original components gained consensus; however, considering feedback from the expert panel, modifications were made to enhance each of these components for participants to reconsider in Round 2. Nine new components arose from Round 1 feedback: three macro-level, four meso-level and two micro-level. Only one original component did not reach consensus in Round 1: *Include a routine question within an ambulance call taker's algorithm that prompts further questioning about a patient's palliative care status and notify paramedics before they arrive on scene.* This component remained unmodified, for participants to reconsider in Round 2. Table 2 highlights the expert panel feedback from Round 1, including the experts panel's comments for the component that did not reach consensus, as well as the modified and new components.

Round 2 Delphi

The six modified components and nine new components arising from Round 1, gained consensus in Round 2 and were included in the Framework. The remaining original component failed to gain consensus in Round 2, reducing its consensus score from 75% agree/strongly agree (median 4, IQR 1) in Round 1, to 72% (median 4, IQR 2) in Round 2. These results rendered the exclusion of the component

from the Framework. Given all components had now either reached consensus or been removed, no further rounds of Delphi were required. Table 4 highlights the results from Round 2, and Table 5 illustrates the final components of the Framework.

Discussion

Main findings from the study

Paramedic provision of palliative and end-of-life care is an emerging frontier for the discipline globally, with significant potential to assist other palliative care services, specialist and generalist alike, in their provision of care. [3, 10] However, standardising best-practice to optimise the role paramedics can play requires a multifactorial approach[8] and geographical nuance, especially in a country as large and diverse as Australia.[12] This study allowed a group of international multidisciplinary experts the chance to deliberate the best available evidence, employing their experiential expertise to achieve consensus on a comprehensive range of 10 macro-, 11 meso- and 11 micro-level components for inclusion in the final framework, suitable for national implementation. Australians were the largest participant pool of the sample, but international experts were added to provide a wider perspective and increase the likelihood the framework could be relevant in other comparable health systems. The components included structural, healthcare service, community, clinician and consumer-level interventions.

Items included in the Framework

Perhaps most prominent amongst the experts' first round of feedback was the demand for stronger inclusion of bi-directional training and multidisciplinary debriefing opportunities between ambulance services and other palliative care providers, as reflected by our modification to meso 17 in Round 2. These findings are supported by Canadian and American models of palliative paramedicine practice, which substantiate the power of formalising communication and education channels between paramedics and palliative care clinicians.[16, 29] By requiring each jurisdiction to establish training and debriefing networks between ambulance services and local palliative care providers (including GPs and aged care), mutual understanding of capacities, strengths and weaknesses could be fostered, leading to greater awareness of interdisciplinary palliative care capabilities and a reduction in siloed care.

To continue challenging the curative treatment and transport orthodoxy of ambulance services worldwide, paramedics need to be supported to make complex clinical decisions with confidence, and navigate holistic care pathways that prioritise referral functions available to other community-based clinicians.[8, 12]Another omission from our original components, as identified by the expert panels' feedback and new meso-level component 19, was the need for clinical back-up support pathways for paramedics at the point of care. Our authorship team assumed this would already occur in a generalist sense, without articulating it in the Australian context, as some jurisdictions already have these processes in place.

However, the Round 1 feedback indicated the expert panel considered specialist palliative care support a desirable framework component, even if only available via telehealth. This is consistent with the findings of a German study, where emergency medical services personnel perceived paediatric palliative care emergencies to be particularly stressful, and requested a local palliative care contact be available 24/7 to provide clinical guidance and backup where necessary.[30] Furthermore, a Canadian study highlighted the utility of patients with a life-limiting illness being enrolled into a novel treat and refer palliative paramedicine clinical pathway. In sixty-eight percent of cases where this pathway was in place, paramedics engaged in a remote clinical consultation to facilitate care in the home, demonstrating how imperative clinical support can be in mitigating risk and reducing unnecessary conveyance to hospital.[1] In conjunction with formalising training and debriefing opportunities between ambulance services and other palliative care providers, ensuring Australian paramedics have a round-the-clock phone number to call for specialist palliative care clinical support will be an integral step towards incorporating paramedicine into the multidisciplinary palliative care landscape.

The only component to not gain consensus across both rounds pertained to modifying ambulance services' call algorithms to prompt further questioning about a patient's palliative care status and notify paramedics when they arrive on scene". While suggested by participants in our previous research to help with triaging, some of the expert panel commented this could be risky strategy and challenging to implement.

Future research ought to explore the barriers, facilitators and challenges that the sector, services, communities and individuals would face implementing the components that gained consensus, to inform a strategy to ensure successful translation of the framework into routine care.[16, 31] Researchers should seek endorsement for the arising implementation strategy from professional associations, apply a theory to guide the next steps, and acknowledge the time and resources required to standardise palliative paramedicine practice across Australia; the findings of which could have resonance for palliative care providers and ambulance services worldwide.

Strengths and limitations

This study employed a rigorous approach, engaging a large panel of international and multidisciplinary experts. A limitation of this study was the research team selecting experts for the process, potentially leading to preferential selection of participants favourable to our intended research goals and perspectives. However, we aimed to counteract this limitation by clearly defining the target population and sampling approach beforehand and inviting participants to share the invitation within their networks to enhance diversity of the expert panel. This Delphi study did not include the opinions of government policy makers on the expert panel, which could have been a missed opportunity. However, these key decision makers will be important stakeholders to engage in the next phase of the research, when developing an implementation strategy for the framework.

Conclusion

Despite their traditional emergency response function, paramedic scope of practice is evolving, and they can offer valuable adjunct generalist capability to specialist services in community-based palliative and end-of-life care provision. This study has developed a national framework with 32 components addressing the macro-, meso- and micro-level interventions required to standardise palliative paramedicine across Australia. The findings may be highly relevant for translation into other countries with similar health systems and services. Future research ought to engage a multidisciplinary team to create an implementation strategy, addressing any perceived barriers, facilitators and challenges for applying the framework into policy and practice.

Declarations

Acknowledgements

The search strategy and Round 1 questionnaire were developed by MJ, JC, PB, PS and MB. The Delphi rounds were coordinated by MJ. All authors contributed to the data analysis and development of Round 2 questionnaire. MJ drafted the manuscript. All authors critically revised the manuscript, making substantial contributions and approving the final version.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethics approval

Ethics approval was sought from the University of Sydney Human Ethics Committee (registration number 2022/914). This study was conducted in accordance with the relevant guidelines and regulations. All participants gave their written informed consent to participate.

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Figure 1: Flowchart of Delphi process

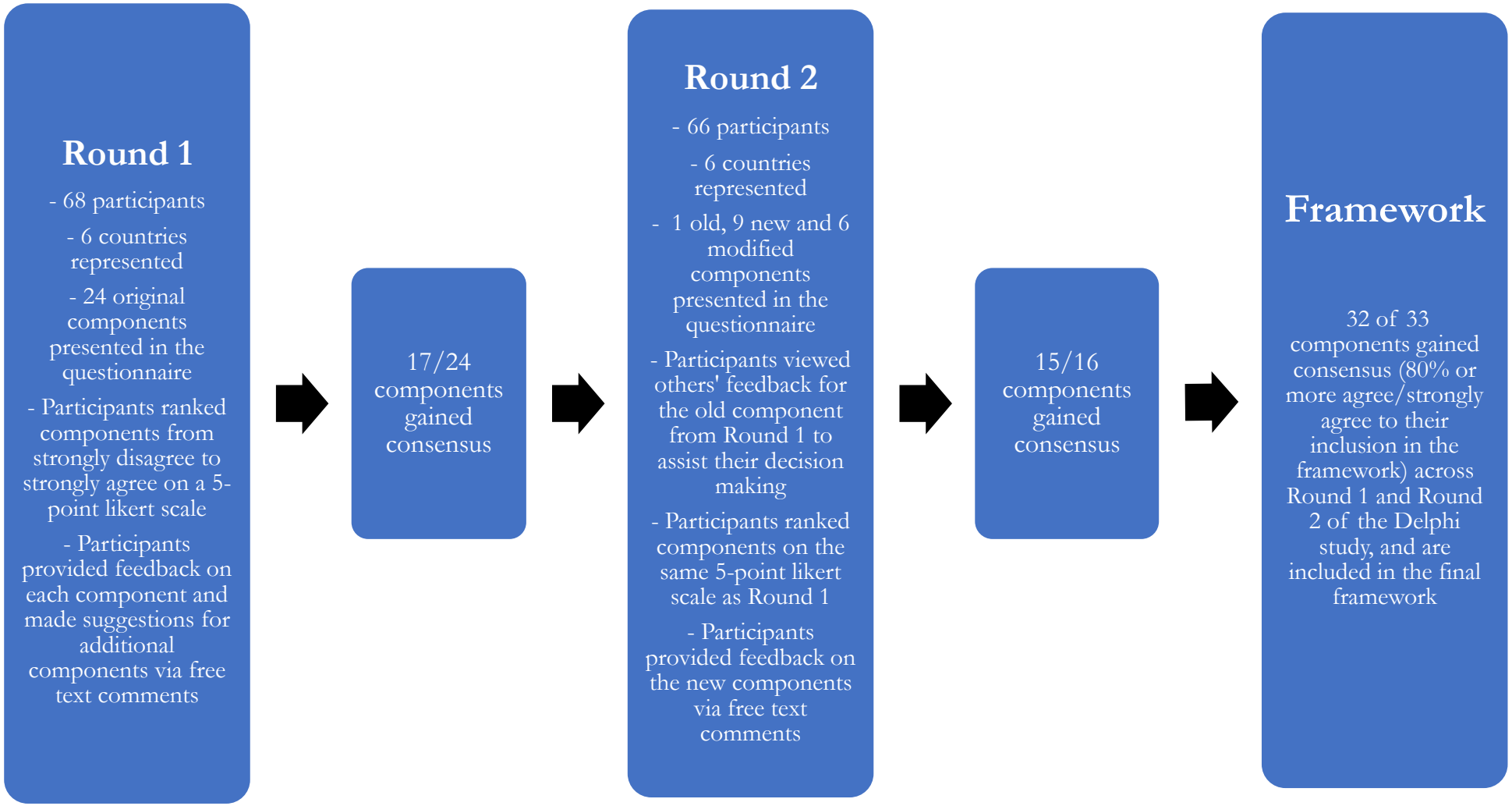

Table 1: Descriptive characteristics of participants
*Percentages rounded to nearest whole number

All participant characteristics	Round 1 Participants (%) N = 68	Round 2 Participants (%) N = 66
Age		
18-24	0 (0)	0 (0)
25-34	4 (6)	4 (6)
35-44	16 (24)	15 (23)
45-54	25 (37)	25 (38)
55-64	19 (28)	18 (27)
65+	4 (6)	4 (6)
Gender		
Male	24 (35)	24 (36)
Female	44 (65)	42 (62)
Non-binary	0 (0)	0 (0)
Australian First Nations identifying		
Aboriginal	1 (1)	1 (2)
Torres Strait Islander	0 (0)	0 (0)
Both	1 (1)	1 (2)
Neither	65 (96)	63 (95)
Prefer not to say	1 (1)	1 (2)
Country of birth		
Australia	48 (71)	46 (70)
Canada	1 (1)	1 (2)
Finland	1 (1)	1 (2)
Germany	1 (1)	1 (2)
Hong Kong	1 (1)	1 (2)
Kenya	1 (1)	1 (2)
Netherlands	1 (1)	1 (2)
New Zealand	2 (3)	2 (3)
Papua New Guinea	1 (1)	1 (2)
Republic of Korea	1 (1)	1 (2)
Singapore	1 (1)	1 (2)
United Kingdom	8 (12)	8 (12)
United States of America	1 (1)	1 (2)
Country of residence		
Australia	61 (90)	59 (89)
Canada	1 (1)	1 (1)
Finland	1 (1)	1 (1)
New Zealand	2 (3)	2 (3)
South Africa	1 (1)	1 (1)
United Kingdom	2 (3)	2 (3)
Employment status		
Full time	56 (82)	55 (83)
Part time or causal	10 (15)	9 (14)
Retired	2 (3)	2 (3)

Professional background		
Emergency medicine	2 (3)	2 (3)
General practice	5 (7)	5 (8)
Palliative care	30 (44)	29 (44)
Paramedicine	27 (40)	26 (39)
Family member/carer	4 (6)	4 (6)
Professional role		
Emergency nurse/academic	1 (1)	1 (2)
Emergency doctor/academic	1 (1)	1 (2)
GP	2 (3)	2 (3)
GP/academic	2 (3)	2 (3)
GP/service manager	1 (1)	1 (2)
Palliative care academic	5 (7)	5 (8)
Palliative care doctor	6 (9)	5 (8)
Palliative care doctor/academic	1 (1)	1 (2)
Palliative care nurse	12 (18)	12 (18)
Palliative care nurse/academic	2 (3)	2 (3)
Palliative care nurse/service manager	3 (4)	3 (5)
Paramedic	8 (12)	8 (12)
Paramedic/academic	12 (18)	12 (18)
Paramedic/service manager	8 (12)	7 (11)
Family member/carer	4 (6)	4 (6)
Years in profession		
Less than 1	0 (0)	0 (0)
1-5	1 (1)	1 (2)
6-9	3 (4)	3 (5)
10-19	24 (35)	23 (35)
20+	40 (59)	39 (59)
Education background		
Completed high/secondary school	1 (1)	1 (2)
Completed high/secondary school to year 10	0 (0)	0 (0)
Completed final year high/secondary school	0 (0)	0 (0)
Professional certificate or vocational school (Diploma)	2 (3)	2 (3)
Undergraduate degree (Bachelor)	12 (18)	11 (17)
Postgraduate degree (Master/MD/PhD)	53 (78)	52 (79)
Jurisdiction		
Australian Capital Territory	3 (4)	3 (5)
New South Wales	16 (24)	16 (24)
Northern Territory	2 (3)	1 (2)
Queensland	14 (21)	14 (21)
South Australia	6 (9)	6 (9)
Tasmania	2 (3)	1 (2)
Victoria	16 (24)	16 (24)
Western Australia	2 (3)	2 (3)
International	7 (10)	7 (11)

Table 2: Modifications and additions to Round 2 following free text comments from Round 1

General comments received in Round 1
• There needs to be paramedic standards and national paramedic clinical practice guidelines related to palliative care. (Paramedic and academic, ID15) • Quality performance/indicators and outcomes designed between patient/carers palliative care and paramedicine sectors. (Palliative care doctor, ID55) • A corresponding national suite of measures to monitor and improve the quality of paramedicine palliative care. (Paramedic and academic, ID16) • Include palliative paramedicine in workforce planning. (Palliative care doctor, ID13) • Ensure paramedic services have policies which are internally consistent, addressing expected death, non-transport, palliative care pathways. (Emergency doctor and academic, ID24) • A recognised advanced communication education which includes "breaking bad news" for all clinicians both as undergraduates and post-graduates. (Palliative care nurse and academic, ID26) • Standardised training and accreditation/reaccreditation requirements for palliative care trained paramedics. (Paramedic, ID49) • Extra training for our current paramedic workforce in Palliative Care in all aspects (referrals, treatments, medications, goals of care). (Paramedic and service manager, ID64) • Consider opportunities for community palliative care clinicians and paramedics to provide education to each other. (Palliative care nurse, ID66) • Paramedic exposure through opportunities to work in hospices. (Paramedic and service manager, ID1) • Is there any training in nursing education re paramedics' role? Paramedics must have a placement in community nursing and palliative care settings as an undergraduate. This would build relationships in the long term. It would also be of benefit if nursing students have a placement with paramedics. (Palliative care nurse, ID59) • At a macro level, it would be good to engage with the current developments around community paramedicine, to allow for a substantial role embedded in a multidisciplinary framework. (Palliative care researcher, ID60) • Interprofessional education should form part of curriculum development throughout paramedicine degrees. This will allow students to develop industry links whilst studying and create a better understanding of the roles each department plays when attending the palliative patient. (Paramedic and academic, ID43) • Ensure ongoing interdisciplinary advisory or stakeholder council meetings to facilitate knowledge exchange around best practice, local care pathways, mutually supportive team approach. (Emergency doctor and academic, ID24) • Multidisciplinary training with GPs to increase understanding and ability to work professionally together. (GP, ID46) • Role of specialist palliative care services in provision of ongoing education to paramedics and collaboration around the changes within Palliative care. (Palliative care nurse, ID58) • Establish a program where for example, a community palliative care nurse would spend allocated time with paramedics, and vice versa. (Paramedic and academic, ID38) • Paramedic exposure through opportunities to work in hospices. (Paramedic and service manager, ID1) • Ensure ongoing inter-disciplinary advisory or stakeholder council meetings to facilitate knowledge exchange around best practice, local care pathways, mutually supportive team approach. (Emergency doctor and academic, ID24) • Training (tertiary ed or in-house or VET) that sees palliative care delivered by a paramedic as core business i.e., via a registered (qualified) paramedic or referral by a qualified paramedic to other care providers, including specialist paramedics. (Paramedic and academic, ID38) • "Story telling" between services of memorable experiences - good or otherwise - can be a significant learning tool in educating each other. (Palliative care nurse, 66) • Paramedic & GP access to point of care clinical support with palliative care specialists - provided by Local Health Districts who oversee patient care. (Paramedic and service manager, ID18)

- Work towards direct contacts between services and local Paramedics, with regular debriefing and reflection. (Palliative care nurse, 66)
- Development of a centralised support resource (paramedic with specific palliative care training) to support the work of paramedics and ambulance officers on the ground, particularly in regional, rural and remote areas in dealing with palliative and end-of-life care clinical situations, A resource with understanding across both the acute paramedic services, and the palliative and end-of-life care space to help facilitate clinical-decision-making in complex end-of-life care cases. (Palliative care doctor, ID11)
- Formal linkages with specialist palliative care providers. (Palliative care nurse and service manager, ID53)
- Ensure systems of support to paramedics e.g., where paramedics are at scene with a palliative care patients that the paramedics can easily obtain appropriate palliative medicine/ care support e.g., through specialist palliative care or primary care physician who knows the patient. Also need to ensure there is a system of the paramedics handing over care to others when the patient is not transferred into hospital. (Palliative care doctor and academic, ID28)
- A forum for a regular handover from local palliative care services to local Paramedic services regarding any potential clients and having the ability for those to be flagged within paramedics. (Palliative care nurse, ID58)
- Death reviews, complex case meetings and debriefing support within local palliative care multidisciplinary team meetings, occurring in both acute and community settings, to improve communication, insights and collegiality. (Palliative care doctor, ID55)
- There is a shortage of advanced paramedics in rural and remote areas. These are the areas that really struggle with support out of hours and on weekends which leads to hospital admissions. I think ensuring access to these types of services in rural and remote areas needs to be written into the framework. (Palliative care nurse, ID2)
- Identify areas where after hours support is limited and liaise directly with the Paramedic service locally to provide information and support to the person requiring care. (Palliative care nurse, ID66)
- Need to be really careful to bolster what already exists for palliative care in the community and that ambulance services are a useful backup service for symptom management and verification of death outside of hours when other support is not readily available. (Paramedic and researcher, ID6)
- Acknowledgement of cultural differences and no single one right way to approach death and dying. Responsibilities to Indigenous Australians and acknowledgement that minority groups have increased risk of poor outcomes and are less likely to access specialised palliative care. (Emergency nurse and academic, ID22)
- Education to chronic disease, and community-controlled healthcare organizations, Aboriginal health workers or liaisons should be included in the team approach as a valuable source of support for paramedics to call on for any Indigenous patients. (Palliative care nurse and service manager, ID30)
- Provision of suitable available medications to Paramedics to support EOLC in urgent circumstances where systems of support have not yet been identified. (Paramedic and service manager, ID45)
- Policies for paramedics to administer 'break through' medications without the need to transport. For example, currently it is standard procedure for all patients who have had opioids to be transported for observation. (Paramedic and service manager, ID1)
- A national 'Authorised care plan' document that can allow standard paramedics to provide symptom management that may be outside of their scope using these care plans, which are written and authorised by a GP, nurse practitioner or other specialist. (Paramedic and academic, ID6)
- Possible option for paramedics to commence, contribute or add additional notes to “care plan” - even if it is simply that a conversation was commenced and request to flag for further discussion with a palliative care team. (Paramedic, ID32)
- Palliative and end-of-life care planning with the person and their family should incorporate the use of paramedics so that it is clear from the outset that they are part of the care model, clearly identifying their role would be important. (Palliative care nurse, ID2)
- Equip paramedics to navigate family conflict around goals of care. Awareness of oncologic emergencies and nuanced scenarios in which transport is appropriate. (Emergency doctor and academic, ID24)

- Funding research which seeks to understand what patients and families experience and need from paramedics at the end of life. (Emergency nurse and academic, ID22)
- Part of high-quality palliative and end of life care is awareness of the law that governs and supports paramedic practice. This is something which I would suggest including. (Palliative care researcher, ID34)
- I think there also need to be consultation with various consumer groups, those who relate to end of life issues, such as disease-based groups and consumer health forums. (Paramedic and academic, ID61)
- Develop an education campaign to improve GP knowledge and practice around community death. Many of the verification of death challenges are due to GPs not understanding the paramedic role in verifying death, and funeral directors not having a standardised approach. This leads to inappropriate utilisation of resources (such as police) and prolonged grief for family and carers due to coronial referral. (Paramedic and service manager, ID18)
- Education is important and having a standard platform for all of Australia would make things easier, especially when a patient may live in a border town. A campaign needs to be conducted to inform all players in health care about the role of a paramedic in palliative care and about palliative care in general. (Family carer, ID51)
- Ensure that at all stages the role of promoting death, grief and bereavement literacy is included. (GP, ID9)

Comments received in Round 1 for component 13 (did not reach consensus)

- This is bigger than just adjusting the requirements of call takers. These algorithms they follow are based on international best practice and would require collaboration with the organisation that holds the certification that all ambulance services must have, in order to remain certified. Great idea for moving forward and it needs to occur, however if adjusting the algorithm, it is a much bigger process. Maybe directing these calls to secondary triage is a better option, as this is already in place and those answering secondary triage calls have a freedom to ask these additional questions in a way that call takers do not. (Paramedic academic, ID37)
- This can prevent the wrong resource being sent to the patient and ensures the patient receives timely care with the right clinical level attending. (Paramedic academic, ID43)
- This could be risky. If interpreted incorrectly by a non-medical call-taker, this could result in a diversion of an ambulance. It also could be seen as sterile and insensitive when scripted. (Palliative care nurse, ID44)
- Unsure about this one - we'd have to be sure the questions had good sensitivity and specificity and that seems quite challenging. (Palliative care nurse, ID22)
- Not sure this is necessary. The public have a hard enough time currently working out what to call an ambulance for and what not. If they called their GP/palliative care specialist who then identified, they would benefit from a paramedic that would result in more appropriate taskings. Palliative care nurses write in the in-home books "any problems, call an Extended Care Paramedic" which annoys their own doctors because the patients call 000 when they would have benefited more from calling the doctor at times. (Paramedic, ID47)
- Currently there is no AMPDS/ProQA determinant for patients at end of life, hence these cases are dispatched as a confused jumble of pain/shortness of breath/bleeding/collapse usually with an under lights response as the severity/acuity is detected during call handling. The problem is that this "under-lights emergency" momentum often carries through and results in inappropriate, undignified, futile and unpleasant resuscitation and/or transport. (Paramedic, ID28)
- Dispatch staff often have to make a decision to sort patients into 'resuscitation' responses and 'end-of-life care' responses. An incorrect decision around the 'sorting' process will have significant detrimental consequences (regardless of whether a resuscitation scenario is mis-identified as 'end-of-life' care, or vice versa). Any decision-making support to minimise error is very important. (Palliative care doctor, ID11)
- I suspect from a practical point of view this would be unworkable. Most services in Australia and New Zealand use AMPDS and the call taking scripts are fairly rigid and hard to change. In addition, I suspect it would be quite confronting for callers. There may a subset of patients in whom it could have some value though. (Palliative care doctor, ID54)
- And advance care plan status, is there one? Just because someone is under palliative care, it does not mean they are not for resus or aggressive treatment of reversible symptoms at times. (Palliative care nurse, ID31)
- This is so important for correct dispatch, and appropriate response and dignity for the family. (Palliative care nurse, ID65)

- I am not certain if this should be routine. I feel this should be something that is prompted by the content of the call. I suspect many ambulance calls will not be related to palliative care or end of life care, so routine questioning may not be appropriate. (Palliative care doctor, ID19)
- Care must be taken as a "palliative care status" could be stigmatising and or prejudicial to care. It has nuances - when stratified into palliative approach (where it is appropriate to attend hospital to have investigations and reversible things reversed i.e. infections,hyperclacemia, toxic AEs of treatment); end of life care where goal is to stay at home for as long as possible but things may change quickly requiring a rapid reorientation of goals; terminal care where patient is imminently dying and attendance may be determined to assist with symptom control or transfer to preferred place of death: in some cases hospital or palliative care unit. (Palliative care doctor, ID55)
- This is a system that can cause carer/ family distress when calling triple 000 for a loved one who was an expected death. This is currently an issue with our dispatch system. Not only will this assist in delivering the most appropriate response and resource to be sent to complete a verification of death certificate when community-based palliative care services are not available/ GP (after hours, public holidays, etc). (Paramedic, ID64)
- I think this has the potential to introduce bias into the patient approach. (Paramedic, ID3)
- The general public often struggle with the word palliative care and consider this to be terminal, not life limiting. This could provide inaccurate information prior to arriving where the patient is. (Palliative care nurse, ID59)
- I think this may be appropriate but would need careful triggers. Do we want to know about palliative care status for the young person with a fractured tibia? (Palliative care academic, ID5)
- Ideally, I would recommend this is asked at the call taker end and not the secondary/ambulance internal triage end. We continue to see episodes where police, fire and ambulance services are called out as a CAT 0 priority to attend to an expected death. This is often a distressing event for all involved. If it could be readily recognised when there is a call for a palliative patient and an expected death that would improve the system greatly. (Palliative care nurse, ID63)

Macro-level	
Original component (Round 1)	*Modified component (Round 2)*
New components (Round 2)	
8. Develop palliative paramedicine quality performance indicators and outcomes through a co-design process between consumers, palliative care and paramedicine sectors. 9. Include paramedicine in workforce planning for palliative and end-of-life care. 10. Ensure equitable access to paramedics providing palliative and end-of-life care for consumers in all geographical settings, including metropolitan, regional, rural and remote areas.	
Meso-level	
Original component (Round 1)	*Modified component (Round 2) - changes in bold*
12. Require all ambulance services to maintain a best practice palliative and end-of-life care guideline, including verification of death processes.	12. Require all ambulance services to maintain a best practice palliative and end-of-life care guideline, including **the ability to deliver specific sub-cutaneous medications for common end-of-life symptoms without transport, and** verification of death processes.
14. Standardise paramedic palliative and end-of-life care education and training, including building capacity for paramedics to verify death.	14. Standardise paramedic palliative and end-of-life care education and training, including building capacity for paramedics to **navigate end-of-life law and** verify death.

17. Establish interprofessional understanding between ambulance services and palliative care, aged care and general practice services through localised networks.	17. Establish interprofessional linkages and understanding between ambulance services and palliative care, aged care and general practice services through localised networks, **bi-directional training and routine multidisciplinary debriefing opportunities.**
18. Develop public health palliative care campaigns to educate health professionals and the public on a paramedic's role in delivering community-based palliative and end-of-life care.	18. Develop public health palliative care campaigns to educate health professionals and the public on a paramedic's role in delivering community-based palliative and end-of-life care, **including verification of death where required.**
New components (Round 2)	
19. Require state and territory palliative care plans to include recommendations for how clinical palliative care back-up support at the point of care will be provided to paramedics within local health jurisdictions. 20. Facilitate the collaboration between state/territory representative palliative care organisations and ambulance services to map the after-hours community-based palliative care service gaps within their respective jurisdictions, to promote needs-based investments of palliative paramedicine and avoid duplication of services. 21. Require state and territory palliative care plans to include recommendations for local health jurisdictions to develop systems to enable paramedics to rapidly identify an individual patient's current palliative care medications and breakthrough doses. 22. Ambulance services to mandate a process for paramedics to complete an electronic (or paper copy) handover upon treating a palliative care patient who is not transferred and remains at home, for other healthcare services to access to promote continuity of care.	
Micro-level	
Original component (Round 1)	*Modified component (Round 2) – changes in bold*
26. Equip paramedics with communication skills to engage patients, families and carers to partner in palliative and end-of-life care through shared decision-making and debriefing.	26. Equip paramedics with communication skills **about death and dying** to **provide support and** engage patients, families and carers to partner in palliative and end-of-life care through shared decision-making and debriefing.
28. Instil family-centred and culturally appropriate care after death principles into paramedic palliative and end-of-life care practice.	28. Instil family-centred and culturally appropriate care **leading up to and** after death principles into paramedic palliative and end-of-life care practice.
New components (Round 2)	
32. Educate families and carers about the role of paramedics in the provision of their palliative care, and when it is helpful to call an ambulance. 33. Equip paramedics with resources to provide families and/or carers with information about care after death, grief and bereavement.	

Table 3: *Levels of agreement for components in Round 1*

Component	**Median score (1-5)** 1 – Strongly disagree 2 – Disagree 3 – Neither agree nor disagree 4 – Agree 5 – Strongly agree	**IQR**	**% agree/strongly agree**	**Level of agreement**	**Achieved consensus** (80% or more agree/strongly agree)
Macro 1: Include paramedicine in national and jurisdictional palliative and end-of-life care policies and frameworks.	5	0	100	Very high	Yes
Macro 2: Include paramedicine in interdisciplinary palliative and end-of-life care policies and frameworks.	5	1	100	High	Yes
Macro 3: Provide paramedic services access to electronic medical records, enabling paramedics to access patients' advance care planning and palliative care details in real time.	5	0	96	Very high	Yes
Macro 4: Develop and implement State/Territory specific documentation for patients, families and/or carers to complete alongside their healthcare team/s to allow paramedics to rapidly identify a patient's palliative and end-of-life goals of care. Ensure processes for the documentation to be uploaded and accessible electronically.	5	1	90	High	Yes
Macro 5: Broaden paramedic scope of practice to verify death on scene where appropriate.	5	1	89	High	Yes
Macro 6: Embed palliative care into all paramedicine undergraduate and postgraduate curriculum, including theoretical and practical components.	5	0	98	Very high	Yes
Macro 7: Acknowledge and broaden the paramedicine profession to include clinical roles beyond an ambulance setting i.e., paramedics with enhanced palliative care capabilities in primary care settings.	5	1	82	High	Yes
Meso 11: Promote healthcare services to recognise the paramedic scope of practice	5	1	97	High	Yes

includes palliative and end-of-life care skills.					
Meso 12: Require all ambulance services to maintain a best practice palliative and end-of-life care guideline, including verification of death processes.	5	1	95	High	Yes *Modified for Round 2 according to Round 1 feedback
Meso 13: Include a routine question within an ambulance call taker's algorithm that prompts further questioning about a patient's palliative care status and notify paramedics before they arrive on scene.	4	1	75	Moderate	No *Put forward in original form for round 2
Meso 14: Standardise paramedic palliative and end-of-life care education and training, including building capacity for paramedics to verify death.	5	1	99	High	Yes *Modified for Round 2 according to Round 1 feedback
Meso 15: Provide specialist training pathways for paramedics expressing interest and capacity in palliative and end-of-life care.	5	1	87	High	Yes
Meso 16: Incorporate and connect paramedics to localised palliative care referral pathways, including alternative referral destinations beyond an Emergency Department.	5	0	96	Very high	Yes
Meso 17: Establish interprofessional understanding between ambulance services and palliative care, aged care and general practice services through localised networks.	5	1	99	High	Yes *Modified for Round 2 according to Round 1 feedback
Meso 18: Develop public health palliative care campaigns to educate health professionals and the public on a paramedic's role in delivering community-based palliative and end-of-life care.	5	1	85	High	Yes *Modified for Round 2 according to Round 1 feedback
Micro 23: Mandate generalist palliative care capabilities for all paramedics.	4	1	83	High	Yes
Micro 24: Create optional specialist palliative care capabilities for interested and willing paramedics to pursue.	5	1	81	High	Yes
Micro 25: Identify and support interested and willing paramedics to become palliative care champions within their	5	1	94	High	Yes

respective workplace. Connect these clinicians with local grass roots palliative care initiatives.					
Micro 26: Equip paramedics with communication skills to engage patients, families and carers to partner in palliative and end-of-life care through shared decision-making and debriefing.	5	1	96	High	Yes *Modified for Round 2 according to Round 1 feedback
Micro 27: Equip paramedics with resources to refer patients, families and/or carers palliative care supportive services.	5	1	91	High	Yes
Micro 28: Instil family-centred and culturally appropriate care after death principles into paramedic palliative and end-of-life care practice.	5	1	94	High	Yes *Modified for Round 2 according to Round 1 feedback
Micro 29: Provide paramedics access to self-care and peer support services, including debriefing opportunities for unexpected and expected deaths.	5	1	96	High	Yes
Micro 30: Equip patients, families and carers with appropriate state/territory advance care planning documentation to share with paramedics upon arrival, to allow for the rapid identification of the patient's palliative and end-of-life goals of care.	5	1	91	High	Yes
Micro 31: Educate families and carers to provide paramedics with contact details of patient's healthcare providers, including GP and specialist palliative care services.	5	1	88	High	Yes

Table 4: Levels of agreement for original, modified and additional components in Round 2

Component **Bold text** – modified component *Italic text* – new component	**Median score (1-5)** 1 – Strongly disagree 2 – Disagree 3 – Neither agree nor disagree 4 – Agree 5 – Strongly agree	**IQR**	**% agree/strongly agree**	**Level of agreement**	**Achieved consensus** (80% or more agree/strongly agree)
Macro 8. Develop palliative paramedicine quality performance indicators and outcomes through a co-design process between consumers, palliative care and paramedicine sectors.	5	1	96	High	Yes
Macro 9. Include paramedicine in workforce planning for palliative and end-of-life care.	5	1	92	High	Yes
Macro 10. Ensure equitable access to paramedics providing palliative and end-of-life care for consumers in all geographical settings, including metropolitan, regional, rural and remote areas.	5	1	86	High	Yes
Meso 12: Require all ambulance services to maintain a best practice palliative and end-of-life care guideline, including **the ability to deliver specific sub-cutaneous medications for common end-of-life symptoms without transport, and** verification of death processes.	5	1	98	High	Yes *Improved from 95% in Round 1
Meso 13: Include a routine question within an ambulance call taker's algorithm that prompts further questioning about a patient's palliative care status and notify paramedics before they arrive on scene.	4	2	72	Moderate	No *Failed to achieve consensus in Round 1 and 2, therefore removed from the framework
Meso 14: Standardise paramedic palliative and end-of-life care education and training, including building capacity for paramedics to **navigate end-of-life law and** verify death.	5	1	94	High	Yes *Reduced from 99% in Round 1
Meso 17: Establish interprofessional **linkages and** understanding between ambulance services and palliative care, aged care and general practice services through localised networks**,**	5	1	99	High	Yes *Remained the same as Round 1

bi-directional training and routine multidisciplinary debriefing opportunities.					
Meso 18: Develop public health palliative care campaigns to educate health professionals and the public on a paramedic's role in delivering community-based palliative and end-of-life care, **including verification of death where required**.	4	1	83	High	Yes *Reduced from 85% in Round 1
Meso 19: Require state and territory palliative care plans to include recommendations for how clinical palliative care back-up support at the point of care will be provided to paramedics within local health jurisdictions.	5	1	91	High	Yes
Meso 20: Facilitate the collaboration between state/territory representative palliative care organisations and ambulance services to map the after-hours community-based palliative care service gaps within their respective jurisdictions, to promote needs-based investments of palliative paramedicine and avoid duplication of services.	5	1	92	High	Yes
Meso 21: Require state and territory palliative care plans to include recommendations for local health jurisdictions to develop systems to enable paramedics to rapidly identify an individual patient's current palliative care medications and breakthrough doses.	5	1	91	High	Yes
Meso 22: Ambulance services to mandate a process for paramedics to complete an electronic (or paper copy) handover upon treating a palliative care patient who is not transferred and remains at home, for other healthcare services to access to promote continuity of care.	5	1	97	High	Yes
Micro 26: Equip paramedics with communication skills **about death and dying to provide support and** engage patients, families and carers to partner in palliative and end-of-life care through shared decision-making and debriefing.	5	0	98	Very high	Yes *Improved from 96% in Round 1

Micro 28: Instil family-centred and culturally appropriate care **leading up to and** after death principles into paramedic palliative and end-of-life care practice.	5	1	97	High	Yes *Improved from 94% in Round 1
Micro 32: Educate families and carers about the role of paramedics in the provision of their palliative care, and when it is helpful to call an ambulance.	5	1	94	High	Yes
Micro 33: Equip paramedics with resources to provide families and/or carers with information about care after death, grief and bereavement.	5	1	89	High	Yes

Table 5: Final framework components

Level	Component
Macro	1. Include paramedicine in national and jurisdictional palliative and end-of-life care policies and frameworks.
	2. Include paramedicine in interdisciplinary palliative and end-of-life care policies and frameworks.
	3. Provide paramedic services access to electronic medical records, enabling paramedics to access patients' advance care planning and palliative care details in real time.
	4. Develop and implement State/Territory specific documentation for patients, families and/or carers to complete alongside their healthcare team/s to allow paramedics to rapidly identify a patient's palliative and end-of-life goals of care. Ensure processes for the documentation to be uploaded and accessible electronically.
	5. Broaden paramedic scope of practice to verify death on scene where appropriate.
	6. Embed palliative care into all paramedicine undergraduate and postgraduate curriculum, including theoretical and practical components.
	7. Acknowledge and broaden the paramedicine profession to include clinical roles beyond an ambulance setting i.e., paramedics with enhanced palliative care capabilities in primary care settings.
	8. Develop palliative paramedicine quality performance indicators and outcomes through a co-design process between consumers, palliative care and paramedicine sectors.
	9. Include paramedicine in workforce planning for palliative and end-of-life care.
	10. Ensure equitable access to paramedics providing palliative and end-of-life care for consumers in all geographical settings, including metropolitan, regional, rural and remote areas.
Meso	11. Promote healthcare services to recognise the paramedic scope of practice includes palliative and end-of-life care skills.
	12. Require all ambulance services to maintain a best practice palliative and end-of-life care guideline, including the ability to deliver specific sub-cutaneous medications for common end-of-life symptoms without transport, and verification of death processes.
	13. Standardise paramedic palliative and end-of-life care education and training, including building capacity for paramedics to navigate end-of-life law and verify death.
	14. Provide specialist training pathways for paramedics expressing interest and capacity in palliative and end-of-life care.
	15. Incorporate and connect paramedics to localised palliative care referral pathways, including alternative referral destinations beyond an Emergency Department.
	16. Establish interprofessional linkages and understanding between ambulance services and palliative care, aged care and general practice services through localised networks, bi-directional training and routine multidisciplinary debriefing opportunities.
	17. Develop public health palliative care campaigns to educate health professionals and the public on a paramedic's role in delivering community-based palliative and end-of-life care, including verification of death where required.
	18. Require state and territory palliative care plans to include recommendations for how clinical palliative care back-up support at the point of care will be provided to paramedics within local health jurisdictions.
	19. Facilitate the collaboration between state/territory representative palliative care organisations and ambulance services to map the after-hours community-based palliative care service gaps within their respective jurisdictions, to promote needs-based investments of palliative paramedicine and avoid duplication of services.
	20. Require state and territory palliative care plans to include recommendations for local health jurisdictions to develop systems to enable paramedics to rapidly identify an individual patient's current palliative care medications and breakthrough doses.
	21. Ambulance services to mandate a process for paramedics to complete an electronic (or paper copy) handover upon treating a palliative care patient who is not transferred and remains at home, for other healthcare services to access to promote continuity of care.
Micro	22. Mandate generalist palliative care capabilities for all paramedics.

	23. Create optional specialist palliative care capabilities for interested and willing paramedics to pursue.
	24. Identify and support interested and willing paramedics to become palliative care champions within their respective workplace. Connect these clinicians with local grass roots palliative care initiatives.
	25. Equip paramedics with communication skills about death and dying to provide support and engage patients, families and carers to partner in palliative and end-of-life care through shared decision-making and debriefing.
	26. Equip paramedics with resources to refer patients, families and/or carers palliative care supportive services.
	27. Instil family-centred and culturally appropriate care leading up to and after death principles into paramedic palliative and end-of-life care practice.
	28. Provide paramedics access to self-care and peer support services, including debriefing opportunities for unexpected and expected deaths.
	29. Equip patients, families and carers with appropriate state/territory advance care planning documentation to share with paramedics upon arrival, to allow for the rapid identification of the patient's palliative and end-of-life goals of care.
	30. Educate families and carers to provide paramedics with contact details of patient's healthcare providers, including GP and specialist palliative care services.
	31. Educate families and carers about the role of paramedics in the provision of their palliative care, and when it is helpful to call an ambulance.
	32. Equip paramedics with resources to provide families and/or carers with information about care after death, grief and bereavement.

Chapter 8: Discussion and conclusion

8.1 Summary of methodological approach and key learnings

This thesis included four phases addressing separate aspects of paramedics delivering PC and EOLC in Australian communities. Phase 1 undertook a review of existing literature on the topic (Chapter 3); Phase 2 analysed the quality and content of palliative paramedicine guidelines (Chapter 4); Phase 3 explored the attitudes and perspectives of key stakeholders with lived experience (Chapters 5 and 6); and Phase 4 developed a national framework to standardise best practice (Chapter 7).

Specifically, this thesis addressed the following aims:

1.) To review and synthesise the international empirical evidence regarding paramedics delivering palliative and end-of-life care in community-based settings (Chapter 3).
2.) To examine the quality and content of existing Australian palliative paramedicine guidelines with a sample of guidelines from comparable Anglo-American ambulance services (Chapter 4).
3.) To elicit paramedics', PC doctors and nurses', general practitioners', residential aged care nurses' and bereaved families and carers' experiences, perspectives, and attitudes on the role, barriers and enablers of paramedics delivering palliative and EOLC in community-based settings (Chapter 5).
4.) To elicit paramedics', PC doctors' and nurses', general practitioners', residential aged care nurses' and bereaved families and carers' attitudes and perspectives on how palliative paramedicine can be improved to better suit the needs of community-based patients, their families and carers, and the clinicians involved in delivering the care (Chapter 6).
5.) To develop a palliative paramedicine framework suitable for national implementation, by determining the components considered most essential for improving the role of paramedics delivering palliative and end-of-life care in Australian communities (Chapter 7).

Both qualitative and consensus methods were used to address these aims. In Chapter 3, thematic analysis was applied to synthesise the qualitative, quantitative and mixed methods studies included in the systematic integrative review. A qualitative collaborative content analysis was employed in Chapter 4 to

evaluate the content of the selected guidelines. In Chapters 5 and 6, semi-structured interviews were analysed using reflexive thematic analysis to describe individual perspectives and attitudes, drawing from a wide range of clinician and family carer expectations and experiences. Finally, Chapter 7 used a Delphi methodology to gain consensus from an international expert panel on a comprehensive multi-level framework. The initial components of this framework were developed using inputs from the previous three studies. The findings from each phase are integrated and discussed in the key learnings below.

8.1.1 Key learning 1 – A whole of system approach is required, but the cultural shift is already underway

At the beginning of this thesis, the original aim was to develop a best practice guideline for national implementation, as we initially considered this an effective way to standardise best practice nationally. Phase 1 supported this direction, highlighting that PC-specific guidelines act as key enablers for broadening paramedic scope of practice. However, throughout the course of the four phases it became apparent that Australian ambulance services had set parameters for the development of their respective guidelines, which were jurisdiction specific. Furthermore, challenging the status quo of what it means to be a paramedic and emboldening clinicians to broaden these established stereotypes emerged as another key facilitator in the systematic integrative review, remaining prominent throughout the course of the thesis.

Findings from Chapter 3 suggested paramedicine is no longer exclusively responding to traditional emergencies; paramedics also play an important role in providing emergency support to patients approaching end-of-life, helping facilitate home-based deaths and reducing avoidable hospital admissions. This emerging scope of practice is driven by community need and is already accepted by many as an integrated component of a modern paramedic's role. Other enablers of palliative paramedicine identified in Chapter 3 included strengthening communication and support channels within multidisciplinary teams, targeted PC training for paramedics and engaging families in shared decision making. These early observations prompted my supervisory team and I to reconsider the suitability of a guideline alone, to adequately broaden paramedic practice to better serve the needs of PC patients, families and carers.

Instead, we deliberated whether we could develop something with national relevance that could feed into local guidelines.

The findings from Phase 2 described the evolving nature of palliative paramedicine, suggesting ambulance service guidelines are shifting away from protocol driven practice to broader clinical models, calling on the discretion and decision-making skills of paramedics that are necessary for PC and EOLC. This study also highlighted the inclusion of specialist clinical back-up across all of the guidelines, suggesting a multidisciplinary approach is necessary to provide effective PC and EOLC in community-based settings. This iterative process reaffirmed our earlier suspicion: in isolation, guidelines are blunt instruments for efficacious policy and practice change. Instead, a multi-faceted approach would be required to address the significant barriers and opportunities for improving palliative paramedicine in Australia, including seeking opportunities to formalise interdisciplinary care and referral pathways for ambulance and PC services.

In Phase 3, it became apparent that systems-level changes would need to precipitate service, community, clinician and consumer-level improvements. In Chapter 5, the findings reinforced a cultural shift is already underway, as participants were mostly supportive of paramedics delivering PC and EOLC. However, some paramedic participants expressed vulnerabilities when taking this approach. They called for greater support to move beyond curative care and challenge the status quo, especially regarding rigid time on scene expectations and treating patients without transport to hospital. Participants also described inconsistencies in ambulance services' governance, training and interdisciplinary approaches, but noted growing unity between ambulance and PC services enabled stronger models of care. Chapter 6 outlined perspectives of interventions that could improve practice, which fitted a macro, meso and micro-level typology, further illustrating the necessity for a whole of system approach. Specifically, participants recommended paramedicine be included in policies and frameworks to ensure this scope of practice was officially considered part of a paramedic's workload.

As outlined earlier in this thesis, Canada pioneered community paramedicine some years ago and has successfully incorporated PC into routine paramedic practice.[1] The innovative *Paramedics Providing Palliative Care at Home* programme was established in Nova Scotia in 2015 and included (1) a guideline specific to PC with new medications and options for paramedics to treat patients without transport to ED; (2)

paramedic PC education; and (3) a database of patient goals of care accessible to paramedics.[2] A 2022 study exploring the alignment of this programme with paramedic professional identity considered the provision of palliative paramedicine a positive growth for the profession, fitting well with its existing identity of service to the community through a patient-centred lens.[2] However, discordant perspectives were apparent amongst the paramedic and specialist PC clinician participants regarding jurisdiction of practice. Paramedics described finding themselves on the periphery of PC discussions with interdisciplinary teams, often feeling a sense of 'turf protection' being established by their community-based PC colleagues.[2] Comparatively, specialist PC participants believed paramedics were a well-established part of their team.[2] This study offers helpful insight from a comparable health system regarding the considerations required for establishing interprofessional trust amongst PC and ambulance services in Australia in the future.

These collective findings shaped the trajectory of the final phase, which gained consensus on a comprehensive set of framework components addressing the multi-level factors required to better enhance the role of paramedics delivering palliative across all sectors. In Chapter 7, the expert panel agreed paramedicine ought to be included in all national, jurisdiction and interdisciplinary PC and EOLC policies, frameworks and workforce planning. Furthermore, panellists affirmed effective change begins in the classroom, and universities must empower students to see PC and EOLC as part of their role, equipping them with the knowledge, skills and experience to adequately respond to these patients upon graduating from their studies. Establishing campaigns to educate health professionals and the public on paramedics' role in PC and EOLC was another significant component that gained consensus and aligned with this key learning.

8.1.2 Key learning 2 – It takes generalists, as well as specialists

In Phase 1, the findings suggested relegating PC and EOLC capacity to specialist roles – including ECPs in Australia and community paramedics in Canada – was a common approach adopted by many ambulance services worldwide. Two of the guidelines included in Phase 2 pertained to such specialist roles. The findings of this study highlighted that these specialist paramedics required advanced training and were permitted to work outside the normal scope of practice, including staying on scene for extended

periods and initiating end-of-life medications beyond usual thresholds. However, accordingly ECPs were not available in all locations 24 hours a day, seven days week like regular paramedics. As a result, we anticipated despite the admirable strengths in specialist paramedic roles, the growing need for community-based PC and EOLC could not be met by ECPs alone. This could become particularly problematic after-hours when other specialist PC services are unavailable.

This idea was reinforced by the anecdotes of participants in Phase 3. In Chapter 5, they described the role of a paramedic evolving in response to the diverse and changing needs of populations, including an increased demand for community-based PC. Participants emphasised the importance of generalists, as well as specialists, being equipped to deliver this type of care. They recounted limitations in current training and education offerings meant normal paramedics lacked sufficient 'tools' to deliver good PC. In Chapter 6, a further nuanced perspective emerged amongst the participants, who noted that although not all paramedics gravitate towards non-traditional elements of paramedicine, including PC, every paramedic ought to have the ability to take a PC approach, with opportunities to specialise in community and PC roles if they wish.

Another study explored patients and caregiver perspectives of lived experiences interacting with ECPs for PC emergencies in one Australian jurisdiction.[3] Participants considered paramedics with expertise and experience in PC as an extension of the specialist community PC team and, similarly to the other study, held them in high regard.[3] However, participants highlighted the importance of a timely, responsive approach and reported ECPs were not always available to respond to their emergency calls. As a result, generalist paramedics lacking PC expertise would arrive without the required skill set, therefore leading to an avoidable hospital admission.[3] These findings reiterate this key learning arising from our research: specialist paramedics, alone, will not adequately meet the need for palliative paramedicine. Instead, we argue for minimal PC capabilities across the paramedic workforce, with opportunities to specialise for those demonstrating aptitude and interest.

These findings informed a series of framework components which were tested in Phase 4. As a result of the Delphi process, the expert panel recommended (1) ambulance services be required to maintain a best practice palliative and end-of-life care guideline; (2) PC and EOLC education and training be standardised

for all paramedics; (3) generalist PC capabilities be mandated for all paramedics; and (4) specialist training pathways be available for paramedics expressing interest and aptitude.

8.1.3 Key learning 3 – Documentation delivers

Another key learning arising from all four phases was the importance of documentation in identifying goals of care, which also helps alleviate the medico-legal ambiguity often associated with palliative paramedicine. Seventeen of the 23 included studies in Phase 1 underscored this finding, highlighting that legible advance care plans outlining a patient's preferences significantly facilitate quality PC. However, ready access to such documentation and the ability to enact discretion around unfeasible end-of-life wishes – especially when a family feels overwhelmed caring for their loved one at home – were other integral findings relating to documentation from this chapter.

In Chapter 4, factors relating to establishing patient decision making capacity, determining proxy decision makers and what constituted valid medical directives within respective jurisdictions, were also discussed. This study found that existing guidelines highlight the unique position paramedics hold in entering patients' homes and gaining information about their social context, which could be used for holistic PC needs assessments in the future. However, the findings also suggested systems need to be in place for paramedics to share their case notes with multidisciplinary teams when a patient is treated in the community by the paramedic but not transported to hospital, in turn facilitating continuity of care.

The findings from Phase 3 complimented earlier findings, identifying advance care planning documentation as a key enabler for allowing paramedics to move beyond traditional models of curative care. In Chapter 5, all participants emphasised the importance of paramedics being able to access information in a timely manner to make sound clinical decisions, calling for greater access to electronic medical records (EMR) and standardised advance care planning documentation for community settings. Participants also supported universal access to standardised documentation in Chapter 6.

Reducing avoidable hospital admissions is also a key topic of focus in the broader literature. A 2021 Australian study explored geriatric and emergency doctors' and nurses', and ECPs' perspectives on the factors impacting an existing hospital avoidance program for acutely unwell residential aged care patients.[4] Although PC outlooks were not included in this study, important take aways relevant to the provision of

palliative paramedicine were noted. In line with our findings, the participants of this study suggested the use of advance care planning documentation was an important factor in preventing unnecessary ED transfers via ambulance services, and overall hospital admissions.[4] However, the study did not explore access to such documentation as a barrier to good care. The findings also supported the notion that positive care transitions for unwell residential aged care patients could be facilitated by developing stronger relationships and communication pathways between residential aged care homes, ambulance services, EDs and GPs.[4]

These findings collectively led to a series of framework components being shaped and endorsed by the consensus process in Phase 4, including (1) providing all ambulance services access to EMR; (2) developing and implementing electronic documentation templates for patients and family carers to complete alongside their healthcare teams to allow paramedics to rapidly identify a patient's goals of care; (3) requiring PC plans to include recommendations for local health jurisdictions to develop systems for paramedics to rapidly identify patient PC medications and breakthrough doses; and (4) mandating ambulance service processes for paramedics to complete electronic handovers upon treating a PC patient who remains at home.

8.1.4 Key learning 4 – Partnering in care through skilled communication

The value of effectively engaging families and carers materialised early on in the research process. Phase 1 identified that these important stakeholders act as gate keepers to accessing a patient's information, noting family discordance can often lead to the paramedic having to decipher conflicting goals of care. The findings suggested paramedics need to be strong communicators, with skills and confidence to navigate disagreements in family care planning. Notably, the findings also reported a greater need for death literacy amongst patients and families to better facilitate a paramedic's ability to provide PC in the home.

Phase 2 reiterated these findings, highlighting that most of the guidelines failed to mention communication approaches for building rapport and support with patients, families and carers in PC emergencies. The study also touched on care after death principles, with some guidelines acknowledging

that family and carer distress following a patient dying required skilled communication and culturally responsive care.

As previously mentioned, responding to a change in a patient's end-of-life plan may be required and paramedics can play an instrumental role in leading this trajectory. In Chapter 5, participants recounted experiences of needing to take patients to hospital despite their initial preference to die at home, due to uncontrolled symptoms and family exhaustion. Having the ability to discern these factors and facilitate shared decision making with the patient and family in emerging and stressful situations, was a skill participants emphasised as integral to the paramedic role. Recognising and harnessing communities, especially informal carers, in delivering PC and EOLC also emerged as a fundamental theme of Chapter 6. This study echoed previous findings, highlighting the need for stronger public health approaches to PC through community death education campaigns, as well as paramedics having the capacity to refer families to grief and PC support services where appropriate.

One evidence-based approach for educating the community about PC and EOLC is the Last Aid Course.[5] This programme was initially developed in Europe in 2014, but has since spread to over 17 countries, including Australia.[5] It aims to increase public awareness and empower people about the role of the individual in the death of loved ones. A recent evaluation of the course reported 100% of participants would recommend the course to others, 90% felt better prepared to encounter death and dying, and 80% felt more prepared to care for dying people after completing the course.[5] Opportunities exist to scaffold the content of this course into community education campaigns for palliative paramedicine within Australia.

Our finding that paramedic participants reported feeling unprepared for the realities of caring for PC patients in the community is also mirrored by a 2022 American qualitative study, which explored similar challenges amongst a group of paramedics with lived experience providing care for palliative patients.[6] The participants described challenges in responding to grief and emotion expressed by families during traumatic events or death notification, in addition to performing in the moment decision-making to determine the course of action after acute, unexpected, and traumatic events.[6] The study identified an

opportunity for ambulance services to provide formal training to paramedics around grief counselling and communication approaches for engaging families and carers in shared decision making.[6]

Phase 4 synthesised these key findings into prospective framework components, which were endorsed by the expert panel in Chapter 7, providing direction for greater engagement between paramedics, other PC providers and family carers. Some of these components included (1) equipping paramedics with communication skills to provide support and engage family carers in shared-decision making; (2) providing paramedics with resources to refer patients and family carers to PC supportive services; (3) educating family carers on the role of palliative paramedicine and when it might be helpful to call an ambulance; and (4) instructing family carers to provide advance care planning documentation and contact details of the patient's GP and PC service to paramedics upon arrival.

Our approach echoes that of *The Lancet Commission on the Value of Death*, which notes that "in high-income countries, death and dying have become unbalanced as they move from the context of family, community, relationships and culture to sit within the health-care system."[7] Despite this well-established shift in care settings, the integral role that informal carers – including family and community members – still play in community-based PC is often under-acknowledged.

A NZ study qualitatively explored bereaved family members' experiences of emergency ambulance care at the end of life, reporting paramedics assist, inform and reassure patients and family caregivers managing distressing symptoms, falls, infections, unexpected events and death itself.[8] However, participants from the study expressed a reluctance to call triple zero in the case of a palliative emergency, as they were aware of the existing pressures on ambulance services, feared losing their independence and associated paramedic intervention with unwanted trips to hospital.[8] Although participants favourably viewed paramedic care, they were eager to avoid EDs as they perceived them as ill-suited to care for those nearing end of life.[8] These findings align with our own, highlighting the need to for paramedics to have alternative referral destinations beyond an ED, such as direct access to specialist in-patient PC units. The study also suggested that even when participants had some awareness their family member was very unwell or had a life-limiting illness, this did not mean that they felt prepared for their death.[8] This gap in family carer knowledge and understanding of PC and EOLC, including the role paramedics can play in

delivering this type of care, was also identified in our research. As our findings demonstrated, paramedics can indeed have the capacity to treat and not transport a PC patient, if supported with adequate scope of practice and clinical back-up.

8.1.5 Key learning 5 – Interdisciplinary practice and support breaks down silos

The final key learning to emerge from all four phases of the thesis related to fostering greater understanding and collaboration between paramedics and other disciplines involved in community-based PC and EOLC. Findings from Phase 1 suggested paramedics should not replace existing specialist community PC teams; instead, they ought to act as an adjunct service, especially after-hours, to support other PC providers. The review also suggested that the paramedic role of rapid response should be accompanied by a clinical back up function, enabling paramedics to call a specialist PC clinician at any time to receive clinical guidance and deliver effective care. This study identified existing literature which argued that paramedics having point of care access to an integrated EMR could also foster stronger communication channels between ambulance services and other healthcare providers.

The findings of Phase 2 supported these assertions. The emphasis on clinical backup pathways in all guidelines reflects the relative infancy of this sub-discipline within paramedicine, and a growing need for more integrated models of care. This line of thought continued into Phase 3. In Chapter 5, participants reported that limited access to specialist support led to paramedics filling a gap, especially in rural and remote areas and out-of-hours. Despite paramedics meeting this unmet need, ambulance services have traditionally worked in siloes, lacking integrated approaches with other healthcare services, including PC and general practice. Specialist PC participants expressed a strong desire to collaborate in shared care models with ambulance services and other generalist PC providers in the future. Cultivating interprofessional understanding and communities of practice was another key finding from Chapter 6. All participants acknowledged the 'multidisciplinary and holistic' nature of PC required multisectoral collaboration. The study's findings called for greater recognition of paramedic capacity and skills across the healthcare sector to strengthen their role in existing interdisciplinary PC networks.

Key learning 5 suggests that improving integration of ambulance services with other community PC providers at macro, meso and micro-levels is necessary to advance sustainable models of interdisciplinary

PC. However, too often paramedicine and other allied health perspectives are excluded from informing PC research, policy and practice.[9] One study recently explored the integrated PC initiatives of five European countries from exclusively specialist PC doctors' and nurses' points of view.[10] Interestingly, this study identified the need for greater inclusivity of generalist PC providers in key decision making and planning, but failed to incorporate such perspectives in its methodological approach.[10] However, the study's findings draw complimentary observations to our own research, emphasising that the fragmentation of healthcare services and late referrals to specialist PC services may prevent many patients from receiving the PC they need at the right time and in the right place, resulting in unmet needs, undesired hospital admissions in the last weeks of life and an inability to die at their preferred place.[10] According to the study's participants, "the dominant strategy for fostering integrated PC is building core teams of PC specialists and extended professional networks based on personal relationships, shared norms, values and mutual trust, rather than developing standardised information exchange and referral pathways."[10]

As a result of this key learning over the first three phases, the finalised framework included many components relating to interprofessional care. Some of which included (1) broadening the paramedicine profession to include clinical roles beyond an ambulance setting; (2) connecting paramedics to localised PC referral pathways; (3) establishing interprofessional linkages and understanding between ambulance services and other community PC providers through localised networks, bi-directional training and routine multidisciplinary debriefing opportunities; (4) requiring PC plans to include recommendations for how clinical PC back-up support will be provided to paramedics within local health jurisdictions; and (5) facilitating the collaboration between PC organisations and ambulance services to map the after-hours community-based PC service gaps within their respective jurisdictions, promoting needs-based investments of palliative paramedicine and avoiding duplication of services.

8.2 Implementing a new framework of best practice

In the field of paramedicine research, it is well established that expanding a service delivery model is challenging and requires complex system change.[11] Importantly, evoking such systemic and sustainable changes will require parallel action at micro, meso and macro-levels.[11] Within the discipline, a number of

multifaceted interventions have already been piloted to broaden PC scope and improve paramedic practice. Most recently, a Canadian provincial ambulance service partnered with the national virtual hospice network to develop a comprehensive clinical pathway, with PC-specific guidelines and education to support paramedics minimising avoidable hospital admissions of patients to ED.[12] The retrospective cohort study found 68% of cases involved a remote clinical consultation between the paramedic and specialist clinical back-up team. The findings of this study highlight the integral role that remote clinical support can have in mitigating risk and facilitating non-conveyance of a patient to hospital, especially when the goals of care documentation is absent or unclear.[12] In addition, the findings demonstrated an emerging aspect of practice, where paramedics provide educative support to patients and their families, including what to expect at end of life, and how to prepare and administer EOLC medications.[12] These conclusions support assertions made within Phase 4 of research, including (1) incorporating and connecting paramedics to localised PC referral pathways, including alternative referral destinations beyond EDs; and (2) equipping paramedics with paramedics with communication skills about death and dying to provide support and engage patients, families and carers to partner in PC through shared decision-making and debriefing.

Incorporating new aspects of care into routine paramedic practice will require considerable behaviour change amongst clinicians and consumers alike.[11] As one recent British study demonstrated, a theory of change model can provide theoretical and testable links from intervention activities to proposed long-term outcomes and indicate the areas for assessment of effectiveness.[13] This 2023 study engaged specialist community paramedics, ambulance call takers and PC doctors and nurses in successive online dialogues to develop an intervention to improve paramedicine EOLC capacity.[13] The participants agreed on four long-term outcome priorities, including: 1) increased use of anticipatory and regular end-of-life medications; 2) reduced end-of-life clinical and medication errors; 3) reduced unnecessary hospitalisations; and 4) increased concordance between patient preferred and actual place of death.[13] As a result, the participants identified the most pressing intervention for paramedics was to have immediate access to information and resources to support EOLC.[13] In contrast to our own research findings, the authors of this study argued a low cost and feasible intervention should supersede higher system-level changes, to facilitate practical improvements that can be implemented efficiently, and result in targeted

paramedic behaviour change.[13] However, this study acknowledged its time and budget limitations, noting with sufficient financial and health services buy in, broader systemic change could be delivered with more comprehensive interventions.[13] These findings highlight the logistical restraints we must consider, and work within, when seeking to implement any future framework in Australia and beyond.

Lastly, healthcare system performance improvement is multifaceted, requiring an integrated approach across disciplines to increase quality of PC and facilitate the preferred location of death.[14] One contemporary study that recognised the merit of a whole of system approach, described the essential elements, barriers and facilitators for implementing, spreading and scaling up the aforementioned Canadian *Paramedics Providing Palliative Care at Home* programme.[14] The study employed the highly regarded Consolidated Framework for Implementation Research (CFIR) to articulate determinants and highlight salient variables of implementing the programme, concluding many facilitators and barriers were inter-connected across a variety of the programme components.[14] The study argued, implementing change based on a single aspect of the programme may not yield the desired results, and cautioned services looking to implement the programme to be clear on what components were ready to launch.[14] They recommended engaging local champions within the ambulance service to facilitate clear expectations, and foster healthy cultural shifts required to implement the programme's features.[14] These astute observations align with many components of our Phase 4 framework, perhaps most notably: (1) identifying and supporting interested and wiling paramedics to become PC champions within their respective workplaces; connecting these clinicians with local grass roots PC initiatives.

8.3 Summary of recommendations

A summary of recommendations with aim to address the various barriers, enablers and opportunities for improving the role of paramedics delivering PC and EOLC, as identified in this thesis, and foster broader healthcare system and community acceptance of palliative paramedicine are provided below. The reader can find more detailed recommendations at the end of each individual chapter above.

1. Maintain annual meetings with the Palliative Paramedicine AG, sharing publications arising from the thesis, seeking the group's official endorsement for the framework and inviting those demonstrating willingness and capacity to participate in future related research.

2. Engage a multidisciplinary team to create an implementation strategy for the framework, which would reflect any perceived barriers, facilitators and challenges for applying the full 32 components into policy and practice.
3. When developing the implementation strategy, seek the endorsement of relevant professional associations, apply a theory of behaviour change to guide the next steps, and acknowledge the time and resources required to standardise palliative paramedicine practice across Australia.

8.4 Strengths and limitations

The strengths and limitations of each phase are provided in more detail in the relevant chapters; this section will focus on the overall thesis. One of the major strengths of this research is its novelty. The studies included in this thesis were conducted to address a gap in empirical evidence supporting the design and delivery of palliative paramedicine in Australia. This thesis contained the first qualitative content analysis of paramedicine guidelines, highlighting opportunities for prospective studies in this field to adopt our carefully curated methodology. Furthermore, we undertook the first qualitative research to explore lived experiences of palliative paramedicine beyond paramedics, family carers, and PC specialists to also include GPs and residential aged care nurses. Combining these qualitative findings to underpin the development of a multi-level framework via consensus methods in our final study, lays the foundations for standardising best practice across Australia in the future. This knowledge further enables us to understand the barriers, enablers and opportunities for implementing this framework and improving the provision of palliative paramedicine, which meets the needs of diverse stakeholders.

Another substantial strength of this PhD is that data was collected from all jurisdictions of Australia across metropolitan, regional, rural and remote settings, in addition to international health systems comparable to our own. This may enhance the transferability and applicability of our findings to broader Anglo-American ambulance service and PC contexts, whilst also preserving their national relevance.[15]

It has been acknowledged since the outset of this PhD, that this research should contribute to building capacity within the sector by generating an Australian and NZ palliative paramedicine community of practice. The ongoing input of the Palliative Paramedicine AG throughout this research was paramount to working within a policy and practice mindset. AG members played an essential role in building trust,

establishing and brokering relationships with the paramedicine sector, maintaining existing relationships with ambulance services and providing practical guidance throughout the research. By engaging the AG in the research from the beginning – in both an advisory capacity and through active participation in the studies – we have been able to see the implementation of our research into policy and practice in real time. During Phase 2, members of the AG self-elected to co-author this study, including Duncan McConnel (St John NT Clinical Practice Manager at the time). In 2021, upon finalising the peer review process and publication of this study, Mr McConnel translated the findings into the new *P014 Palliative Care Clinical Practice Guideline* for St John Ambulance NT with my assistance (Appendix E). This guideline has now been in practice for the past two years.

One key challenge to overcome in the completion of this thesis was the COVID-19 pandemic. I began my PhD in March 2020. Shortly after commencing, Sydney (where I live) went into a series of ongoing lockdowns for the next 22 months. As a result, all data for Phases 2 and 3 were collected via teleconferencing. The gold standard for qualitative data collection is in-person interviews to enable the researcher to pick up on body language, social and facial cues.[16] I initially had concerns about conducting interviews over Zoom, especially with bereaved family carers, as I thought this could limit my ability to connect and build rapport with these participants over such a sensitive topic. I also worried older participants may experience trouble using an online teleconferencing platform due to technological barriers, and therefore limit the pool of participants I could reach. However, despite these early concerns, semi-structured interviews conducted over teleconferencing yielded rich data and my capacity to recruit a broad and representative sample was not hindered. In fact, one positive impact of the pandemic seemed to be greater digital literacy amongst our elderly population. The use of teleconferencing gave voice to many participants located in rural and remote areas of Australia, and those experiencing mobility issues, I would have been otherwise unable to reach in-person.

8.5 Implications for research

The studies in this thesis identified several recommendations for broadening the role of paramedics delivering PC and EOLC in Australia. However, there are several important research gaps that were not addressed in this thesis and additional research topics are proposed below.

1.) Person-centred comprehensive evaluation of the framework post implementation

At its core, the role of palliative paramedicine is to deliver person-centred PC to patients living with a life-limiting illness, and their families and carers in the community. As previously discussed, multifaceted interventions aimed at improving the role paramedics have in PC and EOLC have already been undertaken internationally.[1, 12-14] However, there remains a paucity of evidence evaluating their efficacy and economic impact. From the beginning of this thesis, I aimed to develop practical and sustainable measures to better equip paramedics to deliver PC and EOLC in Australian settings. To ensure the framework is fulfilling its intended purpose once implemented, a comprehensive evaluation, including cost-benefit analysis, should be undertaken. This evaluation ought to examine the efficacy of all individual components of the framework, in addition to the collective whole, to determine its suitability and ensure its sustainability into the future.

2.) ***Translation of the Australian framework into international contexts***

Australians were the largest participant pool of the expert panel in the Delphi study, but international experts were added to provide a wider perspective and increase the likelihood the framework could be relevant and applicable to other comparable health systems. Opportunities exist to translate our findings and the resulting framework into other contexts, including in Franco-German ambulance services, where palliative paramedicine is well under way.[17-19] In addition, the framework could be adapted for low and middle-income countries, including South Africa and Brazil, where significant gaps in paramedic practice have been established[20, 21] and some collaborations already fostered.[22] Investigating the applicability of our framework in alternate settings, through qualitative interviews and quantitative surveys with key stakeholders, could assist in the first stages of translating our framework into future international context-specific policy and best practice. Embarking on this research trajectory could also enable Australia to become a thought leader within the discipline.

8.6 Conclusion

As the first in-depth exploration of palliative paramedicine from an Anglo-American lens, this research highlighted the significant opportunities available for broadening the role of paramedics delivering palliative and end-of-life care in Australian communities. A multifactorial framework that addresses the system, service, community and individual components relevant to improving palliative paramedicine in

Australia has been developed to standardise best practice nationally. By engaging a multidisciplinary team of stakeholders to build capacity and engagement with key stakeholders, a comprehensive implementation strategy can be formulated for translating our developed framework into policy and practice. Future opportunities also exist to evaluate the impact of the framework, and demonstrate international thought leadership in this emerging field, building a global community of palliative paramedicine practice and extending our framework into other healthcare systems.

8.7 References

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Appendices

Appendix A – HREC approval 2021/607

THE UNIVERSITY OF SYDNEY

Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

Monday, 20 September 2021

Prof Josephine Clayton
Northern Clinical School: Medicine; Faculty of Medicine and Health
Email: josephine.clayton@sydney.edu.au

Dear Josephine,

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

I am pleased to inform you that after consideration of your response, your project has been approved.

Details of the approval are as follows:

Project No.:	**2021/607**
Project Title:	**Palliative Paramedicine: A Qualitative Study of Families and Carers**
Authorised Personnel:	**Clayton Josephine; Butow Phyllis; Juhrmann Madeleine; Platts Cara;**
Approval Period:	**20/09/2021 to 20/09/2025**
First Annual Report Due:	**20/09/2022**

Documents Approved:

Date Uploaded	Version Number	Document Name
02/09/2021	Version 2	Families and Carers Interview Guide Clean
02/09/2021	Version 2	Families and Carers Participant Consent Form Clean
02/09/2021	Version 2	Families and Carers Patient Information Form Clean
02/09/2021	Version 2	Families and Carers Email Invitation
02/09/2021	Version 2	Families and Carers Protocol Clean

Condition/s of Approval

- Research must be conducted according to the approved proposal.
- An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
  - Serious or unexpected adverse events (which should be reported within 72 hours).
  - Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.
- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.

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THE UNIVERSITY OF SYDNEY

- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- The Ethics Office may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely,

Associate Professor Mark Arnold
Chair, Human Research Ethics Committee (HREC 2)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2018) and the NHMRC's Australian Code for the Responsible Conduct of Research (2018)

Appendix B – HREC approval 2021/608

THE UNIVERSITY OF SYDNEY

Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

Thursday, 9 September 2021

Prof Josephine Clayton
Northern Clinical School: Medicine; Faculty of Medicine and Health
Email: josephine.clayton@sydney.edu.au

Dear Josephine,

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

I am pleased to inform you that after consideration of your response, your project has been approved.

Details of the approval are as follows:

Project No.:	**2021/608**
Project Title:	**Palliative Paramedicine: A Qualitative Study of Health Professionals**
Authorised Personnel:	**Clayton Josephine; Butow Phyllis; Juhrmann Madeleine; Platts Cara;**
Approval Period:	09/09/2021 to 09/09/2025
First Annual Report Due:	09/09/2022

Documents Approved:

Date Uploaded	Version Number	Document Name
04/07/2021	Version 1	Palliative Paramedicine_Interview Guide_Health Professionals
02/09/2021	Version 2	Health Professionals Participant Information Statement Clean
02/09/2021	Version 2	Health Professionals Study Protocol Clean
02/09/2021	Version 2	Health Professionals Email Invitation Clean
02/09/2021	Version 2	Health Professionals Participant Consent Form Clean

Special Condition/s of Approval

- It will be a condition of approval that a letter of support be obtained from an appropriate authority at any organisation through which the researchers propose to recruit before any recruitment activity occurs via their membership. Evidence of this support does not need to be submitted to the ethics office but should remain on file in case of audit.

Condition/s of Approval

- Research must be conducted according to the approved proposal.
- An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
  - Serious or unexpected adverse events (which should be reported within 72 hours).
  - Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.

Research Integrity & Ethics Administration
Research Portfolio
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NSW 2006 Australia

T +61 2 9036 9161
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ABN 15 211 513 464
CRICOS 00026A

- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.
- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- The Ethics Office may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely,

[redacted]

Associate Professor Mark Arnold
Chair, Human Research Ethics Committee (HREC 2)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2018) and the NHMRC's Australian Code for the Responsible Conduct of Research (2018)

Appendix C – HREC approval 2022/914

THE UNIVERSITY OF SYDNEY

Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

Tuesday, 7 February 2023

Prof Josephine Clayton
Northern Clinical School: Medicine; Faculty of Medicine and Health
Email: josephine.clayton@sydney.edu.au

Dear Josephine,

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

I am pleased to inform you that your project has been approved.

Details of the approval are as follows:

Project No.:	**2022/914**
Project Title:	**Palliative Paramedicine: Delphi Study and Focus Group**
Authorised Personnel:	**Clayton Josephine; Butow Phyllis; Juhrmann Madeleine; Boughey Mark; Simpson Paul;**
Approval Period:	**07/02/23 to 07/02/27**
First Annual Report Due:	**07/02/24**

Documents Approved:

Date Uploaded	Version Number	Document Name
03/02/2023	3	PCF_version 3_clean
03/02/2023	3	PIS_version 3_clean

Special Condition/s of Approval

1) Ensure that data is transferred back from the Welphi platform to a University of Sydney drive or Research Data Store.

Condition/s of Approval

- Research must be conducted according to the approved proposal.
- An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
  - Serious or unexpected adverse events (which should be reported within 72 hours).
  - Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.
- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.

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ABN 15 211 513 464
CRICOS 00026A

- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- The Ethics Office may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely,

Associate Professor Ingrid Gelissen
Interim Chair
Health Review Committee (Low Risk)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2018) and the NHMRC's Australian Code for the Responsible Conduct of Research (2018)

THE UNIVERSITY OF SYDNEY

Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

Tuesday, 21 March 2023

Prof Josephine Clayton
Northern Clinical School: Medicine; Faculty of Medicine and Health
Email: josephine.clayton@sydney.edu.au

Dear Josephine,

Your request to modify this project, which was submitted on 01/03/2023, has been considered.

This project has been approved to proceed with the proposed amendments.

Protocol Number: **2022/914**
Protocol Title: **Palliative Paramedicine: Delphi Study and Focus Group**

Addition of Authorised Persons: **Meredith Makeham**
Removal of Authorised Persons:

New Completion Date:

Annual Report Due: 07/02/2024

Documents Approved:

Date Uploaded	Version Number	Document Name
28/02/2023	Version 3	PIS_Delphi_version 3 ammendment_clean

Please contact the ethics office should you require further information.

Sincerely,

[redacted]

Dr Joanne Hart
Chair
Modification Review Committee Chair (MRC 3)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2018) and the NHMRC's Australian Code for the Responsible Conduct of Research (2018)

Palliative Paramedicine Advisory Group Terms of Reference

Background

Madeleine Juhrmann is a PhD candidate at the University of Sydney. Her Project, titled *Palliative Paramedicine: Broadening the Role of Paramedics Delivering Palliative and End-of-Life Care in Australian Communities*, is supervised by Professor Josephine Clayton and Professor Phyllis Butow and funded from 1st March 2020 until the 31st of December 2023.

The Project aims to:

- Investigate the current role of paramedics in delivering palliative care, exploring how their scope of practice could be expanded to improve patient outcomes during palliative and end-of-life care; and
- Develop a best-practice palliative paramedicine framework suitable for national implementation, to enhance paramedics' ability to provide palliative and end-of-life care in Australian communities.

The Project will feature four key studies:

- **Study 1 – Systematic Integrative Review (2020/early 2021)**
  To review and synthesise the empirical evidence regarding paramedics delivering palliative and end-of-life care in community-based settings.

- **Study 2 – Policy Review (2021)**
  To examine the quality and content of existing Australian palliative paramedicine guidelines with a sample of guidelines from comparable Anglo-American ambulance services.

- **Study 3 – Qualitative Study (late 2021/2022)**
  To elicit stakeholder perspectives, experiences and attitudes on the role of paramedics delivering palliative and end-of-life care in community-based settings.

- **Study 4 – Delphi Study (2023)**
  To gain consensus regarding the framework components considered most essential for improving the role of paramedics delivering palliative and end-of-life care in Australian communities, and to understand barriers and elicit recommended strategies to underscore the future national implementation of a palliative paramedicine framework.

Concurrent with these studies, Madeleine Juhrmann has engaged an Advisory Group (AG) to help guide her Project from a practical perspective.

1. Role of the AG

- To strengthen and promote collaboration between ambulance services on matters related to palliative paramedicine;

- To advise on current operational barriers and developments specific to the provision of palliative and end-of-life care within respective services; and
- To help inform studies to be carried out in the context of the Project, as set out above.

2. Term

These Terms of Reference are effective from the first AG meeting (11 March 2021), through to completion of the PhD project (anticipated date: 31 December 2023).

3. Membership

The AG will be led and chaired by **Madeleine Juhrmann**, PhD candidate and Project Lead, University of Sydney Northern Clinical School.

Group members of the AG with relevant expertise were recruited across all jurisdictions of Australia, and representation from New Zealand. These members include:

- New South Wales: **Angela Vaughan**, Paramedic and Coordinator of End-of-Life Care and Palliative Care, NSW Ambulance
- Australian Capital Territory: **Sam Perillo**, Paramedic and Consumer Liaison Officer Clinical Governance Unit, ACT Ambulance
- Victoria: **Dr David Anderson**, Acting Medical Director, Ambulance Victoria & **A/Prof Mark Boughey**, Director of Palliative Medicine, St Vincent's Hospital Melbourne, Deputy Director Centre for Palliative Care and Clinical Lead Palliative Care SCV Centres of Clinical Excellence
- South Australia: **Andrew Noble**, Extended Care Paramedic and Palliative Care Lead, South Australian Ambulance Service
- Tasmania: **Mike McDermott**, Manager of Medical Services, Ambulance Tasmania
- Western Australia: **Dr Gayle Christie**, Medical Director, St John Ambulance Western Australia
- Northern Territory: **Geoff Bates**, Clinical Manager, St John Ambulance Northern Territory
- Queensland: **Tony Hucker**, Director Clinical Quality and Patient Safety, Queensland Ambulance Service & **Lachlan Parker**, Assistant Medical Director and Clinical Practice Guideline Manager, Queensland Ambulance Service
- New Zealand: **Dr Tony Smith**, Medical Director and Chair Clinical Procedures and Guidelines Working Group, St John New Zealand & **Dr Natalie Anderson**, Registered Nurse and Paramedic Academic, University of Auckland
- Council of Ambulance Authorities: **David Waters**, Chief Executive.

4. Meetings

- All meetings will be chaired by Madeleine Juhrmann.
- Meeting agenda and minutes will be circulated to AG members by Chair, Madeleine Juhrmann.
- Decisions will be informed by the advice and recommendations from the AG. The group will not have final approval or decision-making authority, which is the responsibility of the Project Lead and PhD candidate, Madeleine Juhrmann.
- Meetings will be held annually through the duration of the PhD project and arranged by Madeleine Juhrmann via videoconference.

- Out of meeting input, such as comments and review of documents, may occur from time to time.
- Group members must disclose any conflict of interest in any matters being considered by the AG.

5. Communication with the AG group members:

- Communication between group members outside of meetings will be via email as required.
- Project updates will be sent in between AG meetings as required.
- Matters raised to the AG outside of meetings must be in writing and addressed to the Chair, Madeleine Juhrmann, in the first instance.

5. Other

- Materials developed for the project will be considered confidential and will not be circulated beyond the AG members, until it is made clear in writing (email) by Madeleine Juhrmann that they are ready for circulation.
- The contribution of AG members will be acknowledged in the project reports and publications.
- Co-authorship on any publications arising out of the project will be subject to the usual expectations of active contribution by all authors.
- Members acknowledge and agree that the University of Sydney owns all intellectual property in connection with the AG, in accordance with the University of Sydney Intellectual Property Policy 2016.

6. Amendment, Modification or Variation

These Terms of Reference may be amended, varied or modified in writing by the Chair, after consultation with group members.

Appendix E – St John Northern Territory P014 – Palliative Care Guideline

P014 - Palliative Care

Palliative care aims to improve the quality of life of patients and their families who are facing a life-limiting condition. Palliative care helps people live as fully and comfortably as possible, regardless of age, and can be provided in many different settings. It is a multi-disciplinary approach to care involving many facets- psychological support and pastoral care; treatment and care specific to the disease; symptom management; and support services offered intra-facility and to those who wish to remain at home or in their communities. Palliative care intends to neither hasten nor postpone the process of dying, but accepts that death is a normal process.

It is important all healthcare professionals ensure they know and understand the patient's wishes, both during routine care and end-of-life decisions. We should understand any orders or documentation in place, and work with family and appointed guardians to deliver the right care, and where necessary withhold futile or declined treatment to meet these wishes.

Ambulance services have several different ways in which they may interact in palliative care situations, from non-emergency transport, through to emergency ambulance attendance for incidents/falls/accidents, carer exhaustion or incapacity; or unexpected changes in condition.

Paramedic approach to the palliative care patient

The paramedic needs to determine the reason for the ambulance request and how that fits in with the patient's current palliative care plan.

The initial questions the paramedic then should consider are:

- *Is this reason not related to the palliative illness?* If this is the case, then the paramedic needs to complete a thorough clinical assessment of the patient and implement care, according to current St John NT Clinical Guidelines but modified by patient wishes.
- *Is this reason related to the illness for which the patient is receiving palliative care?* If this is the case, then the paramedic needs to consult with the patient, their carer and if able, consult with the patient's palliative care health practitioner or the NT Palliative Care Consultant via the Royal Darwin Hospital Switch on 08 8922 8888 (Top End) or 08 8951 7777 (Central).
  - > Palliative Care Patients have a 'Red Folder,' which stays with the patient at all times and contains the details of the illness, medication plan, Advanced Personal Plan (APP) and Resuscitation Status Form (RSF).
  - > The Red Folder can assist you in your clinical decision making if you are unable to make contact with the NT Palliative Care Team or Consultant.

Advanced Personal Plan (APP)

The APP is a legal, binding document that details the level of care that the person desires in the event of an adverse event, usually a cardiac or respiratory arrest.

Resuscitation Status Form (RSF)

The RSF is an NT Department of Health form that specifies either not attempting resuscitation in the event of arrest, or with certain limits, e.g. not for intubation, not for CPR. This form is signed by the medical team caring for the patient and the patient themselves, prior to losing their capacity to make a clinical decision about their care.

Palliative Care Medication Pack

The palliative care medication pack generally contains the medications used within the patient's infusion pump, that is delivering these medications subcutaneously over a 12 to 24 hour period. These can include:

- Morphine;
- Midazolam;
- Haloperidol; and,
- Hyoscine butylbromide.

These medications are usually left to ensure there is enough for the pump and any potential breakthrough dosages.

Other medications can include over the counter medications such as:

- Paracetamol;
- NSAIDs; and,
- Various laxative medications

Although some of these medications are not part of the St John NT DTPs, paramedics should be familiar with the types of medications.

Making Patient Care Decisions- Capacity, APPs and RSFs

When determining the patient's wishes in respect to their treatment and transport, the paramedic needs to determine if their patient has the capacity to make decisions about their treatment.

- If your patient is able to still make clinical decisions about their medical / palliative care treatment, then obtain their consent to do so. Such decisions may contradict their most recent APP or RSF and such new decisions are still to be respected.
- If the patient lacks or no longer has the capacity to make clinical decisions related to their care, then the paramedic needs to inquire about what advanced care planning is in place. This would include locating the patient's Red Folder APP and RSF.

Futility and *First, do no harm*

In caring for palliative care patients St John NT staff may be seeing and administering medication doses beyond those normally encountered, and whilst such doses may occur shortly before death, if given with the intent of relieving suffering they are not seen as harming the patient or causing death.

It is important to note that St John NT staff are not compelled to commence or continue treatment that in their professional opinion is futile or harmful to any patient, including advanced life support; regardless of stated wishes of patients and others.

Common presenting problems with palliative care patients

Pain

With appropriate analgesia, pain can normally be managed well in palliative patients. There are times in which your patient may require additional breakthrough pain relief.

To provide breakthrough pain relief administration for a palliative patient, first review the patient's Red Folder to see what is listed on their *valid* medication plan:

- If fentanyl or morphine are listed in doses below or equal to C030 **Pain Management** then give these as indicated in the Red Folder;
- If fentanyl or morphine are already being given as part of a subcut infusion consider giving ***one twelfth of that dose* as a stat SC dose and repeat once after 30 minutes if required**;
- If the above 'one twelfth dose' of fentanyl or morphine or the medication plan exceeds the normal C030 **Pain Management** then such doses can be given once by paramedics and ICPs but must be followed up with at least one of:
  - > consultation with ICP DAP for a disposition;
  - > consultation with the NT Palliative Care Consultant 08 8922 8888 (Top End) or 08 8951 7777 (Central) for a disposition; or
  - > transfer to hospital.

If a Red Folder is unable to be located, medication plan is invalid (e.g. believed to be erroneous, old, patient already exceeded limits), or if the patient is opioid naïve; then commence pain relief per C030 **Pain Management** and consult the NT Palliative Care Consultant for a further plan and disposition.

Ensure to methodically check opioid doses with a colleague, ICP DAT or NT Palliative Care Consultant if a solo-responder.

Nausea and Vomiting

Nausea and vomiting can be related to multiple issues. Examples include:

- Medications (particularly analgesics)
- Severe pain
- The patient's terminal illness; or
- Another medical condition.

Nausea and vomiting can be extremely distressful to patients and it is important that control is attempted.

Non-pharmacological methods include:

- Increasing access to fresh air;
- Changing body position;
- Removing offensive odours;
- Acupressure (see C028 Nausea and Vomiting); and,
- Offering sips of carbonated beverages such as lemonade or soda water.

If non-pharmacological methods do not work, first review the patient's Red Folder and locate the medication plan to see what current antiemetic's the patient is on. If the patient has not had any antiemetic prior to St John NT arrival then treat as per **C028 Nausea and Vomiting.**

If after ten minutes there has been no effect in reducing the patient's nausea or vomiting, or upon review of their medication plan and they have already reached their maximum antiemetic, then:

- Administer **(Adult) Droperidol 0.5mg (0.25mg in frail or under 50kg) IV.**

Managing Breathlessness

If there is anything within the Red Folder medication plan already indicated for breathlessness, then verify with the patient or patient carers, to see if this had already been applied. If it has not been enacted, do so as per the patient's medication plan, preferably with the patient or carer self-administering such medications.

Again consider assisting the patient with non-pharmacological interventions for breathlessness such as position, fresh air, pedestal fan directed at the patient, *et al*.

If the patient's medication plan pharmacology has already been used, is not present or additional breakthrough medication is required, then paramedics should:

- Consider new pathology- e.g. pulmonary embolus, or aspiration with any attendant management options; and,
- Consider **(Adult) Fentanyl 25- 50microg, repeated once at 10 minutes** or **(Adult) Morphine 0.5- 1mg SC, repeated once at 20 minutes** (*Do not* combine fentanyl and morphine, use one or the other).

If any agent has been used for breathlessness other than as prescribed in the medication plan then one of the following is also required:

- consultation with ICP DAP for a disposition;
- consultation with the NT Palliative Care Consultant 08 8922 8888 (Top End) or 08 8951 7777 (Central) for a disposition; or
- transfer to hospital.

Care after death

The death of a patient, even if expected, is still a very challenging environment to work in. Grief is a natural part of death for everyone who is left behind once a family member or friend dies. The way in which people respond to death can be very unpredictable, so paramedics need to be aware of their surrounding and if required retreat from the immediate area and request assistance for NT POL.

Generally, once a patient has died, **Recording of Life Extinct** has been performed **and on consult with general practitioner or NT Palliative Care Consultant there are *no* reasons to consider the patient's case requires referral to the Coroner:**

- Remove monitoring;
- Leave invasive lines in place;
- Place the body supine;
- Place head on pillow;
- Try to close the eyelids and/or mouth;
- Place arms down by the side;
- Cover the body up to the neck with a sheet or similar;
- 'De-medicalise' the area of packs and equipment as much and as quickly as possible;
- If air-conditioning available: turn to cold;
- (Modifying above to any patient or carer expressed cultural considerations).

Family members/ carers may also require assistance with contacting the funeral director, the patient's palliative care healthcare provider / general practitioner or even contact other family members who may be interstate or overseas. Providing assistance where practical and within operational demand, can go a long way in assisting the family in early grief and is often remembered forever by the family/ carers.

Cultural Considerations

St John NT acknowledges that cultural groups are dynamic and evolving in perpetuity. We recognise that cultural groups are not fixed or homogenous and that diversity exists within and across cultural groups. Clinical Procedure **P004 – Cultural Safety and Diversity**, discusses many key aspects of this, and paramedics should make themselves very familiar with this content.

It should also be noted that many cultural beliefs or actions associated with death, to an outsider to that culture can seem very strange. As paramedics we should not view these behaviours, customs or rituals as 'abnormal' or 'wrong' behaviour. What may seem very strange to you, may in fact be a traditional behaviour or cultural belief, bestowed on someone who has recently died, that has been in place for thousands of years.

If at any time you feel uncomfortable, remove yourself to a safe location or speak with either a person you were initially in contact with on scene (if safe to do so) or contact the Duty Manager for further advice.

Special Notes

- It is important that the patient's regular treatment team are aware of the care delivered by St John NT Paramedics. Endeavour to update the patient's normal treating GP or the NT Palliative Care Consultant on 08 8922 8888 (Top End) or 08 8951 7777 (Central) if not transporting to hospital or as part of the case if the patient has died.
- Medications administered from either the St John NT Drug or Palliative Care Medication Pack ***must be documented on the St John NT ePCR.*** It is important to ensure all (including out of scope) medications administered whilst St John NT involved in care of the patient are listed on the ePCR and that reference must be made that states:
  - Patient Name;
  - NT Palliative Care Details for the patient;
  - Palliative care consultant or general practitioner details – if used;
  - Medication name, dosage, route, administration time; and,
  - Where the medication administered came from
    - St John NT Drug Kit; or,
    - Patient's Palliative Care Medication Pack

Appendix F – Interview guide for families and carers: Qualitative study

Introduction and demographic questions

Interviewer to read script:

As written in your Participant Information Form, we are conducting a study titled:

Palliative Paramedicine: A Qualitative Study of Health Professionals, Patients and Families

You have been invited to participate in this study because you are a family member or carer with experience caring for someone who received palliative and end-of-life care from paramedics (or ambulance services) in the community.

Are you still happy to be interviewed, and that the interview will be audio-recorded?

Thankyou. Participation involves a maximum 30-minute interview. If you get tired or need a break at any time, just let me know.

First, I would like to ask some questions about you (so we can describe the people who participated in the study), and then I will ask about your experience and views concerning paramedics delivering palliative and end-of-life care in Australian community-based settings. There are no right and wrong answers; we are simply interested in people's views. If you don't want to answer any of these questions, please just say so.

a. Regarding your demographic characteristics

   i. Current age:

   ii. Gender: M/F

   iii. Country of birth:

   iv. Employment status:
   - Full time
   - Part/time or casual
   - Studying
   - Not employed
   - Other (please specify)

   v. Education background: State
   - Did not complete primary school (before 12 years old)
   - Completed high school/secondary school before year 10
   - Completed high/secondary school to year 10
   - Completed final year of high school/secondary school
   - Professional certificate or vocational school e.g., Diploma
   - Undergraduate/Bachelor's degree
   - Postgraduate degree (Masters/PhD)

   vi. State
   - Australian Capital Territory
   - New South Wales
   - Northern Territory
   - Queensland
   - South Australia
   - Tasmania
   - Victoria
   - Western Australia

vii. Postcode that the person you cared for lived:

viii. Location that the person was cared for
- Major city
- Inner regional
- Outer regional
- Remote and very remote

ix. Relationship with the person you cared for
- Spouse
- Parent/Guardian
- Grandparent
- Sibling
- Child
- Friend
- Other

x. Age range of relative/person you cared for:
- Under 18
- 18-30
- 31-65
- 66-75
- 77-85
- 86+

xi. Relative/person's main underlying life limiting illness:
- Cancer
- Heart failure
- Chronic respiratory disease
- Dementia
- Kidney failure
- Liver failure
- Motor neurone disease
- Other

Patient/family member interview guide

I will now ask you some questions relating to paramedics (or ambulance officers) involvement in the provision of palliative and end-of-life care to patients in community-based settings. Paramedics work for ambulance services that operate 24 hours a day, seven days a week across all locations of Australia. Paramedics traditionally provide emergency care to patients, including those with palliative and end-of-life care needs, and often transport patients who require further care to hospital. In this study, we are focusing on paramedics providing palliative and end-of-life care to patients in community-based settings, including at home or in a residential aged care facility, but not a hospice or hospital. Palliative care is care provided to make a person comfortable, reduce symptoms, and improve quality of life. Palliative care may be provided alongside other treatments for the underlying disease. At the end of life, many patients choose to have palliative care only, as they do not want further invasive and uncomfortable treatments that may not extend their lives at all, or for very long. Also, palliative care can help patients to stay at home, if that is what they want, rather than going into hospital.

1. Role of the paramedic

a) Has a family member or someone you have cared for received palliative care and had input from an ambulance service at home? [If yes], what was it like? How was the ambulance service involved? What other health professionals were involved? What was the outcome for your family member/ person you cared for following the care delivered by the paramedic/s?

b) When and why would you call an ambulance for your family member/person you care for in the case of a palliative care emergency?

c) What are your views on the role of paramedics in palliative and end-of-life care in Australian communities?

d) In your opinion, which health service(s) should be responsible for providing care for patients and family members having a palliative and end-of-life care emergency at home, after hours and why? Prompt: for instance, should it be ambulance services, palliative care community services, GPs, or something else? How should they provide this care? Does this differ depending on where you live? Prompt: metropolitan, regional, rural, or remote.

2. Challenges, barriers and enablers

a) What are the key challenges facing palliative patients and their families/carers who want to remain at home during their end-of-life and why?

b) In your experience, what makes it harder or easier for patients and family members/carers to *receive* palliative and end-of-life care from paramedics in the community and why?

c) What makes it harder or easier for paramedics and/or other health professionals to *deliver* palliative and end-of-life care to patients and their family members/carers in the community? Please explain.

3. Opportunities for improvement

a) How do you think paramedics could help patients, and their families/carers avoid going into hospital when it isn't what the patient would want at the end-of-life?
b) How can paramedics better support a terminally ill person to have a home-based death if this is what is desired?
c) In your experience, how could ambulance services work more effectively with other health services to better support palliative patients and their families to stay at home at the end-of-life when this is what the person prefers? Why?
d) How involved should paramedics be, in delivering palliative and end-of-life care to palliative patients and their families at home? What should they be offering and why? Prompt: supporting patient's goals of care, medication delivery, verification of death, bereavement support.

4. Other

a) Is there anything else you that you think may be important to add?

Appendix G – Interview guide for health professionals: Qualitative study

Introduction and demographic questions

Interviewer to read script:

As written in your Participant Information Form, we are conducting a study titled:

Palliative Paramedicine: A Qualitative Study of Health Professionals, Patients and Families

You have been invited to participate in this study because you are a health professional who cares for palliative care patients in the community.

Are you still happy to be interviewed, and that the interview will be audio-recorded?

Thankyou. Participation involves a maximum 30-minute interview. If you get tired or need a break at any time, just let me know.

First, I would like to ask some questions about you (so we can describe the people who participated in the study), and then I will ask about your experience and views concerning paramedics delivering palliative and end-of-life care in Australian community-based settings. There are no right and wrong answers; we are simply interested in people's views. If you don't want to answer any of these questions, please just say so.

b. Regarding your demographic and clinical characteristics

i. Current age:

ii. Gender: M/F

iii. Country of birth:

iv. Employment status:
- Full time
- Part/time or casual
- Studying
- Not employed
- Other (please specify)

v. State
- Australian Capital Territory
- New South Wales
- Northern Territory
- Queensland
- South Australia
- Tasmania
- Victoria
- Western Australia

vi. Postcode of workplace:

vii. Location or workplace
- Major city
- Inner regional
- Outer regional
- Remote and very remote

viii. Main occupation
- Paramedic
    - Paramedic

    - Intensive care paramedic
    - Extended care paramedic
    - Rescue paramedic
    - Other (please specify)
- Palliative Care Physician
- Palliative Care Nurse
- General Practitioner
- Residential Aged Care Manager
- Other (please specify)

ix. Predominant practice setting
- Ambulance service
    - On road paramedic
    - Other (please specify)
- Palliative care
    - Community consult service
    - Inpatient palliative care unit
    - Acute hospital consult service
    - Mix of settings
- General practice
- Residential aged care facility
- Other (please specify)

x. Work experience in paramedicine, palliative care, general practice or residential aged care
- Less than 1 year
- 1 to 5 years
- 6 to 10 years
- More than 10 years

Health professional interview guide

I will now ask you some questions relating to paramedics delivering palliative and end-of-life care to patients in community-based settings. Paramedics work for ambulance services that operate 24 hours a day, seven days a week across all locations of Australia. Paramedics traditionally provide emergency care to patients, including those with palliative and end-of-life care needs, and often transport patients to hospital that require further care. For the purpose of this study, we are focusing on paramedics providing palliative and end-of-life care to patients in community-based settings, including a home or residential aged care facility, but not a hospice or hospital.

For paramedics and residential aged care manager participants where appropriate: Palliative care is care provided to make a person comfortable, reduce symptoms, and improve quality of life. Palliative care may be provided alongside other treatments for the underlying disease. At the end of life, many patients choose to have palliative care only, as they do not want further invasive and uncomfortable treatments that may not extend their lives at all, or for very long. Also, palliative care can help patients to stay at home or in their aged care home, if that is what they want, rather than going into hospital.

1. Role of the paramedic

a) Could you briefly describe a recent experience of paramedic involvement in the care of a palliative patient in a community-based setting? How was the ambulance service involved? What other health professionals were involved? What was the outcome for the patient following the care delivered by the paramedic(s)?

b) What are your views on the role of paramedics delivering palliative and end-of-life care in Australian communities?

c) In your opinion, which health service(s) should be responsible for after-hours provision of care for palliative and end-of-life care emergencies in the community, and how? Does this differ depending on location/rurality? Prompt: How might paramedics contribute to this service provision?

d.) For paramedic participants: How would you describe your level of professional satisfaction when caring for patients with palliative and end-of-life care needs? How would you describe the emotional impact of caring for patients with palliative and end of life care needs? (probe for paramedic colleagues experiences in this area where applicable)

2. Barriers and enablers

a) In your experience, what are the barriers experienced by paramedics when delivering palliative and end-of-life care for patients in the community? Why?

b) a) In your experience, what are the enablers experienced by paramedics when delivering palliative and end-of-life care for patients in the community? Why?

c) Are there similar/differing barriers and enablers experienced by other health professionals when engaging with or trying to involve paramedics in delivering palliative and end-of-life care in the community? Please explain.

3. Challenges

a) What are the key challenges facing paramedics to deliver high quality palliative and end-of-life care in the community now and into the future and why? Do you have any suggestions for how these could be resolved?

b) What are the challenges faced by other health services when interacting with ambulance services on matters relating to palliative and end-of-life care and why? Do you have any suggestions for how these could be resolved?

4. Opportunities for improvement

a) How can paramedics contribute to reducing avoidable hospital admissions of community-based palliative care patients and better facilitate home-based deaths?

b) How can multidisciplinary palliative care health teams work together to better support paramedics to deliver palliative and end-of-life care in the community?

c) What should be included in a paramedic's scope of practice when delivering palliative and end-of-life care in community-based settings and why? Prompt: consider the current scope of clinical practice guidelines and protocols and how they could be broadened.

d) Beyond a palliative care-specific clinical practice guideline, how can palliative care become better integrated into ambulance services' core business? Prompt: education and training, government policy and legislation, funding, research.

5. Other

a) Is there anything else you that you think may be important to add?

Appendix H – Delphi Round 1 Questionnaire

Demographic questions

i. Current age:

ii. Gender:

iii. Country of birth:

iv. Employment status:
- Full time
- Part/time or casual
- Studying
- Not employed
- Other (please specify)

v. Professional role:

vi. Years in that role:

vii. Education background:
- Completed high/secondary school before year 10
- Completed high/secondary school to year 10
- Completed final year of high school/secondary school
- Professional certificate or vocational school (Diploma)
- Undergraduate degree (Bachelor)
- Postgraduate degree (Master/PhD)

viii. State
- Australian Capital Territory
- New South Wales
- Northern Territory
- Queensland
- South Australia
- Tasmania
- Victoria
- Western Australia

ix. Postcode (at work for health professional participants/ at home for family member and carer participants):

1.) Macro-level components focus on the highest levels of the aggregate health care system for organising specific responses to palliative paramedicine at a structural level.

*Please review the below **macro-level components** and indicate on the scale if you believe they should be included in the framework from strongly agree to strongly disagree.*

Systems

1. Include paramedicine in national and jurisdictional palliative and end-of-life care policies and frameworks.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree

- Strongly disagree

2. Develop interdisciplinary palliative and end-of-life care competencies, including paramedicine as a key stakeholder.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

3. Provide paramedic services access to electronic medical records, enabling paramedics real time access to patients' advance care planning and palliative care details.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

4. Broaden paramedic scope of practice to verify death on scene.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

5. Embed palliative care into all paramedicine undergraduate and postgraduate curriculum, including theoretical and practical components.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

6. Broaden the paramedicine profession to include clinical roles beyond an ambulance setting i.e., paramedic practitioners with specialist palliative care capabilities in primary care settings.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

Other

7. If you have strongly agreed or strongly disagreed to any macro-level component, please provide brief details as to why
   (Qualitative response)

8. Please add any further macro-level components you believe should be included in the framework:
   (Qualitative response)

2.) Meso-level components focus on the intermediate organisational aspects of regulating palliative paramedicine within clinical services and communities.

*Please review the below **meso-level components** and indicate on the scale if you believe they should be included in the framework from strongly agree to strongly disagree.*

Healthcare services

9. Broaden paramedic scope of practice to include palliative and end-of-life care skills and require all ambulance services to maintain a best practice palliative and end-of-life care guideline.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

10. Standardise paramedic palliative and end-of-life care education and training, with specialist pathways available to paramedics expressing interest and capacity.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

11. Coordinate ambulance dispatch to prompt call receivers to enquire about a patient's palliative care status and notify paramedics before they arrive on scene.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

12. Incorporate and connect paramedics to localised palliative care referral pathways, including alternative referral destinations beyond an Emergency Department.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

13. Establish interprofessional understanding between ambulance services and palliative care, aged care and general practice services through bidirectional training and debriefing opportunities, and communities of practice.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

Communities

14. Develop public health palliative care campaigns to educate the public on death literacy and a paramedic's role in delivering community-based palliative care.
   - Strongly agree
   - Agree
   - Neither agree nor disagree
   - Disagree
   - Strongly disagree

15. Connect ambulance services with Compassionate Communities, to enable interested and willing paramedics/services to participate in local palliative and end-of-life care community engagement initiatives.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Other

16. If you have strongly agreed or strongly disagreed to any meso-level component, please provide brief details as to why
(Qualitative response)

17. Please add any further meso-level components you believe should be included in the framework
(Qualitative response)

3.) Micro-level components focus on individual clinicians, patients, families and carers' experiences that take place inside and around clinical encounters.

*Please review the below **micro-level components** and indicate on the scale if you believe they should be included in the framework from strongly agree to strongly disagree.*

Paramedics and other healthcare workers

18. Mandate generalist palliative care capabilities for all paramedics.
    - Strongly agree
    - Agree
    - Neither agree nor disagree
    - Disagree
    - Strongly disagree

19. Create optional specialist palliative care capabilities for interested and willing paramedics to pursue.
    - Strongly agree
    - Agree
    - Neither agree nor disagree
    - Disagree
    - Strongly disagree

20. Identify and support interested and willing paramedics to become palliative care champions within their respective ambulance station.
    - Strongly agree
    - Agree
    - Neither agree nor disagree
    - Disagree
    - Strongly disagree

21. Provide paramedics access to self-care and peer support services.
    - Strongly agree
    - Agree
    - Neither agree nor disagree
    - Disagree
    - Strongly disagree

Patients, families and carers

22. Equip paramedics with skills to engage patients, families and carers to partner in palliative and end-of-life care through shared decision-making and debriefing.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

23. Equip paramedics with skills and resources to provide in-home manual handling support to palliative care patients, families and carers.
    - Strongly agree
    - Agree
    - Neither agree nor disagree
    - Disagree
    - Strongly disagree

24. Equip paramedics with skills and resources to refer patients, families and/or carers palliative care supportive services.
    - Strongly agree
    - Agree
    - Neither agree nor disagree
    - Disagree
    - Strongly disagree

25. Instil family-centred and culturally appropriate care after death principles into paramedic palliative and end-of-life care practice.
    - Strongly agree
    - Agree
    - Neither agree nor disagree
    - Disagree
    - Strongly disagree

Other

26. If you have strongly agreed or strongly disagreed to any micro-level component, please provide brief details as to why:
    (Qualitative response)

27. Please add any further micro-level components you believe should be included in the framework:
    (Qualitative response)

Appendix I – Palliative Care and Social Practice publication not included in the thesis

Palliative Care & Social Practice

Critical Essay

Emergency medical services: the next linking asset for public health approaches to palliative care?

Palliative Care & Social Practice

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Abstract: Emergency medical services (EMS) are a unique workforce providing 24/7 emergency care across high-income countries (HICs) and low- and middle-income countries (LMICs). Although traditionally perceived as first responders to traumatic and medical emergencies, EMS scope of practice has evolved to respond to the changing needs of communities, including a growing demand for community-based palliative care. Public health provides a useful framework to conceptualise palliative and end-of-life care in community-based settings. However, countries lack public policy frameworks recognising the role EMS can play in initiating palliative approaches in the community, facilitating goals of care at end of life and transporting patients to preferred care settings. This article aims to explore the potential role of EMS in a public health palliative care approach in a critical discussion essay format by (1) discussing the utility of EMS within a public health palliative care approach, (2) identifying the current barriers preventing public health approaches to EMS palliative care provision and (3) outlining a way forward through priorities for future research, policy, education and practice. EMS facilitate equitable access, early provision, expert care and efficacious integration of community-based palliative care. However, numerous structural, cultural and practice barriers exist, appearing ubiquitous across both HICs and LMICs. A Public Health Palliative Care approach to EMS Framework highlights the opportunity for EMS to work as a linking asset to build capacity and capability to support palliative care in place; connect patients to health and community supports; integrate alternative pathways by engaging multidisciplinary teams of care; and reduce avoidable hospital admissions by facilitating home-based deaths. This article articulates a public health approach to EMS palliative and end-of-life care provision and offers a preliminary framework to illustrate the components of a potential implementation and policy strategy.

Keywords: ambulance, emergency medical service, palliative care, paramedic, public health, terminal care

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Introduction

Emergency medical services (EMS) are specifically staffed, designed and equipped for the emergency care of patients across metropolitan, regional, rural and remote settings 24 h a day, 7 days a week (24/7). EMS are traditionally perceived as first responders to traumatic and medical emergencies, typically motor vehicle accidents or cardiac arrests.[1] However, as a result of global populations living longer and with more chronic progressive diseases, the EMS scope of practice has evolved to respond to these changing needs of communities.[2] Ageing populations and increasing preferences to die at home have resulted in a growing demand for community-based palliative care.[3]

The World Health Organization (WHO) defines palliative care as

> An approach that improves the quality of life for patients and their families who are facing problems associated with life-limiting illnesses, through the prevention and relief of suffering by means of early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.[4]

End-of-life care (EoLC) typically refers to assessment, care and treatment of patients in their final 12 months prior to death.[5]

Specialist palliative care services are not able to fulfil the needs of these patients in isolation, particularly after hours.[6] As a result, EMS have emerged as 'gap-fillers', providing palliative and EoLC to patients in community-based settings when other services are unavailable, as palliative emergencies arise.[1] This shifting practice of EMS is apparent across both high-income countries (HIC) and low- and middle-income countries (LMIC).[7–12]

Public health provides a useful framework to conceptualise palliative and EoLC in community-based settings,[13–15] recognising that health is determined by a range of social and structural factors impacting on equity of access to palliative care,[16,17] while highlighting the intersecting role of health services and citizens in delivering holistic EoLC, and recognising everyone has a role to play in EoLC.[18]

Palliative care networks have made significant progress to integrate multidisciplinary teams into their provision of care, including emergency departments (EDs).[19,20] However, internationally, countries lack public policy frameworks that acknowledge the unique role EMS can play in initiating palliative approaches in the community, facilitating goals of care at end of life and transporting patients to preferred care settings.[21] Furthermore, the WHO neglects to recognise the role of EMS in key policy documents despite highlighting 'palliative care requires a broad multidisciplinary approach',[22] in addition to 'multisectoral policy and action to address broader determinants of health'.[23]

Current attempts to integrate EMS with palliative care are predominately focussed on protocols and training.[24,25] However, in this discussion essay, we will argue for a broader approach – at a national and global level – which implements integrative policy to compliment education and clinical practice guidelines. To address these gaps, this article aims to explore the potential role of EMS in a public health palliative care approach by (1) discussing the utility of EMS within a public health palliative care approach, (2) identifying the current barriers preventing public health approaches to EMS palliative care provision and (3) outlining a way forward through priorities for future research, policy, education and practice.

Utility of EMS in a public health palliative care approach

EMS are uniquely positioned in healthcare systems as they provide a link between community-based patients and in-hospital settings. This position can be leveraged in the provision of palliative care through EMS facilitating equitable access, early provision, expert care and efficacious integration.

EMS provide access to healthcare through their mobility and round the clock availability. In addition to the provision of traditional emergency care, EMS can deliver palliative care to patients in community-based settings and transport those requiring further specialist care to alternative destinations beyond the ED, including in-patient palliative care units.[26] EMS also offer significant adjunct in-home support to community-based palliative care patients during out-of-hours times when other palliative care services are often unavailable.[27,28]

Internationally, people of low socioeconomic status (SES) and those marginalised from mainstream society are particularly susceptible to experience barriers in receiving palliative care in keeping with the disproportionate challenges they face accessing services in general. Such marginalised and underserved groups may include, but are not limited to, people who are homeless or at risk of homelessness;[29] living in regional, rural and remote areas;[30] living with disability;[31] LGBTQI+ identifying;[32] First Nations identifying;[33] culturally and linguistically diverse;[34] and incarcerated.[35] Targeted initiatives to broaden access to such groups to address these inequities could be facilitated through the provision of EMS palliative care reaching diverse global communities. These groups are often picked up in crisis situations as a direct result of inequitable access.[36,37]

EMS may be the first point of medical contact for palliative care patients,[38] and are therefore

well-positioned to initiate early palliative care at home.[39] This potential benefit for patient comfort, early identification and relief of suffering is significant.[11] As many palliative patients wish to receive care in their homes and avoid transportation to hospitals, with appropriate clinical support, EMS can provide community-based palliative care that ensures patient wishes and autonomy are respected.[40]

The early and timely provision of community-based palliative care has been shown to positively impact both patients and their conditions, improving patient and family quality of life (QoL) satisfaction and confidence.[41] A recent study implementing a specialist EMS palliative care programme resulted in high patient and family satisfaction, and greater consumer recognition of the compassion and skill of EMS personnel when providing palliative symptom management. In addition, the knowledge of the 24/7 availability of the EMS providers in this programme provided confidence and peace of mind for patients, their families and carers, facilitating early grief support and reducing avoidable hospital admissions.[26]

As palliative care patients advance in age, EoLC emergencies are more likely, for which EMS are often called.[42,43] Alarming conditions such as acute pain, dyspnoea, convulsions and sudden loss of consciousness are well documented reasons for EMS attendance to palliative patients.[1,44,45] These conditions, *inter alia*, may cause significant distress for patients, their families and caregivers;[44] however, they also represent areas of EMS expertise which can be readily resolved. As out-of-hospital specialists, EMS are well trained and experienced in managing these emergencies in community-based settings.[11] As such, EMS are well-equipped to attend to palliative care patients in the likely event they deteriorate and require immediate care, especially when only generalist palliative care capacity is required out-of-hours.

Palliative care is, by its very nature, multidisciplinary.[41] However, the EMS discipline represents a field which is rarely involved in formal palliative care partnerships, despite regularly interacting with these patients.[40,46,47] Integrating EMS with other palliative care service providers offers a range of compelling opportunities to enhance public health responses to palliative care. EMS could initiate palliative care to unidentified patients who would benefit from this approach to care. In doing so, EMS personnel are in a unique position to gather first-hand insight into patients' social and structural determinants of health, which may inform future palliative care planning and management. EMS could also connect patients, their families and carers with other relevant community services, including social workers and bereavement groups, thereby activating integrated healthcare pathways.[38] In this way, EMS has the opportunity to provide efficacious integration through a 'treat and refer' function.[48]

Based on these unique abilities of EMS and the resulting benefits to palliative care provision, a public health approach to EMS palliative care is warranted. Targeted public health policy may assist in the integration of EMS with other healthcare systems working within palliative care service provision. Interdisciplinary partnerships could facilitate the delivery of early and home-based palliative care, respect of patient autonomy, improved patient and family QoL, increased patient and family satisfaction and confidence, decreased healthcare costs and enhanced fulfilment of community preferences to die at home.[26]

LMICs may particularly benefit from strengthening public health policy relating to EMS and palliative care system integration. The potential decreased healthcare costs conferred by integrating already existing systems (EMS and palliative care) would represent an efficient use of scarce resources, especially when avoidable hospital admissions are significantly reduced in preference for community-based care.

Barriers preventing public health palliative care approaches to EMS

Despite the aforementioned utility of integrating EMS and palliative care systems through a public health policy approach, several common barriers exist that often result in lamentable patient care,[49] as illustrated by the case study vignette. These barriers, which appear ubiquitous across both HICs and LMICs,[11,45] may be divided into three categories: structural, cultural and practice. We argue changes to public health policy could assist in overcoming many of these barriers.

EMS systems are traditionally designed and perceived by consumers to provide emergency treatment and patient conveyance to tertiary facilities.[1] However, for patients at end of life, transportation is often undesired and inappropriate.[50]

Case study vignette
EMS are dispatched to a cancer patient with dyspnoea. Upon arrival, an 88-year-old male with extensive stage, small cell, lung carcinoma presents. His level of consciousness is decreased, and severe respiratory distress is evident. Attendant adult children of the patient called EMS as they were startled by their father's suffering and were unsure how to relieve his troubled breathing. They express knowledge that their father is dying but wishes to remain at home with his family. In the absence of legal documentation, the EMS crew contact their clinical advisor who recommends treatment and transport to hospital for definitive care. The EMS crew follow this advice, intubate the patient and initiate mechanical ventilation. During transport the patient becomes haemodynamically unstable. An adrenaline infusion is initiated to "keep the patient going" until hospital arrival. "No one dies in the back of the ambulance" being the (un)spoken rule. Shortly after hospital handover, the patient arrests and emergency department staff withhold resuscitative efforts due to the nature of the patient and the now present Do Not Resuscitate (DNR) order. Discussing the case, the EMS crew are satisfied they performed to the best of their abilities and "at least managed to get the patient to hospital alive".

EMS, emergency medical services.

Despite patient and family wishes often contradicting this trajectory, EMS regularly convey palliative patients to a medical facility,[50] and due to a lack of alternate pathways, this almost invariably involves an ED. Murphy-Jones and Timmons described patient transport as a default 'safety net' for EMS providers when managing palliative patients.[50] Where EMS providers deviate from standard practice, there is a perceived lack of legal support and fear of litigation.[51]

However, family members may also call EMS during a palliative care emergency to prevent the dying process of their loved one, and advocate for a patient to be taken to the hospital even if preferences and plans to die at home have been documented.[52] Structural and individual inequities also influence a palliative care patient and their family and carers' capacity to facilitate a home-based death.[53] Literature suggests greater hospital use in the last year of life of patients living in more disadvantaged socioeconomic positions.[54] As a result, EMS ought to be cognisant of these disparities and have the ability to make holistic assessments when considering the need to transport a palliative care patient to hospital.

Medico-legal documentation represents a further challenge to EMS provider decision-making in palliative situations. Advance directives (AD) and do not resuscitate (DNR) orders, for example, are designed to assist decision-making in these scenarios. However, they are largely unavailable.[38,55] Despite this intent, where these documents do exist, they tend to cause greater confusion for EMS providers as there are no clear guidelines for their use and the validity of such documentation in emergency scenarios is questioned.[12,56]

EMS system rigidity and the fear of medico-legal repercussions act as significant structural barriers preventing EMS personnel from challenging the traditional expectations of hospital-based care, and pursuing alternative pathways.[57]

The typical focus of EMS involves immediate measures to preserve life or limb until definitive care is reached.[51] EMS providers are trained to intervene, often invasively, in life-threatening situations and convey their patients to a medical facility for definitive care.[48] In this manner, EMS providers are predisposed to perform curative interventions with the aim of 'saving lives'.[51,55] As a result, the EMS culture is death averse, clearly distinguished from the more holistic palliative approach primarily concerned with the prevention and relief of suffering.[4] Palliative therapeutic goals may, therefore, come into conflict with EMS therapeutic goals.[49,51,58] Thus, when EMS providers are confronted with palliative patients, their interventions may be inappropriate and even harmful.

Because of these disparities, some EMS systems and individual EMS personnel may not identify palliative care as part of their role. To combat this cultural barrier, Lamba *et al.*[38] recommended first identifying 'EMS-palliative care champions' within services who have a strong affinity and willingness to build capacity within services. Despite possible heterogeneity of EMS views and opinions, EMS systems have played increasingly prominent roles in the provision of community-based care.[39] Within this model, there has been a greater recognition of the capacity and capability of EMS to support palliative care in place, and facilitate alternative referral pathways to other health providers when required.[26,39,46,49]

Structural and cultural barriers facing EMS and palliative care system integration directly impact practice. In the case study vignette, the structural barriers of compulsory patient transport and lack of legal documentation, alongside the cultural barrier of death adversity among EMS personnel, resulted in poor practice by the EMS system. Futile interventions were performed, and patient autonomy was ignored. To overcome these barriers, EMS could have access to a 24/7 palliative care specialist via telehealth, who could reassure the EMS personnel to take a palliative approach to care and provide the necessary medico-legal documentation to verify this course of action. As a result, the EMS personnel could administer an opioid to relieve the dyspnoea, provide reassurance to the patient and their family, and leave them at home with follow-up referral to a community palliative care team during regular hours. As a result of this change in practice, a desirable outcome for the patient, their family and the broader healthcare system could be achieved.

While structural and cultural barriers must be overcome to improve practice, unique barriers remain regarding the availability of resources, EMS scope of practice and complex nature of the community-based setting.[11] While several HICs with sufficient resources have developed specialist EMS personnel roles integrating the provision of palliative care (i.e. Extended Care Paramedics in Australia[59] and Community Paramedics in Canada),[60] LMICs lack the necessary resources to develop these novel roles and require individualised approaches given their disparate contexts. Furthermore, not all EMS personnel fall within the same scope of practice. Those with generalist training may be constrained in their ability to practice palliative care, such as a limited scope to administer opioids, especially through the preferred subcutaneous route for palliative patients.[61] The out-of-hospital setting may further challenge EMS' ability to practice palliative care given the uncontrolled and unpredictable environment, often resulting in a dearth of information available to EMS personnel.[38,40,46]

A way forward

Despite the advances made to connect multidisciplinary teams across palliative care settings, too often the potential for EMS integration is missed. Throughout this discourse, a prominent question has been raised: how can EMS better engage with community networks and health/social services to deliver improved outcomes for palliative care patients, families and carers, and empower EMS personnel to confidently adopt palliative approaches to care?

In the past, mental health emergencies have also been perceived as beyond the traditional scope of practice for EMS.[62] However, as a result of increasingly prevalent mental health emergencies in HIC communities,[63,64] coupled with the de-institutionalisation of mental healthcare leading to a greater focus on person-centred community-based care, EMS and other first responder services have adapted their attitudes and approach. Integrated models of mental health emergency first responder care are emerging across HICs, which place mental health workers in police or ambulance call centres, or co-response mobile crisis services alongside police officers and EMS personnel.[65] Specialist mental health workers can provide expert assessment to patients at point of care, reducing the need to invoke involuntary detention on the patient and avoidable transportation to hospital for further assessment.[66]

Police, ambulance, clinician early response (PACER) is an Australian tri-response mobile service which teams a mental health clinician, police officer and EMS personnel together in a first responder vehicle to attend mental health crisis in the community.[67] The pilot programme in one Australian jurisdiction saw 90% of patients assessed by the PACER team able to stay in the community, with only 12% of people requiring transport to the ED – a significant decrease from 56% previously.[68]

Given integrated models of care can have a significant impact on improving timeliness of care pathways and diversions from EDs, a palliative care co-response mobile service could potentially better facilitate community preferences to die at home and engender stronger public health approaches to palliative care, if partnerships with community networks were also pursued. Literature supports the notion that care begins when the emergency number is dialled, highlighting opportunities for palliative care specialists to also be integrated into EMS call centres.[69] However, limitations to both models must be recognised, especially in LMICs and regional, rural and remote areas of HICs, where resources can be scarce.

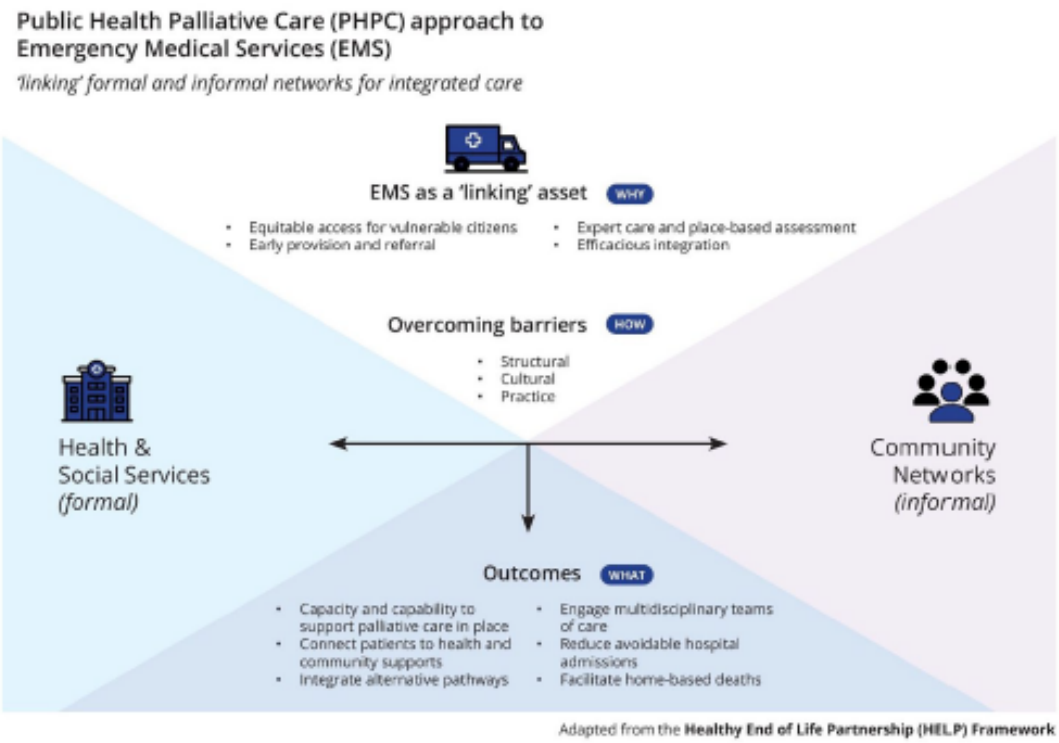

Figure 1. Public health palliative care approach to emergency medical services framework.

Priorities for research, education, policy and practice

To address the barriers previously outlined, EMS ought to first be incorporated into national and international public health palliative care policies and frameworks. We have adapted the Healthy End of Life Program (HELP)[15,18] partnership framework to develop a preliminary Public Health Palliative Care approach to Emergency Medical Services Framework (Framework) proposal for consideration (Figure 1).

This Framework aims to identify EMS as an asset capable of linking formal (health and social services) and informal (community) networks of palliative care to produce equitable access for marginalised and underserved groups in both HICs and LMICs; early provision and referral; expert care and place-based assessment; and efficacious integration. The Framework recognises that structural, cultural and practice barriers must be overcome, through the integration of health and social services with community networks, to produce desirable and sustainable outcomes. As a result, a public health palliative care approach to EMS could facilitate capacity and capability to support palliative care in place; connect patients to health and community supports; integrate alternative pathways; engage multidisciplinary teams of care; reduce avoidable hospital admissions; and facilitate home-based deaths.

To overcome the significant cultural barriers facing EMS in delivering palliative care, clinician attitudes and perceptions regarding the role of EMS must first evolve. Palliative care fundamentals ought to be imbued in education offerings to all EMS personnel, beginning at an undergraduate/student curriculum level and extending to ongoing mandated professional development training for established EMS personnel.[1] Those exhibiting a particular aptitude or passion for palliative care need access to further opportunities to gain advanced practical training in palliative care with specialists, allowing these EMS personnel to become champions within their respective service and contribute to the ongoing sustainability of palliative care expertise.[70]

Patients, families and carers' attitudes and perceptions of the potential function of EMS in community-based palliative care must also be addressed, given their important role in initiating EMS involvement in care with their call to

emergency services. Previous studies that informed the development of the HELP framework highlighted:

> Social attitudes to receiving palliative care help may be a barrier to building collaborative communities, which has profound implications for implementing public health approaches, such as compassionate communities. To be effective, any public health practice model must attempt to modify these social norms. The goals of a public health approach should be to create sustainable community environments with the capacity to engage in end of life discussion, support and practical care, whilst developing community norms that ensure citizens know about and can draw upon these assets when needed.[18]

Shifting societal attitudes to accept EMS as an asset of community-based palliative care, beyond their traditional hospital conveyance role, will require a targeted behaviour change campaign[71] around death literacy and the role of EMS in palliative care provision. Death literacy is defined as 'a set of knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options'.[72] EMS also have the unique opportunity to engage patients and their families and carers in palliative care health promotion, and sign-post locally provided health and community supports.[73]

Investing in the research and implementation of alternate referral pathways for EMS caring for palliative patients in the community must also be prioritised. Initiatives such as the PACER model could be adapted to a palliative care context; however, this would likely be resource intensive and only feasible in metropolitan settings of HICs. A pilot programme should first be conducted to investigate the efficacy of such a partnership, and pending evaluation success, this model of care could be implemented in suitable settings with adequate funding allowing for sustainable provision.

Other avenues to establish integrated models of community-based palliative care, harnessing the assets of health and social service workforces with community networks, must also be developed and piloted. The COVID-19 pandemic has highlighted significant opportunities for integrating specialist support into otherwise geographically inaccessible settings, and proven healthcare systems are adaptive to change.[74] A recent study confirmed Australian EMS have a high level of intention to use a specialist palliative care telehealth service if it were made available to them.[75]

EMS chaplains can offer another avenue of integrated support for community-based palliative care patients and their families and carers. Chaplains can deliver reactive scene support to EMS personnel during palliative care call-outs, providing extended continuity of care and early bereavement to families and carers when the patient dies, allowing EMS to reduce time on scene and be dispatched to other patients.[76]

Future research could investigate key gaps in the current literature, including the differences in context between LMICs and HICs; underserved populations' access and usage of palliative care EMS; and patient, family and carer perspectives.

Embedding a public health palliative care approach to EMS into health systems will ultimately facilitate community preferences to die in place and avoid hospitalisation where appropriate: a goal all countries, regardless of their SES, are likely aspiring towards.

Conclusion

A public health approach to palliative and EoLC acknowledges and facilitates the contribution everyone can make in improving the experiences of seriously ill and dying people. The EMS sector, in particular, offers valuable resources and skills distinct from other services that positions them to provide expertise and support in situations that would otherwise go unmet. This article articulates a public health approach to EMS palliative and EoLC provision and offers a preliminary framework to illustrate the components of a potential implementation and policy strategy.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Author contributions

Madeleine L. Juhrmann: Conceptualisation; Data curation; Formal analysis; Investigation; Methodology; Project administration; Resources;

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Appendix J – Frontiers in Psychiatry publication not included in thesis

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Staff perspectives on end-of-life care for people living with dementia in residential aged care homes: qualitative study

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Introduction: People living with dementia in care homes can benefit from palliative approaches to care; however, not all will require specialist palliative care. The generalist aged care workforce is well placed to provide most of this care with adequate training and support systems in place, but little is known about their experiences.

Objective: To describe staff perspectives on providing quality end-of-life care for people living with dementia in residential care and their families.

Methods: Focus groups and semi-structured interviews were conducted with residential aged care managerial and frontline staff in Australia who were caring for residents living with dementia and end-of life needs. A comprehensive, then snowballing sampling strategy was used in participating care homes. Transcripts were analyzed using reflexive thematic analysis.

Results: Fifteen semi-structured interviews and six focus groups were undertaken with 56 participants across 14 sites across two Australian states. Five themes were identified: putting the resident at the center (creating homes not hospitals, knowing the individual, a case management approach); articulating goals to grant wishes (initiating the conversation, broadening death literacy, avoiding hospitalization); a collective call to action (staffing the home, recognizing deterioration and escalating issues, communication channels and engaging GPs, managing medications, psychosocial supports); educating to empower staff (governance and guidance, mentoring juniors, self-care); and facilitating family acceptance (setting expectations, partnering in care, access at all hours).

Discussion: Aged care staff are committed to providing person-centered palliative and end-of-life care for people living with dementia, recognizing the intrinsic value of each resident, regardless of their declining state. Frontline and managerial staff consider advance care planning, collectively working as part of a multidisciplinary team, access to targeted palliative and end-of-life education and training, and engaging families as key priorities to providing high quality care in care homes.

KEYWORDS

dementia, terminal care, end of life decisions, long term care, nursing homes

1. Introduction

Global health systems are facing growing pressure to care for people living with chronic diseases as a result of aging populations. Dementia is an increasingly prevalent chronic terminal disease: 55 million people currently live with a formal diagnosis and that is expected to rise to 78 million by 2030 (1). Dementia is associated with functional decline and often requires a tailored physical environment, personal care and behavior management in the case of people displaying behavioral and psychological symptoms of dementia. Progressive deterioration can lead to people requiring full-time care in a residential aged care home (care home) (2). Within Australian settings, more than 50% of people living in care homes have a dementia diagnosis (2). Dementia is the leading cause of death for women in Australia, and second leading cause for men (2).

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families who are facing challenges associated with life-threatening illness, through the prevention and relief of suffering through early identification, correct assessment and treatment of other problems, whether physical, psychosocial or spiritual (3). It is well established that people living with dementia can benefit from palliative approaches to care, especially those nearing end-of-life in care homes (4, 5). However, the Royal Commission into Aged Care Quality and Safety has highlighted the significant variation in practice and availability of palliative care within care homes across Australia (6).

A 2014 White Paper provided the first evidence-based definition and priorities of dementia specific palliative care using a consensus approach (7). Literature suggests residents living with advanced dementia would benefit from palliative care that focusses on the management of physical and psychological symptoms, and care home staff need more support from external healthcare services to provide this level of care (8, 9). Dementia specific models of palliative care have emerged in recent years (10–13), including the PACE Steps to Success (14), which identified a generalist and non-disease specific palliative care program for care homes has the potential to improve quality of care and dying in the last month of life for both residents with and without dementia.

Integrating specialist palliative care capabilities into care homes is one approach to address the end-of-life needs of residents living with dementia (15). Yet not all people with dementia in aged care settings will require specialist palliative care, which is an unsustainable approach in isolation, and the generalist aged care workforce is well placed to provide most of this care with adequate training and support systems in place (16).

Previous research suggests clustered domestic residential care homes in Australia result in fewer hospitalizations and better quality of life for residents living with dementia (17). However, a gap remains in the literature on the effect of domestic models of care for residents living with dementia and palliative care needs. Furthermore, little is known about the perspectives of managerial and frontline staff providing end-of-life care to residents living with dementia in care homes (4, 18). These stakeholders offer a unique and practical insight into the complexities of delivering end-of-life care to residents living with dementia, highlighting opportunities for overcoming the challenges and supporting good models of care within this setting. Workforce engagement is also required to help inform and implement best practice palliative and end-of-life care within care homes (14).

This study aims to describe staff perspectives on providing quality end-of-life care to be delivered to people living with dementia in residential aged-care homes and their families.

2. Methods

We used the consolidated criteria for reporting qualitative health research to report this study (19).

2.1. Setting

Within Australia, government funded residential aged care is available for older Australians who are no longer able to live independently in their own home. While models of care may differ between aged care homes, all providers must meet national standards. Participants were eligible if they were a residential care home manager, frontline staff member or volunteer who had been involved with providing palliative and end-of-life care to residents at a large, not-for-profit, Australian residential aged care organization which operates a dementia specific and a predominately clustered cottage model approach to residential aged care (17). The organization's care homes ranged from 40 to 146 beds, each typically organized into 10–18 bed domestic clusters. Most residents have advanced dementia by the time of admission to the care home.

The organization has adopted a "careworker-led" model of care for residents, supported by a multidisciplinary team that includes residential managers, nurses, volunteers, pastoral care workers, allied health staff and the residents' general practitioner. Careworkers are frontline staff who provide most of the day-to-day care to residents. This includes personal care, companionship, assistance with feeding and activities of daily living, on-site meal preparation and cleaning. Residential manager roles vary within the organization. Service managers are most often senior registered nurses, overseeing the day-to-day operations of an individual care home. Clinical care managers are nurses who provide clinical oversight of a care home when the service manager is not a nurse. Assistant managers provide support to service and clinical care managers; all of whom report to operational regional managers, who provide oversight for an entire region consisting of multiple care homes. Nurses are frontline staff who provide clinical care, administer restricted medications and liaise with visiting doctors, health professionals, residents' families and visitors. Volunteers normally visit cottages for short periods of time and provide companionship for residents, including those with palliative and end-of-life care needs. This may include engaging in conversation, games, creative activities and assisting care workers with various activities. Pastoral care workers and some volunteers provide spiritual, religious and emotional support to residents, their families and staff. The organization has an internal mandatory training framework that includes units in dementia and palliative care, to support and equip staff for their unique role.

2.2. Participants and recruitment

Staff members were eligible to participate in this study if they were aged 18 years or older and a residential manager, nurse, careworker,

pastoral care worker or volunteer involved in the provision of end-of-life care for residents living with dementia. We informed all potentially eligible residential managers about the opportunity to participate in a focus group or individual interview by email invitation and flyers at staff meetings, employing a comprehensive sampling approach. Residential managers who expressed interest in taking part were contacted by the researchers and provided with further information about the study. Following this, a snowballing approach was employed, whereby participating residential managers, as well as volunteer and pastoral care coordinators from the organization, informed potentially eligible frontline staff about the study via email and flyers. Interested frontline staff were then followed up by the researchers. All participants provided written consent to take part in the study. Participant characteristics are outlined in Table 1. The study was approved by the University of Sydney Human Research Ethics Committee (*2018/744*).

TABLE 1 Participant characteristics.

Characteristics	Participants (*n*=56)
Mean age, y	48
Female, *n* (%)	40 (71)
Country of birth, *n* (%)	
Australia	33 (59)
Role	
Residential manager	20
Nurse	4
Careworker	15
Pastoral careworker	11
Volunteer	6
Level of education	
Completed high school before year 10	2
Completed year 10 of high school	4
Completed final year of high school	5
Professional certificate	12
Undergraduate	27
Postgraduate	6
Formal training in aged care, n (%)	37 (66)
Mean years of experience in aged care, y	10
Training in palliative care, *n* (%)	
No training	6 (10)
On the job training	24 (43)
Short course	21 (38)
Course with qualification	5 (9)
Training in dementia care, *n* (%)	
No training	2 (4)
On the job training	13 (23)
Short course	29 (52)
Course with qualification	12 (21)

2.3. Data collection

The semi-structured interview and focus group guides (Appendix 1) were informed by a literature review and discussion among the research team, and pilot tested. The questions addressed why they identified certain end-of-life care components important components and how they think end-of-life care could be enabled and improved.

In-person focus groups were organized by staff roles across different geographic networks within the organization, allowing a range of staff from different care homes to participate. Phone interviews were offered to participants who were unable to attend a focus group to obtain more comprehensive data (Appendix 2). Two female health researchers unknown to participants, AT (PhD) and CK (MD, PhD), conducted the focus groups. Another two female health researchers unknown to participants, AR (MD) and JB (MD), conducted the telephone interviews between December 2018 and May 2019. All research personnel had completed training and were experienced in qualitative research methods.

Participants were informed that the purpose of the focus groups and interviews was to enable research into improving care quality within the homes. Participant recruitment ceased when data saturation was reached. No follow-up interviews were undertaken. Interviews and focus groups were digitally audio-recorded and transcribed. The researchers also took field notes for reflection during data collection.

2.4. Data analysis

Drawing on concepts of reflexive thematic analysis (20) and using a social constructivist theoretical framework (21), we employed an inductive approach, coupled with the researchers' existing knowledge, to generate codes and identify themes within the data. All the transcripts were inductively analyzed by a female health researcher, MJ (MPH), and the data thematically coded line by line by, developing a coding structure that captured a comprehensive picture of end-of-life care provision at the study sites. The conceptualized issues and ideas were grouped into themes and sub-themes, which were regularly discussed among MJ, JC (MD, PhD) and JSM (RN) to address triangulation and enhance the analytical framework. Microsoft Office Word was used to store, organize, and support analysis of the anonymized data.

3. Results

A total of six focus groups and 15 individual interviews were conducted between December 2018 and May 2019 with a total of 56 participants, including: 20 residential managers, four nurses, 15 careworkers, 11 pastoral careworkers, and six volunteers (Table 1). Participants' work experience in aged care ranged between one and 47 years. The focus groups and interviews ranged in duration between 79–118 min and 37–71 min, respectively. We identified five themes: putting the resident at the center; articulating goals to grant wishes; a collective call to action; educating to empower staff; and facilitating family acceptance. A thematic diagram of the themes and sub-themes is illustrated in Supplementary Figure 1. A table of practical strategies

TABLE 2 Strategies suggested by participants for improving end-of-life care for residents living with dementia.

Key areas for improvement	Suggested strategies
Family education and participation	- Gently promote family awareness and acceptance of the terminal nature and stages of dementia, death, dying and palliative approaches to care using accessible language.
	- Invite families and carers to personalize the resident's room.
	- Ensure 24/7 visitor access to care homes.
	- Provide carer support sessions for families and carers to facilitate early bereavement.
Advance care planning	- Make advance care planning a national requirement for entry into a care home.
	- Revisit advance care planning with the resident (where possible) and/or the family/substitute decision maker soon after admission.
	- Support families and substitute decision makers to participate in ongoing advance care planning discussions when the resident no longer has capacity.
Staff experience and education	- Provide ongoing opportunities for front line staff to gain practical experience and discuss end-of-life care in a supportive educational manner.
	- Mandate essential palliative care experience training for all staff and volunteers, including care home affiliated GPs.
	- Develop a palliative care committee of champions in the care home, with representation across all staff roles.
	- Ensure staff are adequately supported by pastoral care and/or peer support.
	- Enable staff to participate in cultural rituals related to residents dying.
Clinical approaches to care	- Ensure all staff can recognize deterioration in the resident and escalate issues to appropriate clinical staff.
	- Ensure care homes have adequate clinical back-up support from GPs and linkages to referral pathways for specialist palliative care and/or geriatric services where required.
	- Roster regular staffing patterns to promote continuity of care.
	- Allocate an extra staff member on shift when a resident is nearing end-of-life.
	- Ensure end-of-life medications and equipment are always readily available on site in case of unexpected resident deterioration, and a trained nurse is available to administer.
	- Include pastoral care staff in clinical handovers.

suggested by participants relating to each theme is highlighted in Table 2.

3.1. Putting the resident at the center

3.1.1. Creating homes not hospitals

Participants emphasized creating *"homelike environments"* (careworker 37), where each resident *"has their own room"* (volunteer 42, residential manager 56) and felt *"comfortable in their own home"* (careworker 38). Participants described personalized environments where *"photos of family are put in the eye view of residents"* (pastoral care worker 47) and scented candles or diffusers were used to *"make the room more peaceful"* (operations manager 56) for the residents and their visitors.

3.1.2. Knowing the individual

The importance of *"respecting the resident's wishes"* at end-of-life and ensuring no resident got *"out of bed unless they wanted to"* (careworker 35) was emphasized. Some highlighted the need to prioritize person-centered care and fulfill requests at all times of the day and night—*"if they [resident] want a fried egg at midnight, they get a fried egg"* (21). Moreover, pastoral careworkers were particularly cognisant of the varying needs of each resident and suggested a tailored approach was required for meeting the preferences of each individual resident. One participant suggested documenting these needs and sharing them among careworkers, especially those unfamiliar with the resident:

> *"Not everyone who walks into that room will have a relationship with the resident who's dying, so sometimes staff might need a little cheat-sheet" (pastoral care worker 30).*

3.1.3. A case management approach

To ascertain the individual preferences of each resident and their families, participants advocated for a *"case management approach"* (service manager 1, assistant manager 16). One assistant manager described this as *"an ongoing assessment process"* (service manager 3) consisting of multidisciplinary staff meeting with families at regular prescribed intervals, and if the resident were to deteriorate in between *"we just bring it earlier"* (16). Another service manager reiterated:

> *"All of our care is premised on knowing the person, knowing the individual resident and tailoring care to them, knowing your staff individually, and their strengths and weaknesses, and competency with palliative care. Knowing the families individually and where they're up to in the journey"* (service manager 3).

Accordingly, this:

> *"Relationship-focused model of care empowers staff to build those relationships with other team members, the family and getting to know the resident"* (service manager 1).

Many participants emphasized the importance of eliciting information of past interests from these meetings to help enhance each resident's individual abilities, even during end-of-life. Incorporating elements of music, voice and touch into the care of residents living with dementia nearing end-of-life were recommended by participants across all staff groups to *"make them feel that we are still involved, we are still in their world, and they are still connected"* (careworker 19).

3.2. Articulating goals to grant wishes

3.2.1. Initiating the conversation

According to the clinicians, initiating goals of care and advance care planning discussions within a case management approach required compassionate communication skills and a multidisciplinary team:

> *"We empower and try and equip our [careworker] staff at that level to have conversations that might not always be eloquent, and they might not use all the right language. But when there's a familiarity and there's a family feel and that works well, most of those things are covered. Then the registered nurse comes and supports in the background and then the managers come and have a conversation and turn up at different case conferences that we might have" (service manager, 15).*

Participants recognized family engagement as another key facilitator to establishing goals, suggesting that family members had *"to be ready to hear"* (operations manager 55) and *"be heard"* (careworker 21) for advance care planning conversations to be successful.

3.2.2. Broadening death literacy

Participants believed in the need to explain palliative and end-of-life care to families in *"simplified rather than medical terms"* (clinical care manager 2) and avoid euphemisms of dying as a means of promoting death literacy—the practical knowledge needed to plan well for end-of-life—among family members. Pastoral care participants recognized their *"softer presence"* (31) could offer a unique role during these conversations. They advocated for their involvement during palliative and end-of-life care discussions to address the spiritual distress that can sometimes arise from families and residents.

3.2.3. Avoiding hospitalizations

Participants considered hospitalizations, in most cases, to not be in the best interests of residents living with far advanced dementia, as these unfamiliar environments were *"not going to be able to do anything to change the [palliative] situation"* (pastoral care worker 29). Instead, participants reported prioritizing hospital avoidance as a discussion point during the advance care planning conversations, encouraging families to consider the outcome if their loved one were to be transferred:

> *"So it's about having a conversation about what do the family hope to achieve by them [the resident] going to hospital and being transparent with what the outcome is likely to be. If that outcome is death regardless of where they are, then reassuring them that where they are they're going to get the best possible care with us" (service manager 10).*

These advance care planning conversations were described by participants as a dynamic and ongoing process, *"built on each time"* and progressing with *"more depth and detail"* (clinical care manager 5) as the resident living with dementia deteriorated to the end-of-life phase.

3.3. A collective call to action

3.3.1. Staffing the home

Participants recounted a preference for *"regular staff"* (service manager 3) rostering across all roles to ensure consistency of care. One assistant manager recalled the practice of confirming a nurse from the previous day was always on to make sure *"information is being handed over well"* (18). Other participants discussed the importance of backfilling positions when a resident was dying to ensure a familiar careworker was always *"able to go and sit with that person and know that I'm not leaving two partners short"* (careworker 37). Furthermore, an operations manager suggested without the *"right staff and skills mix you can have all the best intentions, but it does not do much"* (56).

3.3.2. Recognizing deterioration and escalating issues

Careworkers described a unique ability to recognize distress and decline in a resident living with dementia because they were *"at the frontline"* (19) and knew the residents best. However, despite this strong sense of familiarity, non-clinical staff expressed difficulty in responding to deteriorating residents alone, and described a need to be able to escalate issues within the team:

> *"A clinical situation in palliative care can be really challenging for us because maybe we are not all competent enough and we are not that knowledgeable. In that case, registered nurses and the managers would be called to come and help us" (careworker 19).*

Effective communication channels were highlighted by participants as a priority for enabling staff members to *"draw on each other"* (operations manager 6) and *"get to know one another's strengths"* (service manager 3).

3.3.3. Communication channels and engaging GPs

Clinical staff also recognized the importance of using engaging support when an end-of-life scenario arose. Nurse and residential manager participants referred to engaging "Geriatric Flying Squads," specialist outreach clinical teams based in local hospitals, who provide assessment and clinical care for residents experiencing acute decline who might otherwise require transfer to hospital if not seen by these health professionals. Participants described calling these teams to help minimize hospitalization, *"because general practitioners do not always come overnight"*

(clinical care manager 9) and often hesitated when prescribing end-of-life medications. However, despite clinical staff sometimes reporting challenges when engaging general practioners, all participants still considered them to be an integral part of the team:

> *"Getting towards the end stage, it's about having the general practitioner responsive at that point, coming in and making sure that we're all on the right page and what we're seeing is correct and then supporting that for us, being available to talk to the family, if they wish, but also being prepared to provide us with the scripts for sub-cut morphine and things like that if needed" (operations manager 55).*

3.3.4. Managing medications

Participants also recommended a whole-team approach for managing the medication needs of residents living with dementia, highlighting the benefits of clinical staff being well prepared and stocked with *"the right medications and methods of administration"* (service manager 10) for when residents deteriorate. One nurse recounted contacting pharmacists *"three months ahead of time"* to ensure adequate dosages of *"morphine is already in place"* (49). An operations manager cited the value of clinical staff being familiar with palliative medication routes of administration, including *"syringe drivers being available and staff knowing how to use them"* (56). Clinical staff described weekly clinical issues meetings as an imperative opportunity to de-prescribe inappropriate medications and *"think about what's happening for that [end-of-life] resident to help inform conversations about what to do next"* (clinical care manager 11) to help reduce end-of-life symptoms while addressing polypharmacy.

3.3.5. Psychosocial supports

Staff described responding to the spiritual and existential distress of end-of-life residents living with dementia and their loved ones, bringing them *"peace and comfort, aside from just meeting their medical needs"* (service manager 1). Pastoral care workers were considered an essential component of comprehensive end-of-life care by other participant groups, harnessing unique skills that could make the experience a *"very calm and peaceful time, enabling families to connect and understand what's going on"* (operations manager 56). According to participants, pastoral care worked in conjunction with the frontline staff and was inclusive to all residents living with dementia and their families, regardless of their religiosity:

> *"To those that have always declared no faith, don't believe in anything, or their family have said no, they've never been of a faith. Then I support them, I acknowledge them through what they've done in life, if they've been involved in a particular community service, or an organisation, or they've supported something. Everybody has always done something amazing within their communities, so I'll zone in on that, and just sing their praises" (pastoral care worker 46).*

A clinical care manager acknowledged the emotional impact of caring for palliative and end-of-life residents living with dementia had on the team, suggesting pastoral care and psychosocial support was *"not just for the family and the resident, but for staff as well"* (5).

3.4. Educating to empower staff

3.4.1. Governance and guidance

Participants reflected on the utility of clear governance and guidance to facilitate high quality care. A blended model of both *"theoretical and hands on training"* (pastoral care worker 27) was recommended by participants to ensure different learning styles were being catered for. Managers and nurses highlighted their appreciation for team-based education sessions, whereby staff had the opportunity to *"talk through what made them uncomfortable"* (service manager 15) and problem-solve complex situations among one another to normalize uncertainties. One service manager recalled observing and experiencing challenging advance care planning conversations, which prompted her to facilitate multidisciplinary training within her service, including workshopping *"potential responses we can give to the families in the event they ask these tricky questions"* (10). Another clinical care manager employed an end-of-life care flipchart *"that goes through the basics of care"* for nurses to use as a supportive tool for training careworkers, highlighting *"what to expect in every scenario, to be able to provide mouth care, eye care, whatever it may be"* (18). Participants also remarked on the need to train volunteers and *"not just throw them in there"* (pastoral care worker 47). One volunteer conceded, *"in order to provide spiritual care to someone with late-stage dementia, to be most effective you need to have some knowledge of dementia"* (42).

Participants recognized gaps in current training regimes and suggested opportunities for improving future education programs. One careworker emphasized the importance of embedding person-centered care into education, challenging the need to main a rigorous adherence to task-oriented care at the end-of-life:

> *"Staff need training if the resident refuses showering for two, three days or four days, that's fine - let them refuse. At least, it can make a peaceful environment for that resident at end-of-life" (43).*

Other participants recalled the importance of providing *"ongoing training"* (careworker 41), as high attrition of staff necessitated continual learning opportunities being offered, particularly to frontline workers.

3.4.2. Mentoring juniors

Participants discussed the need to entrench supportive and sustainable structures for all new staff members, highlighting the benefits of mentoring *"new graduate nurses and giving them access to advice"* (service manager 1). One careworker reflected on their own experience, acknowledging *"if you have a great companion who works with you from the start, teaches you and makes you feel at home in the sense of whatever you are doing, I found that I was on top of it"* (21). A clinical care manager relayed opportunities for more learned staff to role model their experiences:

> *"Each time you go through end-of-life with somebody it's building on that experience, and then that experience can help junior staff with providing that support as it may be the first resident they are palliating" (5).*

Participants also considered providing new staff the opportunity to observe a positive and accepting death as an essential tool to successfully integrate staff into the workplace:

> *"Bringing new staff along for that journey can help them realise it's an amazing experience. Good death can have such a positive impact on the families and be a great way for them to say goodbye" (operations manager 55).*

3.4.3. Self-care

Participants described leaning on their colleagues, in both a literal and metaphorical sense, to help them grieve after the death of a beloved resident:

> *"Once I really needed a shoulder to cry on when the resident passed away and my partner [staff member] just offered hers" (careworker 24).*

Pastoral care worker participants placed particular emphasis on fostering self-caring environments within the workplace, allowing *"staff to be able to express their grief too"* (31). One participant recalled *"gathering the careworkers around to say a prayer, or something that can be done in that space as a pause point and to acknowledge that this person has died, give thanks for their life and for the care that they have received"* (pastoral care worker 30). Frontline staff also reflected on attending funerals of deceased residents allowing staff to seek closure, *"especially if they had a really good relationship beforehand with the family and the resident who just passed away, to say goodbye, it just makes it so much smoother and calmer"* (careworker 44).

3.5. Enabling family acceptance

3.5.1. Partnering in care

Participants advocated for partnering in care with families and shared decision-making throughout the end-of-life journey. According to participants, this strategy delivered stronger outcomes for the resident living with dementia at end-of-life, cultivating a foundation of intergenerational acceptance and early bereavement among loved ones:

> *"We encourage families not to give up at end-of-life, but to continue to sit with their loved one and to affirm them, and to say what they need to say. It helps families, and I believe it helps the resident too, to form closure" (pastoral care worker 46).*

Participants highlighted the importance of recognizing family needs and preferences to ensure *"everyone in the resident's circle is being cared for, because if they are worrying about their loved one, they are not content, comfortable or peaceful"* (pastoral care worker 48). Participants reported engaging willing family members in meaningful tasks to assist the resident, especially at end-of-life, to help them feel empowered and connected:

> *"Excellence at end-of-life care is also possible where family feel like they are definitely partnering in care and are feeling enabled … washing their clothes or bringing in extra food that they have cooked themselves. Or towards the end of life, being able to clean them, give them mouth care, or hand care. Even after death, if they wish to, or they can be asked if they would like to help with washing the body of their loved one" (careworker 35).*

Many participants recalled demanding moments with families at end-of-life, emphasizing the importance of *"maintaining that relationship and open communication"* (residential manager 7) to overcome adversity. Support groups for carers were raised by multiple participants as a forum for responding to difficult questions, as well as building death literacy among families and carers:

> *"Carer support groups, often being led by our pastoral care staff, actually support families to think further down the line about what's going to happen and to talk about it more publicly. It raises an awareness and reduces some of the stigma for people" (operations manager 56).*

However, frontline staff also recommended remaining open-minded to differing levels of family involvement as the end-of-life journey was challenging for everyone:

> *"Make sure that you are non-judgemental because a lot of the residents' families, a lot of them don't show up, not because they don't care, but they just couldn't handle a loved one dying" (nurse 49).*

3.5.2. Setting expectations

Participants recalled occurrences of families resisting end-of-life care, often driven by a disbelief of their loved one's terminal fate. To address these discrepancies, participants advocated for setting realistic expectations from the beginning and chipping away at denial through meaningful and compassionate conversations:

> *"A big signal for me is if they mention that they hope the person will get better and improve. This person is going to need ongoing conversations, and that decline is going to come as a shock, and they're going to be quite upset" (clinical care manager 14).*

Participants recognized such conversations may need to be *"revisited several times"* (pastoral care worker 26) before a family comes to terms with the terminal nature of dementia. However, participants expressed a need to *"be truthful with the family"* (careworker 40) and lead with vulnerability, noting *"we cry together"* (nurse 45).

3.5.3. Access at all hours

Finally, participants recognized the enduring nature of end-of-life care and fluctuations in a resident's condition required families to be regularly notified. All participants endorsed families having 24/7 access to the care home, emphasizing *"we do not have visiting hours"* (careworker 19). One residential manager acknowledged the benefits of this arrangement, highlighting the respect this practice engendered to families:

> *"Families have all reported how much they feel supported, and they can come and go as they choose, they never feel like a burden" (10).*

Pastoral care worker participants recalled strategies to facilitate after-hours visits, including getting *"lounge chairs in there [resident's room] so families can sleep over"* (29) and *"making sure they are introduced to the kitchen"* (47) to prepare food when staying

out-of-hours. Such measures reportedly enabled families to feel considered and cared for; a sentiment all participants expressed as a priority for high quality end-of-life care for residents living with dementia.

4. Discussion

The participants of this study were committed to providing person-centered palliative and end-of-life care for people living with dementia, recognizing the intrinsic value of each resident regardless of their declining state. Frontline and managerial staff considered ongoing advance care planning, collectively working as part of a multidisciplinary team, access to targeted palliative and end-of-life education and training, and engaging families as key priorities to providing high-quality care in these settings.

The Australian Royal Commission into Aged Care Quality and Safety consistently raised concern over the limitations of aged care workforce capacity (6); a sentiment reinforced worldwide by the extreme demands experienced by aged and health care workers during the COVID pandemic (22, 23). The participants of this study emphasized the observed benefits of continuity of care to residents living with dementia and end-of-life care needs, suggesting regular staffing patterns were integral to achieving this. However, difficulty with staff retention, as echoed in the findings from our study, remains an enduring problem for the aged care sector (24). The international health services community ought to prioritize research that will assist in building a sustainable aged care workforce capable of withstanding the pressures of an aging population, recognizing and responding to the increasing prevalence of dementia among the cohort, and delivering high-quality palliative and end-of-life care to these people.

Acknowledging the different assets within a multidisciplinary team and integrating a strengths-based approach to staffing was another key finding of this study. Participants recalled the merits of a multidisciplinary approach to end-of-life care, harnessing the combined interpersonal skills of care workers, volunteers and pastoral care workers with the clinical decision-making capacity of nurses and GPs to achieve good outcomes for residents living with dementia. However, the participants also recognized significant limitations in achieving timely access of primary and specialist palliative care services for clinical in-reach support. Future research should consider how to alleviate this clinical gap. Building stronger and more sustainable partnerships between aged, primary and specialist palliative care services will help address the workforce capacity and capability challenges facing the sector (25); however, it will require targeted implementation research and translation into practice (26).

Participants described a keen desire to keep residents living with dementia away from hospital due to the distress and disorientation it too often caused them. Death in hospital for patients with dementia is also associated with poorer quality of end-of-life care when compared to death in a care home (27). As such, reducing avoidable hospital admissions of palliative residents living with dementia should remain a key priority for care homes. However, facilitating this goal often requires the prescription of vital end-of-life medications: a skill remaining beholden to the omnipresent scarcity of general practitioners and palliative care nurse practitioners in aged care (18, 28, 29), especially after-hours. Our findings propose general practitioners may also express hesitancy in prescribing end-of-life medications to residents living with dementia. Literature suggests Australian general practioners working in aged care lack knowledge around end-of-life law despite frequently making end-of-life decisions in clinical practice (30), potentially contributing to their reluctance to prescribe end-of-life medications. General practitioners could be better supported to provide high-quality palliative and end-of-life care in care homes through specific training initiatives (31) and greater incentives to work out-of-hours (32). Paramedics could also offer adjunct palliative and end-of-life care support to care homes, especially after hours when general practitioners and community palliative care services might not be available, to reduce avoidable hospital admissions (33).

The findings of our study highlighted opportunities for medical staff to deprescribe medications for palliative residents living with dementia during multidisciplinary clinical issues meetings. Participants described instances where polypharmacy could be identified for residents living with dementia nearing ending of life, and action could be taken by clinical staff to reduce this risk. Facilitating continuity of general practice care for new residents, and more structured transfer to new general practioners upon entering a care home, may prevent potentially inappropriate initiation of medications for people living with dementia (34).

Finally, conversations around goals of care and treatment decisions are recurrent throughout the trajectory of a resident living with advanced dementia in a care home. Given residents with advanced dementia usually no longer have capacity to make health care decisions, families and carers are significant stakeholders in this process and should ideally be involved in shared decision making, which can be assisted with the early and ongoing engagement with families and carers around advance care planning (35). However, as our study reported, families often experience distress during these conversations and need access to information and emotional support throughout the dementia journey (36, 37). Furthermore, advance care planning is commonly approached too late, relying upon proxy-decision making in the care home, in contrast to inclusive and timely supported decision-making with the person living with dementia themselves (38, 39).

To expediate person-centered care at end-of-life, proactive approaches to advance care planning, ensuring people living with dementia have the opportunity to express their wishes and preferences before losing capacity (38), ought to be considered gold standard. Yet the reality is that many people with dementia miss out on having these opportunities in the earlier stages of dementia prior to admission to residential aged care, and by the time of admission many residents already have advanced stages of dementia (39, 40). Therefore, residential aged care staff need access to appropriate dementia-specific education and training to initiate advance care planning conversations with families and carers if the resident no longer has capacity to make healthcare decisions, and the ability to conduct palliative care needs assessments where appropriate (41).

4.1. Limitations and further research

The participants were from one single aged care provider and model of care in Australia, therefore potentially limiting the

transferability of the results within Australia and abroad. We did not note any apparent differences based on the demographic characteristics of the participants. However, a diverse range of roles were included, and their accounts were compared throughout the data analysis process. Further research could investigate the efficacy of differing models of end-of-life care for residents living with dementia in care homes, comparing approaches and economically evaluating a return on investment in each case. Exploring broader perspectives, including those of general practitioners working in residential aged care, as well as families and carers of residents living with dementia, could also be useful in helping shape future models of best practice end-of-life care for residents living with dementia in care homes.

5. Conclusion

Care homes are often where people living with dementia spend their last days. The participants of this study expressed a resounding commitment to providing person-centered end-of-life care for residents living with dementia in care homes, regardless of their diminishing capacity to make decisions. However, participants considered advance care planning, multidisciplinary approaches to care, access to palliative and end-of-life care specific education and training and partnering in care with families' as key priorities for this approach to be successful. This study has identified specific strategies (see Table 2) to enhance the abilities of care home staff to provide high quality end-of-life care to residents living with dementia. When equipped with these tools and strategies, care home staff believed they could provide high quality end-of-life care to residents living with advanced dementia. Findings from this study identified a need for care home staff to have access to appropriate dementia-specific education and training to initiate advance care planning conversations with residents, families and carers; and build capacity of clinical staff to conduct regular palliative care needs assessments for residents. Future research should focus on how to build more sustainable partnerships between aged, primary and specialist palliative care services to address the workforce capacity and capability challenges facing the sector. General practitioners also require dementia-specific palliative care training initiatives and greater incentives to work out-of-hours in residential aged 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 human participants were reviewed and approved by the University of Sydney Human Research Ethics Committee (2018/744). All participants provided written consent. The patients/participants provided their written informed consent to participate in this study.

Author contributions

The search strategy was developed by JC, CP, and AJ. AJ collected the data. MJ conducted the thematic analysis, which was cross-checked by JC and AS, and drafted the manuscript. 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

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1137970/full#supplementary-material

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Appendix K – BMJ Supportive and Palliative Care

To be mortal is human: professional consensus around the need for more psychology in palliative care

White *et al*[1] highlight that death and dying is everyone's business, yet is often neglected in the training of multidisciplinary health professionals (MDHP). While physicians play a critical role in end-of-life care, patients interact with a range of health professionals. As such, it is vital that MDHP are also trained in palliative care, including end-of-life communication. Nursing and allied health professionals also spend considerable time with patients developing strong therapeutic relationships fundamental to the success of challenging conversations when adjusting to incurable illness.[2 3]

Nevertheless, White *et al*'s survey noted considerable variability in the availability of palliative care and end-of-life-related content in UK-based undergraduate nursing and allied health courses. Only 16% of the social work courses surveyed included such training. Similarly, in Australia, 96% of MDHP perceived that their undergraduate education had underprepared them for the clinical realities of working with palliative care patients.[4]

Consistent with identified gaps in the literature, White *et al*'s survey did not include psychologists. Psychologists are ideally placed to provide specialist end-of-life care as they are already trained in sophisticated communication skills and have the capacity to navigate challenging emotional terrain. Assisting individuals grappling with uncertainty, anxiety, grief and loss, demoralisation and hopelessness is psychologists' 'core business'. Further training to apply these high-level therapeutic skills to end-of-life care is critical. Vivekananda *et al* interviewed psychologists, many of whom had specialist end-of-life experience (21/35, 60%) and identified core domains in which psychologists should contribute to end-of-life care (table 1).[5]

There is much to be gained through better integration of psychology into end-of-life care and communication—yet currently, discipline-specific end-of-life training for psychologists appears rare. We collected pilot data from Australian clinical psychologists on their experiences in end-of-life communication and their training needs. Led by the first author, a 1-day experiential workshop on end-of-life communication focused on tailoring these skills to the needs of adolescents and young adults with life-limiting illness (2019). Most clinical psychologists in this small-group workshop (n=11) worked in private practice (n=7, 64%), with an average of 10 years' professional experience (range=0–32 years, SD=10.21), yet with little experience working with young people with incurable illness (none had worked with a young person who had died). Over a third of participants stated that experiential opportunities to practice skills were the most valuable part of the workshop (n=4, 36%). When asked about barriers that prevented them from facilitating these conversations, 'not having the skills personally or knowing how to start' was the main barrier (n=7, 64%).

Our sample identified workshops as the most helpful training method to equip them in future (n=8, 72%), followed by experiential training, hard-copy resources and video resources (n=6, 55% for each). At the conclusion of the workshop, most of our sample still reported moderate anxiety with respect to discussing end-of-life with patients and their families (n=7, 64%). Effective training in end-of-life care is likely to require repeated, experiential learning opportunities.[3]

Psychologists are well equipped to identify and address the natural and common phenomenon of death anxiety. In addition to facilitating end-of-life communication directly with patients and families, psychologists can support the multidisciplinary team with group-level reflective practice

Table 1 Domains of discipline-specific expertise psychologists can contribute to end-of-life care (adapted from Vivekananda *et al*. 2020)[5].

Domain	Example
End-of-life assessment	► Distinguishing between normative distress, maladjustment and mental illness ► Assessing cognitive function and decision-making capacity
End-of-life interventions	► Adjusting to illness and functional limitations ► Pain management ► Improving quality-of-life and subjective well-being ► Interventions addressing death preparedness (eg, existential issues, legacy work and dignity therapy), death anxiety, demoralisation and (anticipatory) grief and supporting patients as they make decisions about their care
Team-related and systems related skills	► Supporting caregivers before and after a person dies ► Fostering communication between patients, families and the multidisciplinary healthcare team ► Developing and delivering accessible community and public-facing psychoeducation around end-of-life, advance-care planning and death ► Supporting health professionals ► Providing liaison and advocacy for end-of-life care at a higher systems level

as the team grapples with their own death anxiety. Psychologists' expertise could be woven into interprofessional training, that is, through innovative 'team member as teacher' models.[3]

Ultimately, the evidence-to-practice gap in end-of-life communication is an implementation problem beset by numerous barriers.[2 5] Some barriers—such as the complexity and unpredictability of care towards end-of-life—could be addressed by more clinicians on the multidisciplinary team being well trained to support these conversations. As patients will develop stronger rapport with different health professionals, any health professional may become the person a patient chooses to speak to—whether a radiation therapist, a night-shift nurse or a psychologist. Advanced communication skills are crucial for health professionals to feel confident about transforming a patient's lingering question to a meaningful conversation about their end-of-life priorities. Equipping MDHP to identify and act on appropriate openings for end-of-life conversations increases the likelihood that these sometimes fleeting conversational moments are embraced. This is especially important when working with seriously ill young people, for whom the autonomy and agency involved in choosing who they confide in and when is critical.[2 3]

One strategy to build both skills and confidence from the start of health professionals' careers might be to expand access to undergraduate-level training resources, such as the Australian Government-funded 'Palliative Care Curriculum for Undergraduates' (https://pcc4u.org.au). Rather than locating expertise (and responsibility) within specific healthcare disciplines, skills in end-of-life communication deserve to be distributed across the multidisciplinary team.

Being mortal is arguably the most human quality. We advocate that improving the training and integration of psychologists into end-of-life communication and care is a crucial development that needs to take place, both in clinical practice and research, to benefit the mortal humans at the heart of the healthcare system.

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