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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.

Methods: 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).

Conclusion: To enhance paramedic capacity to provide palliative care support, improvements targeting systems, services, communities and individuals should be made. This calls for stronger

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inclusion of paramedicine in interdisciplinary palliative care, and greater investment in both the generalist and specialist palliative paramedicine workforce.

Key messages

What is already known on this topic

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

What this study adds

Stakeholders' perspectives support 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. Improvements targeting systems, services, communities and individuals should be prioritised.

How this study might affect research, practice or policy

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. The findings have international resonance for comparable healthcare systems.

INTRODUCTION

Internationally, as people live longer, with more chronic diseases and growing preferences to die at home, demand for community-based palliative care services is increasing.[1] However, the specialist palliative care workforce is insufficient to provide the entirety of this care alone, nor is it necessary or viable for all patients to receive solely specialist support.[2] Instead, the World Health Organisation advocates a multidisciplinary approach to palliative and end-of-life care.[3] Recent literature supports the role paramedics may have in delivering community-based palliative and end-of-life care as an adjunct support, especially out of hours.[1, 2]

In Australia, paramedics work predominately for state and territory-based ambulance services, providing unscheduled care across the spectrum of urgency and acuity for communities 24 hours a day, seven days a week. Palliative care is 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.[4]

Given the evolving nature of palliative paramedicine, there is a growing literature base examining this topic. Previous studies have developed a theory of change-based approach for improving English paramedic responses to patients dying at home,[5] and highlighted the top ten tips American palliative care clinicians should know about improving partnerships with ambulance services.[6] 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 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 exploring key stakeholders' experiences and perspectives of the role, barriers and enablers of palliative paramedicine in Australian communities.[7] 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. Constructivist research is useful for generating a contextual understanding of a defined topic or problem. This paper is reported in adherence to the Consolidated Criteria for Reporting Qualitative Research (COREQ) Guideline.[8]

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 at the end-of-life 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 capture perspectives of all stakeholders involved in palliative paramedicine and ensure varied demographics and clinical experience were represented. Health professionals were recruited through professional organisations; family carer participants were recruited through a national organisation's register of palliative care consumers and carers. Each organisation published an advertisement about the research in their online newsletter and sent an email to their members outlining the study and inviting them to contact researchers if interested in participating. An invitation was also circulated through collegial networks and sent to opinion

leaders with publicly available email addresses. Interested people who contacted researchers could 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 to elicit ways to improve paramedic palliative care practice (Appendix 1 and 2) were developed and pilot tested, informed by discussions with the Australasian Palliative Paramedicine Advisory Group and previous studies.[1, 4]

Two researchers, MJ and CP, experienced in qualitative research methods and unknown to participants, independently conducted interviews and took field notes for reflection. Interviews were audio-recorded and transcribed verbatim. Participant recruitment ceased when no new themes became apparent across sub-groups.

Analysis

Supported by literature, we surmised palliative paramedicine structures exist at systems (macro), service and community (micro), and clinician and consumer (meso) levels.[9] Drawing on Braun and Clarke's six-phase guide in reflexive thematic analysis to ensure rigour and trustworthiness, an inductive approach was employed, coupled with researchers' existing knowledge, to identify interventions that could improve palliative paramedicine at differing structural levels.[10] 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 improving community-based palliative and end-of-life care. However, we remained mindful of this and invited all participant perspectives to be captured, reporting all ideas regardless of their alignment to our own. One researcher read all transcripts, familiarised herself with their content, independently identified potential codes for each structural level and met with the team to discuss and develop the codebook, allowing for consistent interpretation and classification of the data. This codebook guided coding of the remaining transcripts. Consecutive rounds of discussions were held with all researchers to capture multidisciplinary perspectives and enhance the analytical framework. NVivo was used to store and support analysis of anonymised data.

RESULTS

Fifty interviews (18-64 minutes long) were conducted between November 2021 and April 2022, including participants from all Australian states and territories (Table 1). Themes were classified into

macro-, meso- and micro-level interventions (Figure 1), illustrated by quotes identified by role and ID.

All participants strongly supported paramedics' important adjunct role in providing 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

Policy and frameworks: All participant groups considered paramedic inclusion in both international and domestic palliative care policies and frameworks to be a top priority for improving future systems, services and practice. Participants suggested, "*policy needs to acknowledge that the ambulance services can play a very important role in the palliative care of patients*." (Palliative care doctor, 24) However, one participant highlighted that if paramedics are recognised in palliative care policy and framing, "*it's more than likely people need to then incorporate that thinking into their workload." (PC doctor, 26)*

Funding and education: Interdisciplinary palliative and end-of-life care funding and competencies were championed to encourage the *"sustainability"* of palliative care practice through *"a shared care model"* (Palliative care doctor, 22). One paramedic lamented, "*we need to stop considering ourselves as separate entities within health. Start considering ourselves as one health unit with different functions within that unit*" (2).

To promote greater awareness of the role paramedics can play, 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). One participant highlighted the power of this inclusion to challenge the traditional narrative of curative medicine:

> *"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)*

Accessing medical records: Participants advocated for universal healthcare access to electronic medical records to allow paramedics and other clinicians to retrieve patients' medical and social histories in a timely manner:

> *"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…. 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)*

Paramedics emphasised a need for a *"streamlined process"* whereby everyone *"knew what to expect"* (Paramedic, 1) from a standardised document to which paramedics could contribute:

> *"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 paramedics' scope of practice to verify death was seen by participants as an opportunity to reduce avoidable police attendance, in cases of expected death where a doctor or senior nurse is unable to attend the home in a timely manner:

> *"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)*

Participants argued for a national approach, noting paramedics in some jurisdictions are already able to verify a patient's death. Paramedics contended, evoking these macro-level changes will require *"a shift in our culture and identity"* (4), noting the growing professionalisation of the paramedic role would open doors to work *"outside of ambulance services"* (15) in the future:

> *"It's about the health service acknowledging what paramedicine being registered (*as health practitioners*) 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)

Meso-level

Service-level training: Clinicians suggested ambulance services *"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 subspecialisations:

"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)

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). However, participants highlighted the limitations of traditional siloed care amongst disciplines, and a need to improve communication channels:

"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)

Participants from regional, rural and remote backgrounds suggested innovative solutions for 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)

All participants prioritised localised referral pathways, 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). However, paramedic participants described experiences of reluctantly bringing patients to ED as a referral function was lacking:

"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)

Virtual emergency departments were discussed by some as an emerging solution for ambulance services with limited access to specialist palliative care support and referral pathways.

Community expectations: Paramedics noted 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, in addition to compassionate communities' initiatives, to better educate the public about the realities of death and dying, and 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

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)*

> *"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)*

Participants emphasised, those paramedics with 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 at 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:.

> *"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)*

Partnering with families: Participants highlighted that family members and carers could facilitate 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 are often called to simply provide in-home manual handling support for immobile palliative patients, and these 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):

"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)

DISCUSSION

This study identified opportunities for improving a current gap in care for people at end-of-life, especially out-of-hours, by enhancing the existing skill base and presence of paramedics. 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 – is needed to improve patient care and enable better access to paramedics delivering palliative and end-of-life care in conjunction with broader multidisciplinary teams.

However, integrating palliative care into paramedicine core business must strike a balance between enhancing the paramedic's role as an adjunct provider, while preserving the broader medical emergency response function of an ambulance service in the community.[11] Evoking cultural change to overcome the lifesaving orthodoxy of the paramedic role will be one associated challenge.[5, 11, 12] 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.

To strengthen paramedics' role within existing interdisciplinary palliative care networks, greater recognition of their capacity and skills across the healthcare sector is required. Canada pioneered community paramedicine some years ago and has successfully incorporated PC into routine paramedic practice. 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.[12] A 2022 study exploring the

alignment of this programme with paramedic professional identity considered the provision of palliative paramedicine a growth for the profession, fitting well with its existing identity of service to the community through a patient-centred lens.[12] 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.[12] Comparatively, specialist PC participants believed paramedics were a well-established part of their team.[12] 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 and other countries with similar health systems in the future.

Consensus methodology has also been used to establish multidisciplinary core competencies for Australian health and aged care workers in recognition of the ageing population and greater need for collaboration within disciplines.[13] The findings of this study could help inform the development of future multidisciplinary palliative care approaches to also include paramedicine.

Participants in the current study 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 Australian regional, rural and remote areas, where greater levels of continuity of care can foster stronger relationships across sectors.[14] 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.[12, 15] 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.[7]

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 stakeholders involved in palliative

paramedicine. 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. These findings could have international resonance for comparable healthcare systems.

CONCLUSION

Paramedics play an important adjunct role in palliative and end-of-life care in home-based settings. To ensure such care is sustainable, 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. We contend 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.

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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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Ethics approval

The University of Sydney Human Ethics Committee provided ethics approval (registration number 2021/607 and 2021/608). All participants gave written informed consent to participate.

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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 and 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- level interventions

Palliative care subspecialty

- Mandate generalist palliative care capabilities for all paramedics
- 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-level 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-level interventions

Appendix 1: Interview guide for health professionals

1. **Opportunities for improvement**

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

b) How can multidisciplinary teams work together to better support paramedics caring for palliative and end-of-life patients in the community?

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

d) How could paramedics best support families and carers if the patient dies while they are present? ***Prompt: cultural rituals, bereavement support, verification of death, liaising with patient's medical team?***

e) 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.***

2. **Other**

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

Appendix 2: Interview guide for family members and carers

1. 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 caring for palliative patients and their families at home?
What should they be offering and why? ***Prompt: supporting patient's goals of care, medication delivery, family/carer support?***

e) How could paramedics best support families and carers if the patient dies while they are present? ***Prompt: cultural rituals, bereavement support, verification of death, liaising with patient's medical team?***

2. **Other**

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

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	4
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	5 and 15
Non-participation	13	How many people refused to participate or dropped out? Reasons?	3
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	4
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	5 and 15
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	4
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	4
Field notes	20	Were field notes made during and/or after the inter view or focus group?	4
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	4
Transcripts returned	23	Were transcripts returned to participants for comment and/or	4

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	4
Description of the coding tree	25	Did authors provide a description of the coding tree?	4
Derivation of themes	26	Were themes identified in advance or derived from the data?	4
Software	27	What software, if applicable, was used to manage the data?	4
Participant checking	28	Did participants provide feedback on the findings?	4
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	5-10
Data and findings consistent	30	Was there consistency between the data presented and the findings?	5-10
Clarity of major themes	31	Were major themes clearly presented in the findings?	5-10
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	5-12

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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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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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: In this qualitative study underpinned by a social constructivist epistemology, semi-structured interviews were conducted. Participants were interviewed between November 2021-April 2022.

Participants: 50 participants with palliative paramedicine experience, from all jurisdictions of Australia.

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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).

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.

Strengths and limitations of this study:

- Our findings represent the perceptions, experiences and expertise of 50 health professionals from a range of relevant roles, and from all states and territories of Australia, as well as family carers.
- No patients with life-limiting illnesses were recruited for this study, and opportunities exist to explore these important stakeholders' perceptions in the future.
  Conducting the interviews over teleconferencing yielded rich data and gave voice to many participants located in rural and remote areas, and those experiencing mobility issues, we would have been otherwise unable to reach.

INTRODUCTION

Internationally, as people live longer, with more chronic diseases and growing preferences to die at home, demand for community-based palliative care services is increasing.[1] However, the specialist palliative care workforce is insufficient to provide the entirety of this care alone, nor is it necessary or viable for all patients to receive solely specialist support.[2] Instead, the World Health Organisation advocates a multidisciplinary approach to palliative and end-of-life care.[3] Recent literature supports the role paramedics may have in delivering community-based palliative and end-of-life care as an adjunct support, especially out of hours.[1, 2]

In Australia, paramedics work predominately for state and territory-based ambulance services, providing unscheduled care across the spectrum of urgency and acuity for communities 24 hours a day, seven days a week. Palliative care is 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.[4]

Given the evolving nature of palliative paramedicine, there is a growing literature base examining this topic. Previous studies have developed a theory of change-based approach for improving English paramedic responses to patients dying at home,[5] and highlighted the top ten tips American palliative care clinicians should know about improving partnerships with ambulance services.[6] 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 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 exploring key stakeholders' experiences and perspectives of the role, barriers and enablers of palliative paramedicine in Australian communities.[7] 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.[8] Constructivist research is useful for generating a contextual understanding of a defined topic or problem. This paper is reported in adherence to the Consolidated Criteria for Reporting Qualitative Research Guideline.[9]

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 at the end-of-life 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 capture perspectives of all stakeholders involved in palliative paramedicine and ensure varied demographics and clinical experience were represented. Health professionals were recruited through professional organisations; family carer participants were recruited through a national organisation's register of palliative care consumers and carers. Each organisation published an advertisement about the research in their online newsletter and sent an email to their members outlining the study and inviting them to contact researchers if interested in participating. An invitation was also circulated through collegial networks and sent to opinion leaders with publicly available email addresses. Interested people who contacted researchers could 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 to elicit ways to improve paramedic palliative care practice (Appendix 1 and 2) were developed and pilot tested, informed by discussions with the Australasian Palliative Paramedicine Advisory Group and previous studies.[1, 4]

Two researchers experienced in qualitative research methods and unknown to participants, independently conducted interviews and took field notes for reflection. Interviews were audio-recorded and transcribed verbatim. Participant recruitment ceased when no new themes became apparent across sub-groups.

Analysis

Socio-institutional theory into expectations suggests that professions implement change according to formal, regulatory and institutional factors, as well as informal, individual and normative factors.[10] As such, we surmised palliative paramedicine structures exist at systems (macro), service and community (micro), and clinician and consumer (meso) levels. We adhered to Braun and Clarke's

six-phase guide in reflexive thematic analysis: (1) data familiarisation; (2) initial code generation; (3) generating initial themes; (4) theme review; (5) theme defining and naming; and (6) report production.[11-13] An inductive approach was employed, coupled with researchers' existing knowledge, to identify interventions that could improve palliative paramedicine at differing structural levels.[13] This reflexive approach to thematic analysis highlights the researcher's active role in generating knowledge, whereby codes represent the researcher's interpretations of patterns of meaning across the dataset.[12] 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 improving community-based palliative and end-of-life care. However, we remained mindful of this and invited all participant perspectives to be captured, reporting all ideas regardless of their alignment to our own. One researcher read all transcripts, familiarised herself with their content, independently identified potential codes for each structural level and met with the team to discuss and develop the codebook, allowing for consistent interpretation and classification of the data. This codebook guided coding of the remaining transcripts. Consecutive rounds of discussions were held with all researchers to capture multidisciplinary perspectives and enhance the analytical framework. Our positionality was embraced as value adding, not a potential source of bias. We employed meaningful immersion in the data, and engaged in thoughtful discussion amongst the team to ensure our analysis was reflective.[12] NVivo was used to store and support analysis of anonymised data.

Patient and Public Involvement:

Family members and carers involved in the care of someone with palliative care needs who encountered paramedics at the end-of-life in the community were included in this study. The results of this study were disseminated to all participants.

RESULTS

Fifty interviews (18-64 minutes long, mean 43.64 minutes) were conducted between November 2021 and April 2022, including participants from all Australian states and territories (Table 1). Themes were classified into macro-, meso- and micro-level interventions (Figure 1), illustrated by quotes identified by role and ID.

All participants strongly supported paramedics' important adjunct role in providing 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).*

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			

Macro-level

Policy and frameworks: All participant groups considered paramedic inclusion in both international and domestic palliative care policies and frameworks to be a top priority for improving future systems, services and practice. Participants suggested, "*policy needs to acknowledge that the ambulance services can play a very important role in the palliative care of patients*." (Palliative care doctor, 24) However, one participant highlighted that if paramedics are recognised in palliative care policy and framing, "*it's more than likely people need to then incorporate that thinking into their workload." (PC doctor, 26)*

Funding and education: Interdisciplinary palliative and end-of-life care funding and competencies were championed to encourage the *"sustainability"* of palliative care practice through *"a shared care model"* (Palliative care doctor, 22). One paramedic lamented, "*we need to stop considering ourselves as separate entities within health. Start considering ourselves as one health unit with different functions within that unit*" (2).

To promote greater awareness of the role paramedics can play, 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). One participant highlighted the power of this inclusion to challenge the traditional narrative of curative medicine:

> *"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)*

Accessing medical records: Participants advocated for universal healthcare access to electronic medical records to allow paramedics and other clinicians to retrieve patients' medical and social histories in a timely manner:

> *"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…. 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)

Paramedics emphasised a need for a *"streamlined process"* whereby everyone *"knew what to expect"* (Paramedic, 1) from a standardised document to which paramedics could contribute:

"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 paramedics' scope of practice to verify death was seen by participants as an opportunity to reduce avoidable police attendance, in cases of expected death where a doctor or senior nurse is unable to attend the home in a timely manner:

"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)

Participants argued for a national approach, noting paramedics in some jurisdictions are already able to verify a patient's death. Paramedics contended, evoking these macro-level changes will require *"a shift in our culture and identity"* (4), noting the growing professionalisation of the paramedic role would open doors to work *"outside of ambulance services"* (15) in the future:

*"It's about the health service acknowledging what paramedicine being registered (*as health practitioners*) 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)*

Meso-level

Service-level training: Clinicians suggested ambulance services *"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 subspecialisations:

> *"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*)

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). However, participants highlighted the limitations of traditional siloed care amongst disciplines, and a need to improve communication channels:

> *"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)*

Participants from regional, rural and remote backgrounds suggested innovative solutions for 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)*

All participants prioritised localised referral pathways, 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). However, paramedic participants described experiences of reluctantly bringing patients to ED as a referral function was lacking:

> *"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)*

Virtual emergency departments were discussed by some as an emerging solution for ambulance services with limited access to specialist palliative care support and referral pathways.

Community expectations: Paramedics noted 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, in addition to compassionate communities' initiatives, to better educate the public about the realities of death and dying, and 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

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)

"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)

Participants emphasised, those paramedics with 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 at 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:.

"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)

Partnering with families: Participants highlighted that family members and carers could facilitate 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 are often called to simply provide in-home manual handling support for immobile palliative patients, and these 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):

"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)

DISCUSSION

This study identified opportunities for improving a current gap in care for people at end-of-life, especially out-of-hours, by enhancing the existing skill base and presence of paramedics. 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 – is needed to improve patient care and enable better access to paramedics delivering palliative and end-of-life care in conjunction with broader multidisciplinary teams.

However, integrating palliative care into paramedicine core business must strike a balance between enhancing the paramedic's role as an adjunct provider, while preserving the broader medical emergency response function of an ambulance service in the community.[14] Evoking cultural change to overcome the lifesaving orthodoxy of the paramedic role will be one associated challenge.[5, 14, 15] 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.

To strengthen paramedics' role within existing interdisciplinary palliative care networks, greater recognition of their capacity and skills across the healthcare sector is required. Canada pioneered community paramedicine some years ago and has successfully incorporated PC into routine paramedic practice. 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.[15] A 2022 study exploring the alignment of this programme with paramedic professional identity considered the provision of palliative paramedicine a growth for the profession, fitting well with its existing identity of service to the community through a patient-centred lens.[15] 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.[15] Comparatively, specialist PC participants believed paramedics were a well-established part of their team.[15] 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 and other countries with similar health systems in the future.

Consensus methodology has also been used to establish multidisciplinary core competencies for Australian health and aged care workers in recognition of the ageing population and greater need for collaboration within disciplines.[16] The findings of this study could help inform the development of future multidisciplinary palliative care approaches to also include paramedicine.

Participants in the current study 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 Australian regional, rural and remote areas, where greater levels of continuity of care can foster stronger relationships across sectors.[17] 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.[15, 18] 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.[7]

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 stakeholders involved in palliative paramedicine. 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. Zoom interviews were undertaken instead of face-to-face due to COVID-19 pandemic social distancing restrictions in place at the time of data collection. Although the research team initially had concerns about the limiting nature of this format, conducting the interviews over teleconferencing yielded rich data and gave voice to many

participants located in rural and remote areas of Australia, and those experiencing mobility issues, we would have been otherwise unable to reach. 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. These findings could have international resonance for comparable healthcare systems.

CONCLUSION

Paramedics play an important adjunct role in palliative and end-of-life care in home-based settings. To ensure such care is sustainable, 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. We contend 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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Contributors

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.

Competing interests

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The University of Sydney Human Ethics Committee provided ethics approval (registration number 2021/607 and 2021/608). All participants gave written informed consent to participate.

Data availability statement

No additional data available.

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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 and 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- level interventions

Palliative care subspecialty

- Mandate generalist palliative care capabilities for all paramedics
- 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-level 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-level interventions

Appendix 1: Interview guide for health professionals

1. **Opportunities for improvement**

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

b) How can multidisciplinary teams work together to better support paramedics caring for palliative and end-of-life patients in the community?

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

d) How could paramedics best support families and carers if the patient dies while they are present? ***Prompt: cultural rituals, bereavement support, verification of death, liaising with patient's medical team?***

e) 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.***

2. **Other**

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

Appendix 2: Interview guide for family members and carers

1. 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 caring for palliative patients and their families at home?
What should they be offering and why? ***Prompt: supporting patient's goals of care, medication delivery, family/carer support?***

e) How could paramedics best support families and carers if the patient dies while they are present? ***Prompt: cultural rituals, bereavement support, verification of death, liaising with patient's medical team?***

2. **Other**

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

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	4
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	5 and 15
Non-participation	13	How many people refused to participate or dropped out? Reasons?	3
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	4
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	5 and 15
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	4
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	4
Field notes	20	Were field notes made during and/or after the inter view or focus group?	4
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	4
Transcripts returned	23	Were transcripts returned to participants for comment and/or	4

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	4
Description of the coding tree	25	Did authors provide a description of the coding tree?	4
Derivation of themes	26	Were themes identified in advance or derived from the data?	4
Software	27	What software, if applicable, was used to manage the data?	4
Participant checking	28	Did participants provide feedback on the findings?	4
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	5-10
Data and findings consistent	30	Was there consistency between the data presented and the findings?	5-10
Clarity of major themes	31	Were major themes clearly presented in the findings?	5-10
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	5-12

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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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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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: In this qualitative study underpinned by a social constructivist epistemology, semi-structured interviews were conducted.

Setting and participants: 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

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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).

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.

Strengths and limitations of this study

- Our findings represent the perceptions, experiences and expertise of 50 health professionals from a range of relevant roles, and from all states and territories of Australia, as well as family carers.
- Conducting the interviews over teleconferencing yielded rich data and gave voice to many participants located in rural and remote areas, and those experiencing mobility issues, we would have been otherwise unable to reach.
- No patients with life-limiting illnesses were recruited for this study, and opportunities exist to explore these important stakeholders' perceptions in the future.

INTRODUCTION

Internationally, as people live longer, with more chronic diseases and growing preferences to die at home, demand for community-based palliative care services is increasing.[1] However, the specialist palliative care workforce is insufficient to provide the entirety of this care alone, nor is it necessary or viable for all patients to receive solely specialist support.[2] Instead, the World Health Organisation advocates a multidisciplinary approach to palliative and end-of-life care.[3] Recent literature supports the role paramedics may have in delivering community-based palliative and end-of-life care as an adjunct support, especially out of hours.[1, 2]

In Australia, paramedics work predominately for state and territory-based ambulance services, providing unscheduled care across the spectrum of urgency and acuity for communities 24 hours a day, seven days a week. Palliative care is 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.[4]

Given the evolving nature of palliative paramedicine, there is a growing literature base examining this topic. Previous studies have developed a theory of change-based approach for improving English paramedic responses to patients dying at home,[5] and highlighted the top ten tips American palliative care clinicians should know about improving partnerships with ambulance services.[6] 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 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 exploring key stakeholders' experiences and perspectives of the role, barriers and enablers of palliative paramedicine in Australian communities.[7] 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.[8] Constructivist research is useful for generating a contextual understanding of a defined topic or problem. This paper is reported in adherence to the Consolidated Criteria for Reporting Qualitative Research Guideline.[9]

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 at the end-of-life 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 capture perspectives of all stakeholders involved in palliative paramedicine and ensure varied demographics and clinical experience were represented. Health professionals were recruited through professional organisations; family carer participants were recruited through a national organisation's register of palliative care consumers and carers. Each organisation published an advertisement about the research in their online newsletter and sent an email to their members outlining the study and inviting them to contact researchers if interested in participating. An invitation was also circulated through collegial networks and sent to opinion leaders with publicly available email addresses. Interested people who contacted researchers could 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 to elicit ways to improve paramedic palliative care practice (Appendix 1 and 2) were developed and pilot tested, informed by discussions with the Australasian Palliative Paramedicine Advisory Group and previous studies.[1, 4]

Two researchers experienced in qualitative research methods and unknown to participants, independently conducted interviews and took field notes for reflection. Interviews were audio-recorded and transcribed verbatim. Participant recruitment ceased when no new themes became apparent across sub-groups.

Analysis

Socio-institutional theory into expectations suggests that professions implement change according to formal, regulatory and institutional factors, as well as informal, individual and normative factors.[10] As such, we surmised palliative paramedicine structures exist at systems (macro), service and community (micro), and clinician and consumer (meso) levels. We adhered to Braun and Clarke's six-

phase guide in reflexive thematic analysis: (1) data familiarisation; (2) initial code generation; (3) generating initial themes; (4) theme review; (5) theme defining and naming; and (6) report production.[11-13] An inductive approach was employed, coupled with researchers' existing knowledge, to identify interventions that could improve palliative paramedicine at differing structural levels.[13] This reflexive approach to thematic analysis highlights the researcher's active role in generating knowledge, whereby codes represent the researcher's interpretations of patterns of meaning across the dataset.[12] 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 improving community-based palliative and end-of-life care. However, we remained mindful of this and invited all participant perspectives to be captured, reporting all ideas regardless of their alignment to our own. One researcher read all transcripts, familiarised herself with their content, independently identified potential codes for each structural level and met with the team to discuss and develop the codebook, allowing for consistent interpretation and classification of the data. This codebook guided coding of the remaining transcripts. Consecutive rounds of discussions were held with all researchers to capture multidisciplinary perspectives and enhance the analytical framework. Our positionality was embraced as value adding, not a potential source of bias. We employed meaningful immersion in the data, and engaged in thoughtful discussion amongst the team to ensure our analysis was reflective.[12] NVivo was used to store and support analysis of anonymised data.

Patient and public involvement

None.

RESULTS

Fifty interviews (18-64 minutes long, mean 43.64 minutes) were conducted between November 2021 and April 2022, including participants from all Australian states and territories (Table 1). Themes were classified into macro-, meso- and micro-level interventions (Figure 1), illustrated by quotes identified by role and ID.

All participants strongly supported paramedics' important adjunct role in providing 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).*

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			

Macro-level

Policy and frameworks: All participant groups considered paramedic inclusion in both international and domestic palliative care policies and frameworks to be a top priority for improving future systems, services and practice. Participants suggested, "*policy needs to acknowledge that the ambulance services can play a very important role in the palliative care of patients*." (Palliative care doctor, 24) However, one participant highlighted that if paramedics are recognised in palliative care policy and framing, "*it's more than likely people need to then incorporate that thinking into their workload." (PC doctor, 26)*

Funding and education: Interdisciplinary palliative and end-of-life care funding and competencies were championed to encourage the *"sustainability"* of palliative care practice through *"a shared care model"* (Palliative care doctor, 22). One paramedic lamented, "*we need to stop considering ourselves as separate entities within health. Start considering ourselves as one health unit with different functions within that unit*" (2).

To promote greater awareness of the role paramedics can play, 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). One participant highlighted the power of this inclusion to challenge the traditional narrative of curative medicine:

> *"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)*

Accessing medical records: Participants advocated for universal healthcare access to electronic medical records to allow paramedics and other clinicians to retrieve patients' medical and social histories in a timely manner:

> *"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…. 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)

Paramedics emphasised a need for a *"streamlined process"* whereby everyone *"knew what to expect"* (Paramedic, 1) from a standardised document to which paramedics could contribute:

"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 paramedics' scope of practice to verify death was seen by participants as an opportunity to reduce avoidable police attendance, in cases of expected death where a doctor or senior nurse is unable to attend the home in a timely manner:

"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)

Participants argued for a national approach, noting paramedics in some jurisdictions are already able to verify a patient's death. Paramedics contended, evoking these macro-level changes will require *"a shift in our culture and identity"* (4), noting the growing professionalisation of the paramedic role would open doors to work *"outside of ambulance services"* (15) in the future:

*"It's about the health service acknowledging what paramedicine being registered (*as health practitioners*) 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)*

Meso-level

Service-level training: Clinicians suggested ambulance services *"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 subspecialisations:

> *"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*)

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). However, participants highlighted the limitations of traditional siloed care amongst disciplines, and a need to improve communication channels:

> *"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)*

Participants from regional, rural and remote backgrounds suggested innovative solutions for 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)*

All participants prioritised localised referral pathways, 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). However, paramedic participants described experiences of reluctantly bringing patients to ED as a referral function was lacking:

> *"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)*

Virtual emergency departments were discussed by some as an emerging solution for ambulance services with limited access to specialist palliative care support and referral pathways.

Community expectations: Paramedics noted 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, in addition to compassionate communities' initiatives, to better educate the public about the realities of death and dying, and 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

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)

"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)

Participants emphasised, those paramedics with 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 at 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:.

"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)

Partnering with families: Participants highlighted that family members and carers could facilitate 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 are often called to simply provide in-home manual handling support for immobile palliative patients, and these 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):

"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)

DISCUSSION

This study identified opportunities for improving a current gap in care for people at end-of-life, especially out-of-hours, by enhancing the existing skill base and presence of paramedics. 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 – is needed to improve patient care and enable better access to paramedics delivering palliative and end-of-life care in conjunction with broader multidisciplinary teams.

However, integrating palliative care into paramedicine core business must strike a balance between enhancing the paramedic's role as an adjunct provider, while preserving the broader medical emergency response function of an ambulance service in the community.[14] Evoking cultural change to overcome the lifesaving orthodoxy of the paramedic role will be one associated challenge.[5, 14, 15] 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.

To strengthen paramedics' role within existing interdisciplinary palliative care networks, greater recognition of their capacity and skills across the healthcare sector is required. Canada pioneered community paramedicine some years ago and has successfully incorporated PC into routine paramedic practice. 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.[15] A 2022 study exploring the alignment of this programme with paramedic professional identity considered the provision of palliative paramedicine a growth for the profession, fitting well with its existing identity of service to the community through a patient-centred lens.[15] 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.[15] Comparatively, specialist PC participants believed paramedics were a well-established part of their team.[15] 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 and other countries with similar health systems in the future.

Consensus methodology has also been used to establish multidisciplinary core competencies for Australian health and aged care workers in recognition of the ageing population and greater need for collaboration within disciplines.[16] The findings of this study could help inform the development of future multidisciplinary palliative care approaches to also include paramedicine.

Participants in the current study 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 Australian regional, rural and remote areas, where greater levels of continuity of care can foster stronger relationships across sectors.[17] 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.[15, 18] 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.[7]

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 stakeholders involved in palliative paramedicine. 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. Zoom interviews were undertaken instead of face-to-face due to COVID-19 pandemic social distancing restrictions in place at the time of data collection. Although the research team initially had concerns about the limiting nature of this format, conducting the interviews over teleconferencing yielded rich data and gave voice to many

participants located in rural and remote areas of Australia, and those experiencing mobility issues, we would have been otherwise unable to reach. These findings are supported by a recent study, which suggests digital interviewing via platforms like Zoom during COVID-19 were beneficial due to their ability to maintain research continuity by overcoming geographic and logistical barriers, reducing costs and saving time.[19] 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. These findings could have international resonance for comparable healthcare systems.

CONCLUSION

Paramedics play an important adjunct role in palliative and end-of-life care in home-based settings. To ensure such care is sustainable, 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. We contend 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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Contributors

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. MJ is the guarantor.

Competing interests

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Ethics approval and consent to participate

The University of Sydney Human Ethics Committee provided ethics approval (registration number 2021/607 and 2021/608). All participants gave written informed consent to participate.

Data availability statement

No additional data available.

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FIGURE TITLE

Figure 1 Thematic summary of interventions to improve palliative paramedicine practice

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 and 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- level interventions

Palliative care subspecialty

- Mandate generalist palliative care capabilities for all paramedics
- 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-level 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-level interventions

Appendix 1: Interview guide for health professionals

1. **Opportunities for improvement**

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

b) How can multidisciplinary teams work together to better support paramedics caring for palliative and end-of-life patients in the community?

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

d) How could paramedics best support families and carers if the patient dies while they are present? ***Prompt: cultural rituals, bereavement support, verification of death, liaising with patient's medical team?***

e) 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.***

2. **Other**

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

Appendix 2: Interview guide for family members and carers

1. 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 caring for palliative patients and their families at home?
What should they be offering and why? ***Prompt: supporting patient's goals of care, medication delivery, family/carer support?***

e) How could paramedics best support families and carers if the patient dies while they are present? ***Prompt: cultural rituals, bereavement support, verification of death, liaising with patient's medical team?***

2. **Other**

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

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	4
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	5 and 15
Non-participation	13	How many people refused to participate or dropped out? Reasons?	3
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	4
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	5 and 15
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	4
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	4
Field notes	20	Were field notes made during and/or after the inter view or focus group?	4
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	4
Transcripts returned	23	Were transcripts returned to participants for comment and/or	4

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	4
Description of the coding tree	25	Did authors provide a description of the coding tree?	4
Derivation of themes	26	Were themes identified in advance or derived from the data?	4
Software	27	What software, if applicable, was used to manage the data?	4
Participant checking	28	Did participants provide feedback on the findings?	4
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	5-10
Data and findings consistent	30	Was there consistency between the data presented and the findings?	5-10
Clarity of major themes	31	Were major themes clearly presented in the findings?	5-10
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	5-12

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.