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

Madeleine Juhrmann ,[1,2] Phyllis Butow,[3] Cara Platts,[4,5] Mark Boughey,[6,5] Paul Simpson,[7] Josephine M Clayton[1,2]

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For numbered affiliations see end of article.

Correspondence to
Dr Madeleine Juhrmann; mjuh9730@uni.sydney.edu.au

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, semistructured interviews were conducted.

Setting and participants 50 participants with palliative paramedicine experience, from all jurisdictions of Australia. Participants were interviewed between November 2021 and 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: macrolevel (policy and frameworks; funding and education; accessing medical records and a widening scope); mesolevel (service-level training; interprofessional understanding and communities of practice and community expectations) and microlevel (palliative care subspecialty; debriefing and self-care 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 (PC) services is increasing.[1] However, the specialist PC 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 WHO 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 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, 7 days a week. PC 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 10 tips American PC 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 PC 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 subset 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 PC needs who encountered paramedics at the end of life in the community. Health professional subgroups included paramedics, general practitioners (GPs), PC nurses, PC doctors and residential aged care home managers.

Participants were purposively sampled to capture the perspectives of all stakeholders involved in palliative paramedicine and ensure varied demographics and clinical experiences were represented. Health professionals were recruited through professional organisations; family carer participants were recruited through a national organisation's register of PC 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 semistructured interviews were conducted via Zoom between November 2021 and April 2022. Interview guides to elicit ways to improve paramedic PC practice (online supplemental 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 subgroups.

Analysis

Socioinstitutional 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 with 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 the 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 among the team to ensure our analysis was reflective.[12] NVivo was used to store and support the analysis of anonymised data.

Patient and public involvement

None.

RESULTS

50 interviews (18–64 min long, mean 43.64 min) were conducted between November 2021 and April 2022, including participants from all Australian states and territories (table 1). Themes were classified into macrolevel,

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
UK	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		

Continued

Table 1 Continued

Family member/carer participant characteristics	Participants (n=8)	%
Dementia		
Kidney failure		
Liver failure		
Motor neuron disease		
Other		

GP, general practitioner.

mesolevel and microlevel 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*).

Macrolevel

Policy and frameworks

All participant groups considered paramedic inclusion in both international and domestic PC 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 PC 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 PC 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)

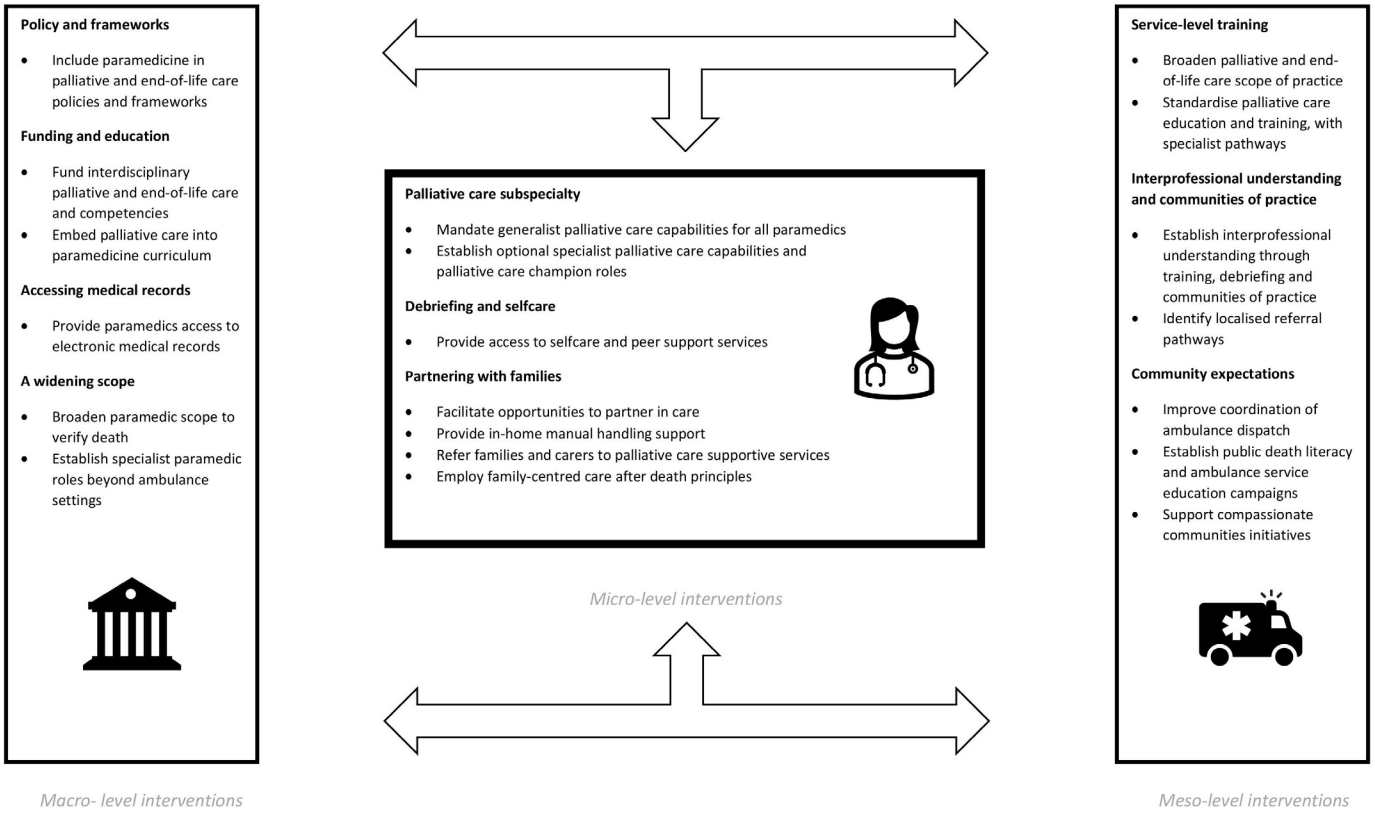

Figure 1 Thematic summary of interventions to improve palliative paramedicine practice.

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 macrolevel 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)

Mesolevel

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 PC 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 PC providers, including GPs, to establish interprofessional understanding and communities of practice (Palliative care doctor, 27). However, participants highlighted the limitations of traditional siloed care among 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 vs 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 PC 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 PC 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 PC 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 PC 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)

Microlevel

PC generalist versus specialist capability

Although participants recognised not all paramedics gravitate towards non-traditional elements of paramedicine, including PC, they recommended every paramedic ought to have a mandatory generalist PC capability, with pathways to specialise in community and PC 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 PC champions within their networks to '*drive that direction to keep the palliative approach going*' (Palliative care nurse, 31).

Debriefing and self-care

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 PC 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 the 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 PC 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 PC 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 among 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 among 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 PC 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 into their social and structural determinants of health if a referral to GP and/or PC services became available.[15 18] However, not all paramedics will have a sustained passion for working in the PC space. From our findings, we recommend individual paramedics ought to have a generalist scope of PC 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 PC 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 and 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 was 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 macrolevel, mesolevel and microlevel 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 macrolevel, mesolevel and microlevel 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 PC and greater investment in both the generalist and specialist palliative paramedicine workforce ought to be prioritised.

Author affiliations
[1]The University of Sydney Northern Clinical School, St Leonards, New South Wales, Australia
[2]HammondCare, Sydney, New South Wales, Australia
[3]The University of Sydney School of Psychology, Sydney, New South Wales, Australia
[4]St Vincent's Hospital Melbourne Pty Ltd, Fitzroy, Victoria, Australia
[5]The University of Melbourne Melbourne Medical School, Melbourne, Victoria, Australia
[6]Palliative Medicine, St Vincent's Hospital (Melbourne) Limited, Fitzroy, Victoria, Australia
[7]Western Sydney University School of Health Sciences, Penrith, New South Wales, Australia

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and 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. Participants gave informed consent to participate in the study before taking part.

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ORCID iD
Madeleine Juhrmann http://orcid.org/0000-0001-5500-4330

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