

Paramedic care of the dying, deceased and bereaved in Aotearoa, New Zealand

Authors:

Dr Natalie Elizabeth Anderson, PhD ^{1,2}

Email: na.anderson@auckland.ac.nz

ORCID: <http://orcid.org/0000-0001-6852-1660>

Twitter: [@CerebralNurse](https://twitter.com/CerebralNurse)

Dr Jackie Robinson, PhD ^{1,2}

Email: j.robinson@auckland.ac.nz

ORCID: <http://orcid.org/0000-0002-9678-2005>

Twitter: [@JackieRob434](https://twitter.com/JackieRob434)

Dr Tess Moeke-Maxwell, PhD

Email: t.moeke-maxwell@auckland.ac.nz

ORCID: <https://orcid.org/0000-0002-3980-3228>

Professor Merryn Gott, PhD¹

Email: m.gott@auckland.ac.nz

ORCID: <http://orcid.org/0000-0003-4399-962X>

Twitter: [@MerrynGott](https://twitter.com/MerrynGott)

1. School of Nursing, Faculty of Medical & Health Sciences, University of Auckland, Auckland, New Zealand
2. Auckland District Health Board, Auckland, New Zealand

Corresponding Author: Dr Natalie Elizabeth Anderson

Email: na.anderson@auckland.ac.nz

Phone: +6499237874 Facsimile: +6493677158

Postal address: University of Auckland, School of Nursing, Private Bag 92019, Victoria Street West, Auckland 1142, New Zealand

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Keywords

Paramedic; End of life; Death; Emergency medical service; Palliative care; New Zealand

Abstract

Paramedics play an essential and distinct role as providers of care to the dying, deceased and bereaved in Aotearoa, New Zealand and around the world. In this paper, we highlight what is known about the features, barriers and facilitators of quality end-of-life care by emergency ambulance personnel. We also identify priorities for future policy and practice, education and research in this area. Paramedics provide urgent and after-hours support to those with known life-limiting illness and their caregivers, but also attend sudden deaths, from unexpected or unknown causes. Paramedic care at the end of life may involve attempted resuscitation; challenging decision-making and communication; symptom relief; recognition of irreversible dying; provision of compassionate, culturally responsive support for co-responders, bystanders and the bereaved. There is an insufficient acknowledgement of the critical and unique role of paramedics, as providers of urgent care to the dying deceased and bereaved. Ambulance personnel around the world want better preparation and support for end-of-life care. Future research should aim to evaluate and improve this vital care, explore the needs and experiences of those who call an ambulance in the context of death, dying or bereavement and address equity and cultural responsiveness.

Background

Emergency ambulance personnel encounter dying, death and bereavement in the community in many guises. They support individuals and whānau (families) when death is expected due to known life-limiting illness or advanced age [1, 2]. Indeed, even with carefully-made plans, patients, families or caregivers may face sudden unexpected crises or feel overwhelmed. Moreover, in situations where access to hospice or GPs is limited due to service hours, or remote location, an emergency ambulance response may be the only available option. Paramedics also respond to sudden, unexpected or unexplained deaths resulting from undiagnosed underlying conditions, sudden exacerbations of known chronic conditions or death secondary to trauma, suicide, choking or drowning [3, 4]. If resuscitation is withheld or eventually terminated, paramedics need to transition their focus away from patient care and towards care of the family, caregivers and other responders at the scene [5]. After death care may include breaking bad news, providing support to bereaved family or caregivers, initiating post-mortem care or certification processes and debriefing bystanders, co-responders and colleagues [6].

The overall purpose of this discussion paper is to highlight the unique and essential role paramedics play as providers of care to the dying, deceased and bereaved. The specific aims of this paper are to address the following questions within the context of Aotearoa New Zealand:

1. How are paramedics caring for the dying, deceased & bereaved?
2. What facilitates quality paramedic care at the end of life?
3. What are the barriers to quality paramedic care at the end of life?

4. What are the priorities for future policy and practice, education and research?

How are paramedics caring for the dying, deceased & bereaved in Aotearoa, New Zealand?

The New Zealand Context

Aotearoa New Zealand is a topographically and demographically diverse island nation, with a total population of 5 million [7]. Around 86% of New Zealanders reside in urban areas, but the overall population density is low, and remaining residents live in rural and remote areas [8]. Māori are the indigenous people of Aotearoa New Zealand [9]. New Zealand has clear obligations under the Treaty of Waitangi, to uphold the rights, culture and wellbeing of Māori. Despite these historical and legal obligations, colonisation has had an adverse effect on Māori in all of these areas [10]. Today, Māori are subject to racial discrimination and deprivation and have inequitable access to healthcare and education, lower life expectancy and higher rates of morbidity and mortality [11, 12].

St John provides Emergency Ambulance Services across 97% of New Zealand's geographical area, with the remaining area serviced by Wellington Free Ambulance [13]. Ambulance services are funded by a complex mix of government and community contracts, Accident Compensation Commission funding, private part-charges and charitable donations and bequests [14, 15]. Emergency ambulance personnel consist of First Responders (who have advanced first aid training), Emergency Medical Technicians (EMT) (who have undertaken Diploma-level

training), Paramedics (who have typically completed a degree in paramedicine) and Intensive Care Paramedics (who usually hold post-graduate qualifications)[13].

New Zealand ambulance personnel at EMT level and above can withhold or terminate resuscitation following Clinical Procedures and Guidelines [16] and verify death in the field. In New Zealand - as in many other countries – standardised cardiac arrest registry data is collected, describing ambulance responses to people found unconscious and pulseless [13, 17, 18]. Emergency ambulance crews attend over 4500 people in cardiac arrest, every year. In around 55% of these cases, resuscitation is not attempted and in a further 32% resuscitation is ultimately terminated on scene. From this data it can be extrapolated that New Zealand emergency ambulance crews are present at the scene of nearly 4,000 deaths per annum [19].

New Zealand aligns itself with a generalist specialist model of palliative care. At the end of life most people are cared for by usual community providers including General Practitioners and District Nurses. Only those with the most complex palliative care needs will be referred to hospice [20]. Availability of out of hours support varies around the country with coverage particularly poor in some rural areas [21]. Even where health professionals have tried to effectively communicate that death is imminent, families and patients may not fully comprehend or accept this prognosis, or may need reassurance or support managing symptoms of active dying [1].

Emergency Ambulance Care at the End of Life

Paramedics provide end-of-life care in diverse circumstances. Adapting findings from an American study by Waldrop et al. [22] paramedics provide end-of-life care in four broadly-grouped decision-making contexts. These are presented in Table 1:
Emergency ambulance end-of-life contexts.

Table 1: Emergency ambulance end-of-life contexts

End-of-life context	Examples	Possible paramedic actions
Family/caregivers are aware patient is dying, and patient wishes are known.	Patient with known end-stage life-limiting illness, advanced care plan completed, family aware death is imminent.	Symptom relief, caregiver support, verification of death, breaking bad news, practical and emotional support to bereaved.
Family/caregivers are aware patient is dying, but patient wishes are unknown or unclear.	Patient with end-stage life-limiting illness but wishes at end of life have not been discussed.	NZ paramedics exercise clinical judgement and may or may not attempt resuscitation.
Family/caregivers unaware patient is dying, but patient wishes known.	Sudden deterioration in a person of very advanced age, rest home caregiver aware patient has signed DNR on file.	Patient wishes regarding resuscitation prioritised when considering the best approach to care.
Family/caregivers unaware patient is dying, and patient wishes unknown.	Sudden cardiac arrest e.g. undiagnosed heart disease, trauma, choking. Sudden cardiac arrest in a patient with complex comorbidities, but mortality and patient wishes never discussed.	NZ paramedics will often attempt resuscitation but can withhold or terminate these efforts if they become aware of overwhelmingly negative prognostic factors.

As shown in Table 1, emergency ambulance care at the end of life does not always occur in a context where palliation, patient wishes or family support needs are clearly-identified priorities. Paramedics are often meeting the patient, family and caregivers for the first time [6]. There is significant time-pressure to quickly determine if resuscitation is the best course of action [23]. Once commenced, resuscitation efforts are demanding, making it difficult to elicit and integrate contextual information. In New Zealand, clear clinical procedures guide resuscitation decision-making [16] but even the most experienced paramedics can find it challenging to withhold or terminate resuscitation [24]. Resuscitation decision-making requires elicitation and complex integration of known prognostic factors (e.g. presenting rhythm, time since collapse) with patient, scene and arrest-specific variables (e.g. patient wishes, family expectations, scene safety and privacy) [25, 26]. For New Zealand paramedics, prognostic certainty or patient wishes are necessary but not sufficient grounds to enact a decision to stop resuscitation [26]. The paramedic who enacts that decision needs confidence and experience with breaking bad news, managing the scene of a death and supporting first responders, bystanders, family and crew [3].

What facilitates quality paramedic care at the end of life?

Experienced paramedics develop many skills that facilitate excellent care in the context of death, dying and bereavement. They have learned to quickly and efficiently elicit critical information and establish a calm leadership presence [27].

Paramedics also know the importance of rapidly building rapport and supporting people who are anxious, overwhelmed or otherwise in crisis [28, 29].

When providing emergency ambulance care in the context of expected or irreversible death, paramedics in New Zealand are authorised to prioritise palliative care in keeping with known patient wishes, withhold or terminate resuscitation and verify death [16]. Internationally, there is a call for clear clinical guidelines and clinical support for paramedics providing palliative care in their communities [30]. Paramedic comfort with resuscitation decision-making is aided by a clear understanding of the evidence supporting termination of resuscitation rules or guidelines. This includes knowledge of the limitations of resuscitation and prognostic factors [31, 32, 33]. Both broad life experience and clinical exposure are considered most useful in preparing paramedics for patient death, dying and bereavement [3, 34].

Care at the end-of-life should be context-specific and not formulaic. Paramedics may face unfamiliar, unusual or challenging end-of-life situations where clinical guidelines may not provide sufficient support. In these situations, New Zealand ambulance personnel can access on-scene backup or phone an experienced paramedic, via a clinical support desk [3]. Overseas, collaborative communication with specialist palliative care providers has helped to facilitate quality ambulance care and confident decision-making in the context of death, dying, and bereavement [35]. In a UK feasibility study, hospice nurses provided telephone advice to ambulance clinicians attending patients with palliative care needs. The trial saw paramedics confidently managing most patient and family needs on-scene [36]. Another UK ambulance service partnered with Macmillan Cancer Support on a two year programme which aimed to reduce inappropriate hospital conveyance and increase staff knowledge and confidence in end-of-life care [37]. In Canada, a multifaceted Paramedics

Providing Palliative Care at Home Program was evaluated favourably by patients, families and paramedics [38]. However, not everyone has palliative care needs which require referral to a specialist palliative care service, and evidence has shown that some groups are less likely to be referred to a hospice service [39]. Ideally, support for ambulance personnel in decision making at the end of life needs to also be available from the patient's usual care providers such as general practice teams and district nursing services.

What are the barriers to quality paramedic care at the end of life?

Multiple studies have highlighted a lack of paramedic training in after-death care, particularly breaking bad news and supporting the bereaved. A recent study of New Zealand paramedic graduates highlighted concerns about feeling overwhelmed by acute grief reactions [40]. A fear of death and uncertainty about emotional responses may prevent experienced ambulance personnel from engaging with care of the bereaved [41, 42].

Resuscitation decision-making can be made challenging when there is evidence of a life-limiting illness, but family cannot provide information about the patient's medical history or wishes [2, 22, 38]. In New Zealand, as in many countries, paramedics have limited or no access to digital patient medical records [43]. Documented patient wishes are rarely encountered, with a low uptake of advanced care planning in New Zealand [44] and around the world [45].

Patient autonomy is a highly-valued ethical principle in many healthcare systems, but when paramedics arrive on scene to find a patient who is near death or in cardiac arrest, eliciting that person's preferences for treatment can be difficult. There is increasing awareness of the importance of documented patient preferences -

particularly in the context of advanced age or a life-limiting illness - although the form and legal standing of these documents varies between regions and countries [46]. Even where patient wishes have been discussed and documented, these may not always be available to ambulance personnel, up-to-date, legally-binding or applicable to the specific event [47].

Death is generally seen as a negative outcome measure in emergency ambulance care, and ambulance care after death receives relatively little attention in care evaluation, research or clinical practice guidelines. Lack of acknowledgement of after-death care quality may send a message that time spent on scene after a patient has died is not important – or even an inappropriate use of scarce emergency ambulance resources.

Providing a rapid emergency ambulance response is made challenging by New Zealand's mountainous geography and geographically dispersed population. A recently published study suggests 16% of New Zealanders lack timely access to emergency ambulance services and advanced-level hospital care, due to rural and remote location [8]. New Zealand's emergency ambulance response in rural and remote areas is dependent on volunteers and first responders [14]. Rural and remote responders are also more likely to know the patient or family, which can make end-of-life decision-making more emotionally and ethically challenging [3]. There is also a lack of access to specialist palliative care services in rural and remote areas of New Zealand [48].

Lack of Māori Responsiveness

Māori are over-represented in chronic life-limiting illness, more likely to be living in deprivation and more likely to die in a hospital setting [49]. Māori are also under-

represented across all New Zealand health professions, including the emergency ambulance workforce [50]. New Zealanders pay a substantial part-charge for each response by emergency ambulance services, which limits access for those without financial means. When responding, it is vital that paramedics are able to provide culturally safe care which supports Māori whānau at the end of life [51]. New Zealanders have a commitment to improving Māori health outcomes, and access to support from emergency ambulance and specialist end-of-life care services are critical, due to these known health and sociodemographic inequities. Māori are also less likely to access hospice services [52] so if systems are reliant on hospice to support ambulance personnel with end-of-life decision-making, Māori may be doubly disadvantaged. Ambulance care needs to be flexible (responsive) to the varying cultural needs of whānau, which in turn requires greater consultation, awareness and understanding of experiences, values, barriers and facilitators[12, 51, 53].

What are the priorities for policy and practice?

People are living in the community with complex care issues related to a wide range of different chronic, life-limiting illnesses. Care and death at home is being prioritised by governments in resource-rich countries [54]. This places increasing pressure on healthcare services in the community, including that which is provided by ambulance services. Their role is integral to supporting people to be cared for and die at home. At present, New Zealand and Australian palliative care reports and guidelines make minimal or no reference to ambulance responses [20, 30, 55]. Policy should reflect the integration of ambulance into the overall model of palliative care provision in the community.

Provision of care to patients, families and bystanders at the end of life is important and rewarding work. Paramedic procedural guidelines and competency assessments prioritise technical and life-saving skills. Non-technical skills including so-called 'emotion work' [29] receive less attention in research, education, guidelines, evaluations and competency assessment [56]. This is also, arguably, at-odds with the ideals of palliative care – which are underpinned by kindness and a holistic approach to care, taking into account all domains; emotional, psychosocial, spiritual and physical. Palliative care also values the role of family and considers the family and ill person as the unit of care [57, 58, 59, 60].

Caring for Māori whānau at the end of life requires paramedics to not only provide the best medical care regardless of expected, sudden, traumatic or unexpected death but also, their practice must be culturally competent to engage with the dying and their bereaved or distressed whānau [61, 62]. Paramedic policies must prioritise Māori whānau access to ambulance services to ensure equitable end-of-life care and cultural guidelines are now needed to strengthen Māori responsiveness [58]. Policy development and training is needed to strengthen paramedics to work confidently to uphold the cultural needs of diverse Māori whānau as end-of-life customs may differ between tribes, whānau and geographic locations. Time and space for example, should be allowed for cultural rituals (karanga [calling], karakia [prayers, chants, incantations], and waiata [singing]) to be performed before, during and after death [59]. Allowing space for whānau to touch, or be with the body following death is highly likely to be important. Knowing how to identify and then communicate information to the right person within the whānau, or a family spokesperson, can enable paramedics to deliver important information on the post-death process to the

whānau (i.e. process for caring for the tūpāpaku [body] after the ambulance leaves)[63].

What are the priorities for education?

In countries where emergency ambulance services are paramedic led - notably New Zealand, Australia [64], the UK [65] and Canada [66] - the knowledge and skills of ambulance personnel have expanded significantly with the evolution of the paramedic role. A growing percentage of the Australasian emergency ambulance workforce have completed paramedicine degrees [67, 68]. Paramedics should receive training and education in symptom management and the principles which underpin palliative care. It is important that care in the context of death, dying and bereavement is given explicit attention in paramedic degree training. Ambulance personnel around the world want more training on after-death care [34]. Critical learning areas include breaking bad news, culturally safe care of the deceased, practical and emotional support for the bereaved and post-event care of bystanders, co-responders and colleagues [3, 69, 70] . Early experiences with patient death can be impactful and formative, for novice clinicians [71, 72]. Clinical and life experience are both considered vital contributors to confident, skilled paramedic care at the end of life [3, 69]. It is therefore important that qualified paramedics have opportunities to continue to learn and reflect, through case review and ongoing professional development.

Paramedic students are eager for tools to aide communication with the bereaved and (ideally) an opportunity to observe other skilled clinicians and/or rehearse breaking bad news under simulation conditions [40, 69]. Whilst there are a range of initiatives to address paramedic end-of-life education, there is a lack of evidence to

support any particular approach [34, 73]. This ties-in to the third area for development, priorities for research.

What are the priorities for research?

In order to provide an evidence base for quality care, we need to understand the needs of those who call an ambulance when someone dies. At present, there is little known about why people call an ambulance even when death is expected. Globally, we need to understand why people call an ambulance when death is expected. We should be evaluating what support is most valued following a sudden unexpected death. In the context of attempted resuscitation, there is still a lot to be learned about the support needs for family, first responders, co-responders, bystanders and ambulance personnel. We cannot strive to achieve quality emergency ambulance care to the dying, deceased and bereaved without understanding what patients, families and bystanders need and value in these situations.

In the New Zealand setting, we need to specifically address the needs of Māori whānau when they call an ambulance in the context of death, dying and bereavement. We also need to establish the needs and best ways to support rural and remote emergency ambulance personnel, who may face some of the most challenging end-of-life situations, without access to onsite backup.

It is also important to integrate the role of ambulance personnel into future models of palliative care. At present, emergency ambulance responses in the context of expected death and dying are sometimes seen as a poor use of resources or sign of avoidable 'crisis' rather than part of planned community care.

Conclusion

People are living and dying in the community at an advanced age and with complex comorbidities. Even where death is anticipated, family, patients and caregivers may feel inadequately resourced and require assistance. Paramedics in New Zealand and around the world are key providers of emergency community care to the dying, deceased and bereaved. There are important opportunities for development in this area, to improve education and support and develop an evidence base which reflects the needs of those who call an ambulance in the context of death, dying or bereavement.

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