

***‘Mum, I think we might ring the ambulance, okay?’* A qualitative exploration of bereaved family members’ experiences of emergency ambulance care at the end of life**

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Abstract

Background: In the context of a sudden or unexpected event, people with a life-limiting illness and their family caregivers may be dependent on emergency ambulance services

Aim: To explore bereaved family members’ experiences of emergency ambulance care at the end of life.

Design: A qualitative study using reflexive thematic analysis of data collected from semi-structured phone interviews.

Setting/Participants: A purposive sample of 38 family caregivers identified from a database of deaths in Aotearoa, New Zealand.

Results: Emergency ambulance personnel assist, inform and reassure patients and family caregivers managing distressing symptoms, falls,

infections, unexpected events and death itself. Family members and patients are aware of the pressure on emergency services and sometimes hesitate to call an ambulance. Associating ambulances with unwanted transport to hospital is also a source of reluctance.

Conclusions: The generalist palliative care provided by emergency ambulance personnel is a vital service for patients in the last year of life, and their caregivers. This must be acknowledged in palliative care policy and supported with training, specialist consultation and adequate resources.

Keywords

Palliative care, terminal care, emergency medical services, ambulances

What is already known about the topic?

- Access to specialist palliative care may be limited at night, on weekends or in rural and remote areas
- Emergency ambulance providers are key providers of urgent and out-of-hours end-of-life care
- Family caregivers play an essential role caring for people in the community nearing the end of life, but the role of emergency ambulance services is not well understood

What this paper adds

- Emergency ambulance response is an essential service for family members and caregivers
- Those with a life-limiting illness can feel reluctant to call an ambulance
- Bereaved family members in caregiving roles value emergency ambulance support with challenging events, including the death event itself

Implications for practice, theory or policy

- After hours and urgent services need to be prioritised and adequately resourced to meet the needs of people living at home with a life limiting illness

- Development of palliative care services in policy and practice needs to include emergency ambulance providers
 - Providing effective support for caregivers and bereaved family members needs to be a focus of emergency ambulance education, policy and research
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Background

In many countries, paramedics are frequent providers of patient care in the last weeks of life¹ including for those with specialist palliative care needs.^{2,3} In the context of a sudden or unexpected event, people with a life-limiting illness and their family caregivers may be dependent on an emergency ambulance response. However, little is known about patient and family caregiver experiences of end-of-life emergency ambulance care.^{4,5} A need for more research into the role of paramedics as generalist palliative care providers has been identified.^{2,5-7}

People in developed countries are living longer, with more complex chronic illnesses and a desire to live and die in their own homes. This requires an increase in community support for those at the end of lives.⁸ A recent systematic review exploring paramedic palliative care found that care of the family was a crucial part of emergency ambulance care at the end of life.² Informal and family caregivers provide vital care to people living with chronic illness and nearing the end of their lives in the community. Research exploring family carers experiences of generalist palliative emergency ambulance care is needed^{4,9,10}

Aim: To explore bereaved family members' experiences of emergency ambulance care at the end of life.

Study design

This paper draws on data from two larger studies exploring the experiences of end-of-life care in the community, from the perspectives of bereaved family carers. A qualitative design was underpinned by a critical realist approach, seeking to explore the experiences of bereaved family, as described in their own words.^{11,12}

Setting

Less than a third of New Zealanders are referred to specialised palliative care at the end of life and most of those referrals are for patients with cancer as a primary diagnosis. For the majority, care needs at the end of

life will be provided by aged care staff or other community providers including district nurses, general practitioners and emergency ambulance personnel.¹³ In line with Australia, the United Kingdom and Canada, emergency ambulance services in Aotearoa New Zealand function under various funding and organisational models characterised by increasing paramedic autonomy and professionalisation.¹⁴ Emergency ambulance responses in Aotearoa New Zealand usually include a registered paramedic qualified to provide urgent and primary healthcare in the community.^{15,16} Most ambulance personnel in Aotearoa New Zealand are authorised to provide symptom relief, verify death in the field as well as terminate or withhold resuscitation in accordance with Clinical Procedures and Guidelines.^{17,18} Many of those attended by an emergency ambulance will be in the last days of life, but few have a documented plan for end of life care.^{6,19}

Population

In both studies, datasets of adults (>18 years) who had died between January and December 2019 were provided large urban district health boards in Aotearoa New Zealand. District Health Boards provide care for a population within a specific geographical area. The combined databases included details for approximately 5000 people who had died, including the name, relationship and contact details of a primary (next-of-kin) contact. These bereaved family members were recruited to participate in this study.

Sample

In Study 1, a stratified randomised sampling approach was used to ensure bereaved family experiences included deaths with both cancer, and non-cancer primary diagnoses. The sample in Study 2 was randomly selected from those whose relative had died with a primary diagnosis of heart disease, as this was the focus of that larger research project. Bereaved family members needed to be aged over 18 years and speak English in order to be eligible to participate.

Recruitment

Senior nurses from the District Health Boards sent letters of invitation along with study information to eligible participants introducing the study and asking them to contact researchers should they wish to participate. Fifty letters of invitation were sent out every fortnight, until

sufficient participants were recruited for each study. Across the two studies, a total of 350 recruitment letters were sent.

Data collection

Data were collected using semi-structured phone interviews to explore participants' experiences of care provided to their deceased family in the last year of their life. In both studies, the focus was on family caregiver experiences of end-of-life care in the community. All interviews were undertaken between June and December 2020 and transcribed by the same experienced nurse researcher (HG) who did not have any prior relationship with the participants. Using NVivo 12 to facilitate data coding, descriptions of emergency ambulance and out-of-hours care were extracted as a data subset. Whilst describing their deceased family members' care in the last year of life, some participants spontaneously included emergency ambulance care. Others were prompted with 'Did [deceased family member] ever need an ambulance?' or 'Can you tell me more about when the ambulance came?'

Data analysis

The interview transcript data subset described above was analysed using an inductive, reflexive thematic analysis approach.¹² Data were managed in NVivo 12, facilitating initial familiarisation, coding and notation. Interview transcripts were reviewed by the research team as a whole, who worked collaboratively to iteratively develop a coding framework. Analysis was led by NA and regular meetings with the wider research team informed the development of themes.

Ethics

Ethics approval was provided by the New Zealand Health and Disability Ethics Committee (Ref: 19/CEN/78/AM03) and the University of Auckland Human Participants Ethics Committee (UAHPC: 017662).

Findings

Thirty-eight next of kin participants were interviewed. Most commonly participants were next of kin to a parent (21) or spouse (10) who had died. Others were describing the death of a sibling, adult child or other relative. No other participant demographic data were collected, but characteristics of the deceased family member are included in [Table 1](#).

Table 1.
Characteristics of deceased family members.

	<i>N</i> = 38
Primary diagnosis at death	
Cancer	21
Heart disease	10
Other	7
Gender of deceased	
Male	15
Female	
Age of deceased at death	
18–50	4
51–65	7
66–75	19
76–90	5
>90	
Prioritised ethnicity of deceased	
New Zealand European	28
Other European	5
Chinese	1
Indian	1
Fijian	1
Samoan	1
Māori	1

Most (30/38) participants recalled using emergency ambulance services for their family member in the last year of life. Participants described ambulance responses to falls, confusion, pain, infection, bleeding, breathlessness, collapse and imminent death. As shown in [Table 2](#), three key themes were developed, highlighting family experiences with emergency ambulance care at the end of life.

Table 2.
Family experiences with emergency ambulance care at the end of life.

Theme	Description	Illustrative quote
1. ‘We’d phone them & they’d come, no problem at all’: Supporting living and dying at home	Ambulance care provided was invaluable when family, friends or neighbours aren’t available or able to manage a situation at home	‘They took every, every minute that they needed. They didn’t rush him. They helped and they told mum and I to just let them do it and they checked him over and they just said, you know, if you ever need to call us, don’t feel bad about it’. Participant #6
2. ‘I didn’t actually realise she was	Participants called on emergency services when faced with events	‘That’s what I think got us so shocked is that when it did happen, we were

Theme	Description	Illustrative quote
dying': Urgent & unexpected events	that were considered 'urgent' or unexpected including falls, infections, new or worsening symptoms, or at the time of death.	just in a state of shock. Because nobody prepared us or told us'. Participant #12
3. "I'm sure they had more serious problems": Reluctance in calling an ambulance	Participants and their family members had reservations about calling an ambulance. They were concerned about unwanted hospital admission and being a low priority in the context of emergency care.	'So, you know, he was probably not a high priority, like, it wasn't an accident'. Participant #14

Theme 1 'We'd phone them & they'd come, no problem at all': Supporting living and dying at home

Family, friends and neighbours often acted as 'first responders' when there was a crisis. Participants were grateful that an emergency ambulance response was easy to contact if this social network of carers needed urgent support.

"So you knew, you know, how to contact them and the service provided was really beneficial ...if you're worried about anything particularly, ring 111" Participant #11

Family members involved in caregiving described emergency ambulance services as invaluable, and their overall satisfaction with ambulance care was very high. Several participants noted that emergency ambulance services helped them continue caring for their family members at home, even when faced with falls and other challenges.

"Well, they got to know dad because we would phone them and just say he'd fallen and we couldn't get him off the floor. And they would, they would come and no problem at all, they would get him off the floor and either into his chair or onto his bed. If he needed, if it was, like, he was trying to get to the toilet, then they would take him to the toilet". Participant #6

Theme two 'I didn't actually realise she was dying': Urgent and unexpected events

Although participants had some awareness that their family member was very unwell or had a life-limiting illness, this did not mean that they felt prepared for their death.

'...and one of her friends came in and said your mother's just, she's really having trouble breathing. And I went in and looked at her and she'd just gone pale and clammy. And I said Mum, I think we might ring the ambulance, okay? And she said yes, all right. And that was pretty much the last thing she said to me. So yeah, we called the ambulance and she didn't make it to the hospital. She died ... in the ambulance.... And I guess had the ambulance taken 20 minutes longer she would've died at home surrounded by us. But even now I look back and I was like, I was just packing, you know, the ambulance was on its way and her friends were with her and I was packing her bag and making sure she had her favourite blanket. Like it was a bit of a routine, it was the third time we were going to hospital in six months. So it was like, you know, I was so busy packing all her things I didn't actually realise she was dying'.
Participant #2

Even where ambulance staff had suggested death might be near, family members may not have accepted this.

'Yeah. They did say, the ambulance lady did say if he has another heart attack he will die, he's so weak. But the way he was, it was like, oh no he's all good, you know for, for a bit'. Participant #15

A sense of urgency often compelled participants to call an ambulance. Being able to talk to a 111 call-taker provided reassurance, even if an ambulance response took some time

'But the [ambulance] came and the 111 call people were on the phone until they got there, virtually... and yeah, they were wonderful'. Participant #11

Theme 3 'I'm sure they had more serious problems': Reluctance in calling an ambulance

Participants often stated that their family member was reluctant to call an ambulance. Key causes of this reluctance were fear of losing independence, stoicism and a desire to stay at home. In several instances, patients tolerated discomfort for hours or days, hoping to avoid an ambulance or a trip to the hospital.

'There'd be times where he's just not feeling the best and he'd wait for days, and days, and days before he'd let me bring him to the A&E'. Participant #15

'... he knew that if he pushed the button for [the ambulance service] he might go to hospital, which he didn't want to do'. Participant #4

Some participants also felt that some events in the last days of life weren't a priority for busy emergency services. This perception of low importance did not appear to be related to behaviour on the responding ambulance personnel. As highlighted in the first theme, there were numerous comments praising their compassionate and skilled service.

'We had to call for help and it was awful having to get the ambulance guys in 'cause I'm sure they had more, you know, well, not more important, but, you know what I mean, more serious problems'. Participant #6

Although ambulance care in the home was favourably viewed, participants were eager to avoid emergency departments. There were a number of comments which suggested family, patients and healthcare providers considered emergency departments were ill-suited to care for those nearing the end of life.

'And [the paramedics] said well we can take her to hospital now but maybe just leave her at home 'cause like it's pretty busy in the hospital at the moment and she probably won't get seen until three or four o'clock in the morning. So she's better off staying at home and you just keep an eye on her and if there's any problems we can come around again'. Participant #7

'...you know there's triaging and they have to prioritise, and we understand that. And I thought, you know he can't sit up in a chair and wait for hours and hours ... he's better lying in our bed you know, in bed at home'. Participant #16

Discussion

Findings from this study suggest that emergency ambulance responders are providing an important service in supporting family carers of people living in the community with a life limiting illness. Previous studies have focussed on emergency response experiences of those with identified specialist palliative care needs²⁰ but this study sample was drawn from all adult deaths and was not reliant on specific services being involved,

such as specialist palliative care. Having a service that was known to be timely and responsive at any time of the day or night offered a level of comfort and support to family carers. We believe this is an important and novel finding as emergency ambulance personnel are often the only service that does not have limitations to its availability and may be considered as ‘only a phone call away’. This is particularly important given the ongoing challenges in providing palliative care out of hours and at weekends.^{21,22}

The uncertainty around disease trajectories at the end of life can have an adverse impact on bereaved family members’ experiences.²³ A key finding from this study was the role of emergency ambulance responders in supporting family with unexpected changes in the ill person’s medical condition. In the context of palliative care, anticipating and planning for acute deterioration is essential. However, in line with previous research,²³ findings from this study suggest that deterioration was often unexpected. In addition, the acute symptoms that occurred created a sense of urgency for family culminating in a call to the ambulance service rather than a primary healthcare or palliative care service. Feeling responsible for making the right decision when someone is acutely unwell can be challenging for family carers in palliative care.²⁴ When acute symptoms such as difficulty breathing or a change in consciousness occurs, the need to make the right decision quickly is even greater. Calling an ambulance may be a natural response for many people experiencing anxiety and fear of death.²⁵

Interestingly, evidence has shown that calling an ambulance is a major decision, often prompted by a sense of being overwhelmed or powerless.²⁶ When a situation becomes unbearable, the need for immediate help becomes urgent.²⁷ Participants in this study felt unsure about requesting an emergency ambulance response when they perceived their need was not urgent enough. They also described delaying or avoiding ambulance care due to fear of unwanted transport to hospital. Although some members of the public continue to see emergency ambulance personnel as ‘ambulance drivers’²⁸ many paramedics are qualified to provide definitive primary and palliative care in the community.^{10,29} Research suggests paramedics are keen to facilitate end-of-life care in the home but face barriers including limited patient information, limited community services out-of-hours and organisational prioritisation of emergency care.^{5,26,30} For patients known to have palliative care needs, trials integrating paramedics in palliative care in Finland³¹ and Canada³² have had promising results, often avoiding unwanted transport to a hospital. With advances in education and autonomy, paramedics should be recognised for their skilled

provision out of hospital care.³³ Family members should feel reassured that emergency ambulance care can be provided in the home, and will not inevitably result in transport to hospital.

Strengths and limitations

This is one of the first studies to explore emergency ambulance end-of-life care from the perspective of bereaved family members. Although the sample was recruited from a database of all adult deaths, those who did not have up-to-date contact information in that database or did not speak English were not able to participate in this research. Participants were asked to describe events which had taken place 6–36 months prior to their interview, which may limit their recall.

It is essential to recognise that the nature of emergency ambulance end-of-life care is changing and impacted by numerous national, organisational, professional, and interpersonal factors. Notably, the experiences described by family members in this study pre-dated the community spread of COVID-19 in Aotearoa New Zealand. Research suggests COVID-19 outbreaks are associated with an increase in home as a place of death meaning the role of emergency ambulance personnel may have grown in importance.³⁴

Implications

This research has shed some light on caregiver experiences, but further research is needed to understand what family, caregivers and bystanders need from emergency ambulance personnel in the context of death and dying. Mortality is often considered a negative outcome measure in paramedicine, with research and education focussed squarely on prevention of deterioration and death. It would be valuable to know more about the care of the dying and deceased in an emergency ambulance context and what practical and emotional support is needed when people have died in the community. It would also be helpful to understand why people call an ambulance – or are reluctant to call an ambulance – for someone nearing the end of life.

Conclusion

Emergency ambulance personnel are essential providers of generalist palliative care in the community. They assist, inform and reassure patients and caregivers managing distressing symptoms, falls, infections, unexpected events and death itself. Family members and patients are

aware of the pressure on emergency services and sometimes hesitate to call an ambulance. Ambulance personnel have a vital role in the provision of generalist palliative. This role must be acknowledged with integration into palliative care policy and practice, and supported with training, specialist consultation and adequate resourcing.

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