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Exploring New Zealand paramedic attitudes towards advance directives: An ethical analysis

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Research

Exploring New Zealand paramedic attitudes towards advance directives: An ethical analysis

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Abstract

Introduction
Advance directives are known to present challenging ethical issues in health care practice, however there is a paucity of research into paramedic perspectives of advance directives. In situations where the patient has not considered end-of-life provisions, or is unable to communicate their wishes, this contributes to an ethically complex decision-making environment for practitioners. Ethical deliberation contributes to practitioners' critical thinking skills and helps prepare them for decision-making under uncertainty. This research aims to highlight and explore underlying values within ethically complex practice-based decisions.

Methods
An exploratory, interpretive study using the 'Values Exchange', a web-based ethical decision-making tool, explored 18 urban-based New Zealand paramedics' deliberative perspectives on a controversial end-of-life scenario.

Results
Thematic analysis of participants' responses ascertained the breadth of views on advanced directives, with the emergence of three dominant themes; legal tensions, multiple constructs of dignity and seeking solutions that support clinical practice.

Conclusion
Findings revealed that when considering situations involving advance directives, participants regarded the duty to uphold patient dignity as paramount. There was a desire for greater legal guidance and a call for increased professional education in law and ethics. This study provides insight into New Zealand urban-based paramedics' views and experiences of this ethically challenging aspect of patient care.

Keywords:
advance directives, paramedic, ethical decision-making, Values Exchange

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Introduction

New Zealand (NZ) paramedics operate under three scopes of practice: emergency medical technician (EMT), intermediate life support (ILS), and intensive care paramedic (ICP). The primary function of the ambulance sector in New Zealand is to deliver pre-hospital clinical care including triage, treatment and transport. There are two land-based ambulance services and 21 air ambulances (1) that serve a population of 4,242,042 across a landmass of 271,000 km2 (2). St John is the largest land-based ambulance service provider in New Zealand. It operates 610 ambulances and employs 2481 staff members who are supported by 2782 ambulance volunteers. In 2012, St John received 366,509 emergency 111 calls, attended 350,985 emergency calls and treated 403,261 patients. During 2012, St John attended more than 2000 cardiac arrests (3).

Advance directives are written or oral statements, made when people have capacity, regarding their treatment wishes when they are no longer able to demonstrate capacity to consent (4,5). A patient initialised Do Not Resuscitate (DNR) order is an example of an advance directive commonly found in the literature (4,9,10).

International research highlights the complexity of advance directives in out-of-hospital cardiac arrest decisions, especially in terms of conflict between family and patient wishes, assessment of futility and unclear decision-making criteria, especially in the absence of a written DNR order (6). In the United States (US), members of the emergency medical services report an increased sense of empowerment where policy permits the acceptance of verbal DNR requests (7), as opposed to more formal written orders, while a Canadian study highlighted that most EMTs were comfortable upholding DNR orders, even when such actions may contradict local regulations (8).

In the New Zealand setting, an advanced directive is recognised by both Section 11 of the New Zealand Bill of Rights 1990 and Section 7(7) of the Code of Health and Disability Services Consumers' Rights (9,10). The Protection of Personal and Property Rights Act 1988 allows for an enduring power of attorney and welfare guardianship, however these proxies do not have the right to refuse standard medical treatment necessary to save a person's life (8,11). In New Zealand, advance directives do not need to be signed by an individual or witnessed by a health practitioner, solicitor or Justice of the Peace (4). An advance directive's validity is based on whether the consumer 'was competent to make the particular decision, when the decision was made; and made the decision free from undue influence; was sufficiently informed to make the decision; and intended his or her directive or choice to apply to the present' (14).

Adding to the complexity, the notion of patients consenting in advance to the refusal of life saving treatment may create tensions when New Zealand health practitioners also have an obligation to provide necessaries of life as codified in section 151 of the Crimes Act 1961 (15). While there may be opportunities to discuss end-of-life decisions in a hospital environment where attending health professionals are familiar with the patient, the already complex challenges of enacting an advance directive may well be compounded in the pre-hospital emergency environment. For example, when a cardiac arrest occurs in the community, the responding paramedics usually do not know the person requiring resuscitation and need to make immediate decisions with respect to advance directives, often with little to inform them of the patient's wishes and having to evaluate the oral statements of relatives in highly acute clinical situations.

Understanding the complexity of advance directives and being aware of multiple perspectives provide the opportunity to gain insight into the ethical and legal frames that influence paramedic practice. While practitioners attempt to administer competent practice such as cardiopulmonary resuscitation (CPR) and rely on current research on how to do this effectively, perhaps more difficult is the values based decision about whether to actually conduct CPR or not. The role of values in the decision-making process is increasingly acknowledged in the health care environment (16-18). A greater awareness of values and their role in decisions can help people to understand their own, and others' decision-making processes and the Values Exchange (Vx) provides a vehicle for achieving this (18-21). Based on earlier iterations of Seedhouse's Ethical Grid and Rings of Uncertainty (22), the Vx reflects a values based approach to ethical decision-making, where a 'value' is seen as merely an 'expression of preference', and a value judgement, a decision based on preferred values (22, pxxii). The Vx presents a range of values concepts, such as dignity, law, rights, truth, risk, integrity and care, with users providing justification for their preferred concept choices and the weighted importance given to them. This perception of values differs from other examples in the emergency medical services (EMS) literature, which utilise the Managerial Value Profile (MVP) instrument (23-24). While there is consensus that values are at the heart of decision-making, the MVP is outcome based and aims to measure statistical significance in relation to paired general statements, with a distinct employee/organisation focus. In comparison, the Vx tool is scenario specific and process orientated, utilising values that can be applied in any setting and interpreted in unique ways by the user. While its database has the capacity to track users' concept choices and to present them quantitatively, this study focused on the database's qualitative data, derived from users' free text justifications for a specific practice based scenario.

This research aims to highlight and explore underlying values present within practice-based decisions that focus on advance directives. It is not intended as a legal review. This may help to demystify and provide a schema to hinge new learnings in relation to this ethically challenging area of pre-hospital care.

Methods

Study design

This was an exploratory, interpretive study using Vx, a web-based ethical decision-making tool, to explore urban-based paramedics' perspectives on advance directives. Exploratory research is seen as appropriate where little is known about a phenomenon and so can act as a starting point for an emerging area of interest (25). Given the limited New Zealand specific research in the area of advance directives in the out of hospital setting justifies this approach.

Participants

A total of 18 urban Auckland based paramedics agreed to participate in the study. The gender composition was: thirteen male, four female and one person of undisclosed gender. Inclusion criteria were that participants were working paramedics in the Auckland metropolitan area. Paramedics from other areas of New Zealand or who were undertaking studies toward paramedic qualifications were excluded from the study. The participants' paramedic experience varied, with eight having more than 10 years' experience in the ambulance service, seven having 5–10 years, and two with less than 3 years' experience. Twelve were aged more than 30 years and four were aged less than 30 years, with one choosing not to disclose their age. The participants comprised of four EMTs, three ILS, 10 ICP and one participant who chose not to disclose this information.

Instrumentation

The Vx is an educational web-based decision-making tool that provides users with a framework for working through complex practice based ethical issues. The tool facilitates semi-structured in depth decision-making using a series of interactive screens based on established ethical theory and key contextual considerations (26). Its format and philosophy provides users with prompts for critical thinking and opportunities to explain the relevance and weighting of chosen ethical concepts. Importantly, the Vx recognises the role of both evidence and values in the decision-making process.

Procedures

The first part of the Vx process is that participants are asked to consider a case scenario. The following scenario was presented:

Mr Jones, 79 years of age, lives at home with his wife Mrs Jones. Mr Jones has chronic obstructive airways disease that limits his activity. Mr Jones phones the ambulance because he is struggling to breath and his wife is not home. When you and your crew partner arrive you find Mr Jones collapsed on the floor, cyanosed and not breathing. You and your partner start CPR. The defibrillator is connected, coarse ventricular fibrillation (VF) is noted and you defibrillate – he remains in coarse VF. Half way through the 2-minute cycle of CPR Mrs Jones arrives home and becomes obviously distressed and asks you to stop CPR. Mrs Jones says that her husband had made it clear to her that he would never want to be resuscitated.

The Vx then asked participants to decide whether or not they agree with the proposal that they continue CPR. Once they either agreed, strongly agreed, disagreed or strongly disagreed, the Vx asked participants who they believed was the most important stakeholder in the scenario. This could be the patient, the patient and their family, the profession, wider society or the participant. The Vx then guides participants to complete a more detailed and in depth deliberation of the scenario via two main screens: the Reactions and the Reasons screens. Using a combination of free text and structured interactive components, the Reactions screen requires users to consider and prioritise a set of pre-determined value concepts (dignity, law, rights, risk, your emotion and your role) and to justify their selections (Figure 1).

When completed, users then move to the Reasons screen (Figure 2), in which participants are given the opportunity to expand their thinking. Using a range of theoretical ideas as well as other contextual factors, such as the users own experience and the available evidence, this screen facilitates development of an argument for the position they have taken on the scenario, as well as considering alternative ways to resolve the issues.

Data analysis

Upon completion of any Vx case deliberation, users gain instant access to reports that show their own and others' responses to the scenario. The Vx has the capacity to generate a number of reports that can be initiated by any case responder. In this study, the researchers exported basic quantitative data reflecting demographic information, agreement status and cumulative weightings of key value concepts. Throughout the deliberative process users are invited to add justifications for each of their choices, providing a rich database of qualitative data for analysis. These data representing participants' free text responses underwent manual thematic analysis to ascertain the breadth of views on advanced directives and identified underlying values. Thematic analysis, unlike content analysis, usually involves both manifest and latent content with description and interpretation inseparable (27). Using Braun and Clarke's six step process (28) for the qualitative analysis, the researchers became familiar with the data, generated initial codes, searched for themes, reviewed themes, defined themes and produced a report; a method previously used to successfully analyse Vx data (18,20,21). To minimise bias and ensure validity, the data was analysed independently by all researchers and agreement reached. Potential themes were noted and significant points of difference identified with continual refining and crystallising of themes.

Figure 1. Reactions screen

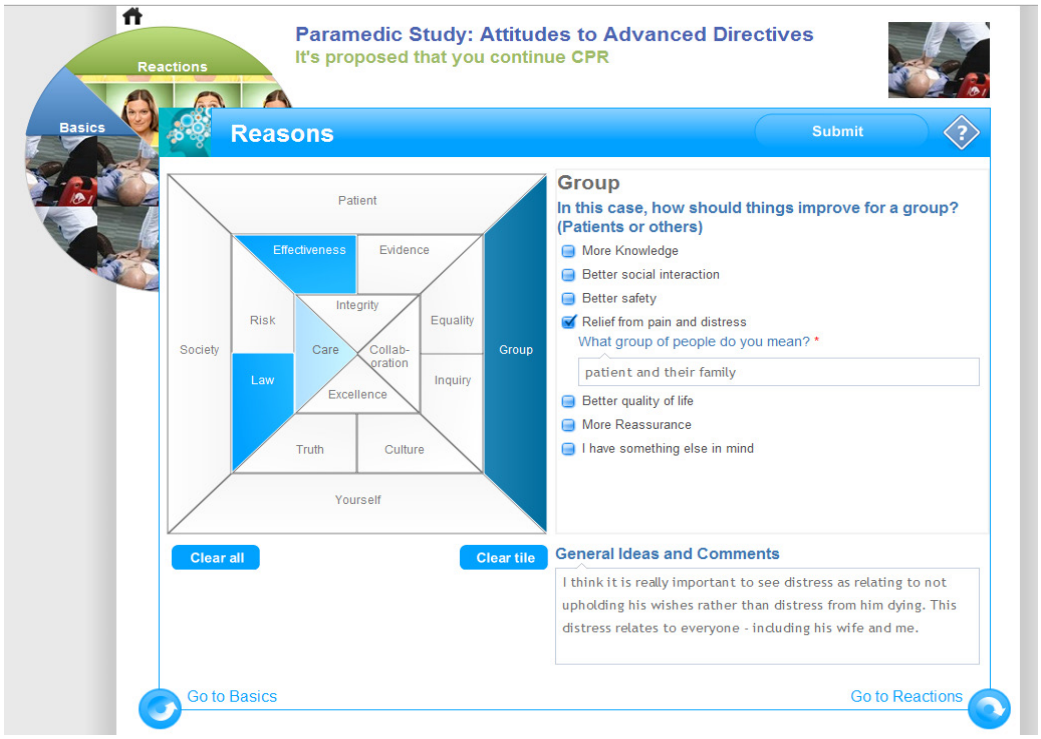

Figure 2. Reasons screen

Ethics

The study was approved by AUTEC, AUT University's ethics committee and registered with St John.

Results

Of the 18 participants six agreed or strongly agreed with the proposal that in this scenario they would continue CPR, while 12 disagreed or strongly disagreed. As part of their deliberation using the Reactions screen, the participants based their arguments on a mix of key ethical concepts (Figure 3). For those who agreed with the case proposal, 'Law' was slightly more prominent than the other key concepts, while 'Rights' was of greatest consideration for those who disagreed with continuing CPR (Figure 3). Overall, the weighting given to the key concepts by the participants was similar for all proposal positions.

In addition to the quantitative data reports from the Vx, manual thematic analysis of participants' free text responses ascertained the breadth of views on advanced directives and identified underlying values with three dominant themes emerging:

1. Legal tensions: clarity and fears
2. Enduring and multiple constructs of dignity and rights
3. Seeking solutions that support paramedic clinical practice.

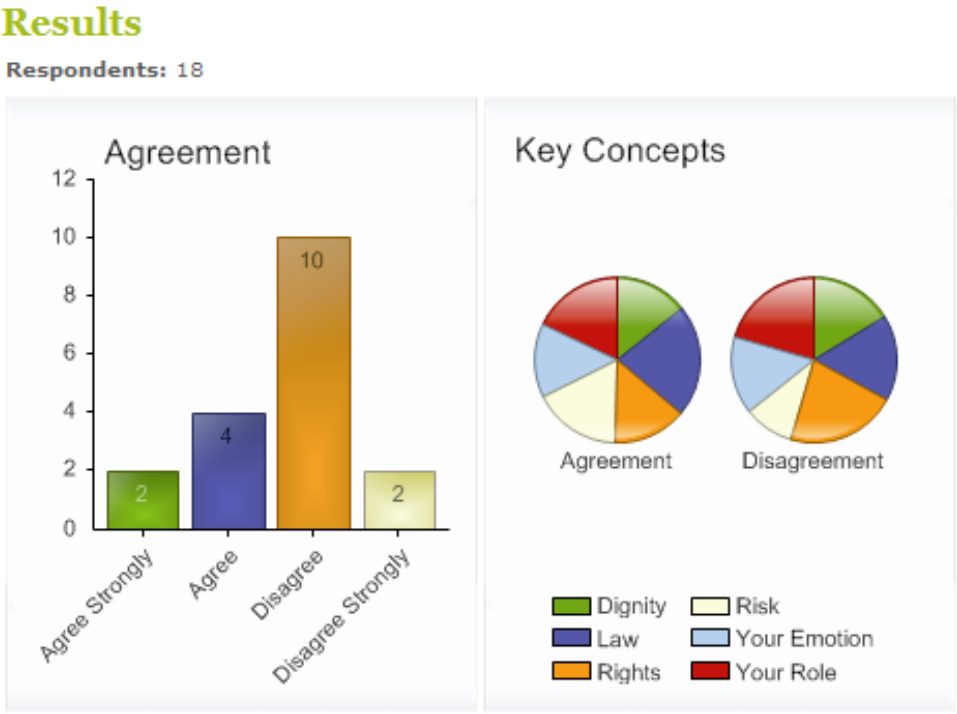

Figure 3. Results overview as generated by the Vx

Discussion

Legal tensions: clarity and fears

All health providers face complex ethical situations. For paramedics, decisions must often be made with urgency. Sandman and Nordmark suggested that there is a 'lack of in-depth discussion of ethical issues in the pre-hospital emergency field' (29, p.593). When paramedics experience urgency, they may rely on existing standards of practice or personal judgements rather than explicit ethical frameworks or the law (30). In addition, professional protocols may provide insufficient guidance about the 'right' way to respond in complex emergencies. Legal guidance, which may offer optimal help with the luxury of time, may in fact create tensions and fears within the time constraints of the pre-hospital emergency environment. It may also be possible that even if the law was clear the issues raised in such end-of-life decisions may still be conflicting for paramedics. As Gillet notes, 'A patient's advance directive confronts a clinician with a quasi-legal document of uncertain status in different jurisdictions and therefore a challenge to her or his clinical acumen and skill' (31, p.751).

Our participants did look to the law for guidance in the field, with some finding clear and certain guidance about how it guided them to respond in this scenario.

'The right to accept or decline treatment is law' (paramedic 17).
'The Health and Disability Commissioner has these rights to protect consumers and providers. Patients have the right to choose whether they be resuscitated or not' (paramedic 18).
'There is a legal requirement for us to follow the wishes of the patient' (paramedic 34).

However, while all 18 participants chose 'Law' as a key concept within their Vx deliberation, not all participants felt this certainty and three clear areas of concern were expressed: a desire for legal clarity; tensions between law and ethics; and fears and consequences.

Despite a desire to adhere to the law, and initial confidence in locating and understanding the law, some participants noted that the guidance on advanced directives lacks clarity. Describing the law as 'grey', several paramedics in this study wanted the law to offer more definitive guidance.

'I feel uncomfortable about this case, because it seems to be such a grey area, where we are given very limited guidance on what to do as a paramedic, even though we are exposed to situations like the above very frequently' (paramedic 2).
'Anything short of having a written directive/signed DNR is complicated' and that without this level of clarity the situation was 'not clear legally' (paramedic 17).

'Ideally the patient would have their advance directives noted in advance' (paramedic 13).

However, looking to the law for guidance was not the focus of all participants. While paramedics recognised the role of the law to guide practice decisions in some situations a broader lens may be beneficial, indicating a tension between the law and other ethical considerations.

'The crew have blindly started CPR as 'per the guidelines' and need to be able to step back and look at the bigger picture of what is right for the patient and partner' (paramedic 1).

The participants gave a clear sense that, at times, the law may not guide the paramedic to make what they see as the 'right' decision. For example, the following response indicates that the participant considers that what is legal is not always right:

'The proposal is legal in that implied consent applies here, however it is also not the right thing to do' (paramedic 1).

Another participant also identified this tension:

'Legal issues are a concern, however the patient's views are my primary concern' (paramedic 13).

The lack of legal clarity was associated with fears and consequences for the participants. This created an emotional tension and impacted on the paramedics.

'I think the law around advanced directives needs addressed. Taking a DNR verbally from a relative places a lot of stress on a paramedic. It's hard to say whether (the family members) they are in fact telling the truth or not' (paramedic 18).

A lack of legal clarity seemed to also elicit unrealistic and unfounded fears about legal consequences.

'Anything short of having a written DNR is complicated… possible potential for lawsuit?' (paramedic 17).
'The follow on effect of an undesirable outcome… may reflect on our practise and subject us to lawsuits and loss of practising ability' (paramedic 18).

New Zealand's unique legal health care environment established by the 'no fault' Accident Compensation Act means that litigation, while a possibility, is highly unlikely (32). To date we could find no evidence within New Zealand of a paramedic being subject to litigation relating to their clinical practice, yet some participants had a clear perception that they were at risk of legal consequences.

There are documented advantages of rule-based decision-making. Avery describes deontological principles as being 'the cornerstone of health care ethics' (33, p.31). Having rules to follow, whether laws or professional codes of ethics, provides a consistent framework that helps to ensure predictable outcomes, a universal law that must be adhered to without exception (26,34). However, our participants' responses reflect one of the main disadvantages of this approach: which takes primacy if there is more than one set of rules to follow? When faced with the law and our own sense of 'right' action, deontology fails to guide, leaving the paramedic to decide which principle or set of rules to follow. Despite attempts for the law to offer clarity, participants seem to have perceived their primary duty as respecting dignity over adherence to the law. This is in line with findings by Sherbino et al (8) who found that a significant number of Canadian EMS personnel were comfortable upholding DNR orders in the absence of regulations permitting such actions.

Enduring and multiple constructs of dignity and rights

Participants identified upholding the dignity and rights of the patient and their family as key factors associated with the case. Upholding dignity and rights is congruent with the Kantian Categorical Imperative: 'One must act to treat every person as an end and never as a means only' (35, p.345). In particular, participants emphasised the importance of preserving patient dignity in end-of-life care. Fifteen paramedics chose 'dignity' as a key concept and several paramedics referred to the need to extend respect for dignity beyond life.

'We preserve peoples dignity when treating live patients, this should not cease with their death' (paramedic 17).
'Dignity is essential for all patients but especially in end-of-life cares' (paramedic 13).
'The right for a patient to make a choice about the care they receive is incredibly important even in death' (paramedic 15).

A recurring aspect to this theme was the indignity for the patient of an inappropriate resuscitation, and that the paramedic should enable the patient to die with dignity. To that end, dignity may not be confined to an abstract notion of upholding the patient's supposed refusal of treatment. Dignity may also mean that people are not subject to futile traumatic procedures.

'Let the patient die with dignity' (paramedic 1).
'I feel strongly that there should be dignity in dying and that at times doing nothing for the patient is best for them' (paramedic 21).
'… ensuring that CPR does not just prolong the dying process' (paramedic 4).
'The indignity of inappropriate resus or watching, knowing that it was against the persons wishes' (paramedic 17).
'The emotional stress and distress that witnessing a loved one undergo an invasive procedure such as a resuscitation attempt when you know it is against their wishes' (paramedic 28).

Findings by Bremer et al (6) that saving the patient's life as first priority was not confirmed by this study, with New Zealand based paramedics centring their decision-making on upholding patient dignity, open to the possibility that not saving the patient's life was sometimes the most dignified outcome. Gillett describes the common misconception among health professionals that they have a duty to always save a life, where possible. The standard of best interests, based on societal norms of a tolerable and worthwhile life, is ambiguous, but serves 'to mitigate an aggressive life at all costs stance' (31, p.753). The philosophy of acting in the patient's best interest is commonly visible in the paramedics' responses, although 'best interests' is not well defined.

'My role is to provide a service I consider to be in the best interest of the patient' (paramedics 1, 2, 20 and 25).
'… establish the facts and act in the best interests of the patient rather than giving in to emotion' (paramedic 18).
'Working in a professional team to define and act in the best interest of the patient' (paramedic 19).

While other studies (6,7) reported instances where personnel justified futile CPR for the sake of the family, respondents in this study prioritised patient wishes over the interests of others.

Contemporaneous consent from the patient is generally impossible to obtain in the setting of cardiac arrest (36). In the absence of a written advance directive the participants explain that in such situations the paramedic may have to rely on the veracity of the relatives to convey the patient's wishes.

'We have to trust that the wife is accurately conveying the patient's wishes with no ulterior motive' (paramedic 17).
'It is possible that the wife... may indeed be telling the truth' (paramedic 18).

The paramedics' concern over accepting the relative's account of the patient's wishes was focused on enabling the patient's right of self-determination. In this case, the patient called the ambulance for help prior to collapsing. No respondent suggested that this act implied the desire for resuscitation, accepting the wife's account of the patient's wishes of not wanting to be resuscitated as creating the complex decision-making situation.

One tension associated with a surrogate or relative describing the inclination of the patient is that the surrogate may not necessarily be expressing the wishes of the patient. Studies have shown that a significant proportion of decisions by surrogates do not align with the desires of the patient; some surrogates prefer extraordinary life saving measures in the face of the death of a loved one and so are not promoting the patient's autonomy (4,37-39). The converse is also a possibility in that an unscrupulous relative may purposefully misrepresent the medical preferences of the patient for self-gain, devaluing the consent process and not respecting the patient's autonomy.

Seeking solutions that support paramedic practice

Avery (33) describes a common paradox for health practitioners in which they are faced with two conflicting paradigms: on the one hand their professional training is heavily influenced by deontological principles, however their practice reality requires them to consider the consequences of their actions. Participants recognised this complexity by communicating within their responses that there was a need for additional guidance to assist in situations concerning advance directives.

'We are given very little guidance on what to do as a paramedic, even though we are exposed to situations like the above very frequently' (paramedic 2).

In keeping with the known problem-solving nature of the profession, many of the paramedics suggested potential ways forward with respect to advance directives.

In line with findings other studies in the literature (8), participants' recommendations included suggestions for improved concrete guidance in the form of greater emphasis on written documents.

'Anything short of having a written directive/signed DNR is complicated' (paramedic 17).
'Formal written documents should be provided. This then protects crews and patients from any adverse events. We need a legally binding DNR signed by the patient who was legally competent' (paramedic 18).

Better methods of informing responders of the patient's wishes were suggested, such as tattoos or medic alert bracelets. These were also similar to suggestions reported by Sherbino et al (8). Other participants in this study suggested increased debate on the issue of advance directives with discussions to include the views of professional colleagues, and the public with one participant stating that:

'Talking to patients and their families was important as they would potentially benefit from end-of-life plans' (paramedic 28).

Including the public was also seen as a useful strategy by Marco et al (40), who argued that this would not only help guide policy development but may also lead to increased numbers of the public having a personal advance directive in place.

A further group of participants reported that guidance needed to come from further education for those working in the ambulance service. In particular increased education in the areas of health law and ethics was suggested with the goal to further develop reasoning skills.

'Clarity around the [legal] issues for the inexperienced' (paramedic 20).
'[A] research project needs to be initiated looking into paramedic understanding of health law and ethics' (paramedic 34).

Further research

Findings in this study indicate the need to replicate this study with participants from rural paramedic practice in order to build a fuller picture of advance directive decision-making processes across the New Zealand ambulance sector. The structure and delivery of pre-hospital care in New Zealand includes a significant rural sector, with a broad range of qualifications represented and, in particular, a higher proportion of volunteer staff, forms an integral part of the ambulance service and as such the perceptions of its crews will add a further layer of understanding to this aspect of paramedic practice.

Limitations

The sample size in this study was small and this may be seen as a limitation, although generalisability was not part of the methodology. Because the study focused on urban-based paramedics the demographics and qualifications of participants may not be representative of the sector as a whole. In addition, participants were presented with a hypothetical scenario. While this was peer reviewed for authenticity, it is unknown to what extent participants would act in the same way, if faced with the scenario in practice.

Conclusion

This small qualitative study has demonstrated not only the complexity around advance directive decision making but has also illuminated the critical thinking undertaken by urban based paramedics when considering end-of-life care situations. While the law was looked to for guidance, our participating paramedics based their decision-making on upholding and preserving patient dignity. Of particular relevance to participants was the value of dignity beyond

life, a state where the realm of current advance directive law does not extend and raises questions about how dignity can be upheld both during and after death in the pre-hospital emergency care context.

With limited research that focuses on paramedic practice in New Zealand, this study, while not generalisable, illuminates paramedic concerns about advanced directives in the emergency care setting, and through the use of the Vx, demonstrates the ability of paramedics to engage in robust, thoughtful consideration of ethically complex end-of-life decisions. The study also highlights a call for further education for the sector. Participants described discomfort and insecurity stemming from a lack of guidance and called for greater debate, clearer laws, and further education for paramedics in health law and ethics.

It is hoped that with further research a clearer picture of advance directives will continue to emerge with the ability to inform professional education and sector guidance for contemporary pre-hospital care in the New Zealand health care environment.

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Conflict of interest

The authors declare they have no competing interests. Each author of this paper has completed the ICMJE conflict of interest statement.

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