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## Paramedics' perceptions and educational needs with respect to palliative care

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## Research

# Paramedics' perceptions and educational needs with respect to palliative care

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## Abstract

### Introduction

In recent years the scope of palliative care has been redefined to include patients earlier in the course of their illness, and those suffering from life-limiting conditions. Paramedics may be involved in the care of these patients, especially in situations of carer distress, sudden deterioration and imminent death, as well as in non-emergent situations such as inter-facility transfers. In these scenarios, clinical decisions regarding patient care initiated by paramedics may set the trajectory for subsequent care.

### Objective

To identify and measure paramedics' perspectives and educational needs regarding palliative care provision, as well as their understanding of the common causes of death.

### Methods

All St John Ambulance Western Australia paramedics were invited to complete a mixed methods qualitative and quantitative survey using a tool previously validated in studies involving other emergency care providers. Quantitative results are reported using descriptive statistics, while Likert-type scales were converted to ordinal variables and expressed as means +/- SD. Qualitative data was analysed using content analysis techniques and reported as themes.

### Results

Twenty-nine paramedics returned completed surveys. They considered palliative care to be strongly focused on end-of-life care, symptom control and holistic care. The dominant educational needs identified were ethical issues, end-of-life communication and the use of structured patient care pathways. Cancer diagnoses were overrepresented as conditions considered most suitable for palliative care, compared with their frequency as a cause of death. Conditions often experienced in ambulance practice, such as heart failure, trauma and cardiac arrhythmias were overestimated in their frequency as causes of death.

### Conclusions

Paramedics have a sound grasp of some important aspects of palliative care including symptom control and the holistic nature of the palliative approach. They did, however, tend to equate palliative care with care occurring in the terminal phase and saw it as being particularly applied to cancer diagnoses. Paramedic palliative care educational efforts should be focused on: ethical issues, end-of-life communication, increasing understanding of the common causes of death, and education regarding those illnesses where a palliative approach might be beneficial.

### Keywords:

paramedicine; palliative care; end-of-life; paramedic

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## Introduction

Historically, a palliative care approach was typically considered appropriate only for patients with advanced malignancy. However, in recent years the scope of palliative care has been substantially redefined to include patients earlier in the course of their illness and those suffering from any life-limiting condition(s) including heart, respiratory, renal and neurodegenerative diseases (1). Paramedics may well be involved in the care of such patients, especially in situations of carer distress, sudden deterioration and imminent death, as well as in non-emergent situations such as inter-facility transfers. In each of these scenarios, clinical decisions regarding patient care initiated by paramedics may set the trajectory for subsequent care. To help equip paramedics to manage the complex physical and psychosocial needs of such palliative patients and their families it is necessary to first understand the knowledge, skills and attitudes of paramedics with regards to palliative care.

Increasingly, palliative care is being recognised as an important skill for emergency care providers more broadly (2-6), and the perspectives of Australian emergency department (ED) staff in providing palliative care have recently been explored (7-8). Research focused on pre-hospital emergency care providers is limited and mostly deals with end-of-life issues (9-11) including moral and legal issues related to withholding resuscitation (12-13) and advance or present directives (14-15). One study, using a focus group methodology, explored Australian paramedics' knowledge and attitudes related to the care of patients requiring palliative care (15). This report noted that paramedics lacked practice guidelines for palliative care, education in palliative care, and awareness of available palliative care and community support services. Managing family dynamics, conflicts in care goals, legal concerns and time constraints were also cited as significant challenges (15). These issues, together with paramedics' concerns about deviating from organisational policies (15) may limit their ability to provide effective care to palliative patients.

We have recently reported a study with Australian ED staff (7) exploring issues in palliative care provision. Using a similar methodology the primary aim of this study was to identify Australian paramedics' perspectives and educational needs regarding palliative care provision. Secondary aims were to investigate paramedics' views about death and dying, their awareness of common causes of death in Australia, and opinions as to those for which a palliative approach is appropriate.

## Methods

### Study design

A qualitative and quantitative mixed method approach using an online survey.

### Setting

St John Ambulance is the sole provider of road-based emergency ambulance services to the geographically isolated

state of Western Australia. A combination of paid and volunteer ambulance officers serve a population of more than 2.5 million people (16) and cover a land area of 2,526,786 square kilometres (17).

### Survey administration and content

The study used a previously validated survey tool adapted from Eagar and colleagues, 'The palliative care evaluation toolkit: a compendium of tools to aid in the evaluation of palliative care projects' (item 2.1) (18). This tool was subsequently used in a palliative care study involving Australian ED staff (7), the report of which describes the methodology in detail. The survey tool comprises three major domains: patient/family interactions and clinical management, views about death and dying, and attitudes towards palliative care. The multiple items within each domain are addressed by either 4-point (ranging from need further basic instruction to confident to perform independently) or 5-point (disagree strongly to agree strongly) Likert scale-style responses.

Demographic questions regarding ambulance officer role, clinical experience and specific palliative care training were included. Respondents were also asked to respond to the open-ended question: 'What do you understand by palliative care?' and had the opportunity to identify areas in which they would like further education from a list of education topics with space for 'other' topics to be included. Further, respondents were asked to nominate what they believed to be the five most common causes of death in Australia by choosing from an alphabetical list of the 20 most common causes as reported by the Australia Bureau of Statistics (19). They were also asked to nominate the five causes of death that they considered most appropriate for a palliative approach to care. Space for additional free text comments was provided at the end of the survey.

The clarity, validity and apparent internal consistency of the survey content were assessed through a pilot involving eight paramedics. A minimum consensus of 70% was achieved for the majority (n=35) of the 43 scale response items. Of the eight items that did not achieve consensus, two were modified to improve clarity. The other six items were considered by respondents to be outside of the scope of paramedic practice. They were, however, retained in the survey tool because the authors considered it conceivable that paramedics are exposed to these issues in their work and it was thought relevant to seek their views in these areas.

### Participants and recruitment

Paramedics employed by St John Ambulance Western Australia between June and September 2014 were invited to participate in the survey. All the estimated 800 potentially eligible respondents received an invitation within a monthly e-bulletin. This invitation to participate contained a participant information sheet with a hyperlink to the Survey Monkey™ study tool. In addition, senior clinical support paramedics gave verbal reminders. Participation was voluntary and anonymity was guaranteed as no personal identifying data was recorded. Consent was implied by questionnaire completion.

## Data analysis

Descriptive statistics were used to describe demographic variables. Likert-type scale responses were translated into ordinal variables and mean values calculated. All analyses were completed using SPSS software (Version 22.0, Armonk, NY, IBM Corp). For qualitative data, open-ended responses were transcribed verbatim and analysed using content analysis techniques. In this content analysis process, text responses were coded into areas, themes and sub-themes to detect patterns and consistencies. Two researchers working independently, who then conferred to resolve any discrepancies, performed this process.

## Ethics

The research protocol was approved by the Human Research Ethics Committees of St John of God Health Care and Curtin University.

## Results

There were 29 respondents to the survey, of whom 21 (72%) were male. The mean and median age of the group was 38 years. All respondents were salaried ambulance officers and most (25 of 29) worked in a metropolitan setting. Four (14%) respondents had been qualified as a health professional for less than 2 years, 14 (48%) between 2-5 years, and the remaining 11 (38%) for more than 5 years. Respondents rated their palliative care knowledge as either 'limited' (39%) or 'working' (61%), with none reporting 'extensive' knowledge. Despite this,

one respondent reported their highest level of palliative care training to be at a post-graduate diploma level.

In response to the open text question: 'What do you understand by palliative care?' content analysis reached early saturation with the dominant themes identified as symptom control, end-of-life care and holistic care. Identified factors are listed in Table 1.

Factor	N (28)
End-of-life care	18
Symptom control	18
Holistic care	15
Expanded treatment unit including family	6
Withdrawing active treatment	6
Across an extended illness time course	4
Life threatening illness	2

Table 1. Responses to the question: 'What do you understand by palliative care?' As a free text response each respondent's answer could include multiple identified themes

With regard to patient/family interaction and patient management topics as assessed on a 4-point Likert scale (from 'need further basic instruction' = ordinal score of 1 to 'confident to perform independently' = ordinal score of 4), the greatest confidence was expressed for 'supporting the patient or family member when they become upset', and the least confidence for 'informing people of the support services available' (see Table 2).

Statement	Mean	SD
Answering patients' questions about the dying process	2.38	1.39
Supporting the patient or family member when they become upset	3.38	0.53
Informing people of the support services available	1.86	0.91
Discussing care environment (eg. hospital, home, family)	2.10	1.24
Discussing patients' wishes for after their death	2.62	1.53
Answering queries about the effects of certain medications	2.41	0.89
Reacting to reports of pain from the patient	3.28	0.78
Reacting to and coping with terminal delirium	2.52	1.47
Reacting to and coping with terminal dyspnoea	2.93	1.28
Reacting to and coping with nausea/vomiting	3.28	0.92
Reacting to and coping with reports of constipation	2.69	1.44
Reacting to and coping with limited patient decision-making capacity	2.83	1.29

Table 2. Likert (4-point) scale responses to patient/family interaction and patient management topics

With regard to views about death and dying as assessed on a 5-point Likert scale (from 'disagree strongly' = ordinal score of 1 to 'agree strongly' = ordinal score of 5), the strongest agreement was for the statement 'families have the right to refuse a

medical treatment' while the strongest disagreement was for 'little can be done to help someone achieve a sense of peace at the end of life' (see Table 3).

Statement	Mean	SD
The end-of-life is a time of great suffering	2.00	1.00
Little can be done to help someone achieve a sense of peace at the end of life	1.38	0.74
The use of strong pain medication can cause the person to stop breathing	3.34	1.23
I am not comfortable caring for a dying patient	1.59	0.47
I am not comfortable talking to patients about death	1.66	0.38
When a patient dies I feel that something went wrong	1.66	0.38
Feeding tubes should be used to prevent starvation at the end of life	2.28	0.85
Hospitals are good places to die	2.97	1.53
Families have the right to refuse a medical treatment	3.97	1.53
Dying patients should be referred to a hospice or acute care	2.79	0.88

Table 3. Likert (5 point) scale responses to views about death and dying.

When assessing attitudes towards palliative care on a 5-point Likert scale (from 'disagree strongly' = ordinal score of 1 to 'agree strongly' = ordinal score of 5), strongest agreement was for the statement 'patients should have the right to determine

their own degree of medical intervention' while the strongest disagreement was for 'a patient should experience discomfort prior to receiving the next dose of pain medications' (see Table 4).

Statement	Mean	SD
Pain at the end-of-life is an inevitable part of the dying process	1.93	0.81
Pain medication should be given as needed to terminally ill patients	4.71	0.21
Spiritual care should include counselling the terminally ill patient	3.96	0.55
I do not like talking about death and dying with patients	1.82	0.45
Palliative care should be the standard medical treatment for patients who are suffering from terminal illness	3.89	0.64
Patients should have the right to determine their own degree of medical intervention	4.82	0.15
Addiction to oral morphine is not a serious issue given that terminally ill patients have a short time to live	3.61	1.21
Discussing end-of-life care should be deferred until there is no further effective curative treatment available	1.89	0.91
Estimation of pain by a paramedic is a more valid measure of pain than patient self-reporting	2.00	1.04
Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition such as cancer	4.21	0.40
Patients have a right to determine their own degree of psychosocial intervention	4.46	0.41
The most appropriate person to make end-of-life decisions is the patient's primary care provider	2.54	0.92
A patient should experience discomfort prior to receiving the next dose of pain medications	1.54	0.70
Patients should be maintained in a pain free state	4.29	0.43
As a rule, terminally ill patients prefer not to talk about death and dying	2.04	0.70

Table 4. Likert (5-point) scale responses on attitudes towards palliative care

The self-reported education needs of the 29 respondents are detailed in Table 5, with the three most frequently selected

topics being ethical issues, end-of-life communication skills and use of the Liverpool Care Pathway.

Education topic	N (%)
Ethical issues: NFR orders, advance care directives, patients decision making capacity	28 (96.6)
End-of-life communication skills: giving bad news, talking with family, discussing prognosis, discussing treatment options	23 (79.3)
Use of the Liverpool Care Pathway	19 (65.5)
Dealing with delirium	16 (55.2)
Use of intravenous hydration and/or non-oral feeding in end-of-life care	15 (51.7)
Dealing with breathlessness	13 (44.8)
Pain assessment and management	12 (41.4)
Spirituality and cultural aspects of end-of-life care	12 (41.4)
Dealing with bowel problems	11 (37.9)
Dealing with nausea and vomiting	10 (34.5)
Dealing with appetite problems	10 (34.5)
Dealing with insomnia problems	10 (34.5)

Table 5. Desired further education topics selected by respondents. Multiple responses were allowed

Described in Table 6 are the outcomes of the question regarding knowledge of the most common causes of death in Australian and respondents' judgement as to which of these causes of

death most warrant a palliative care approach. These are compared with those of the Australian Bureau of Statistics (ABS).

Cause of death	ABS ranking	Respondent ranking	Palliative approach ranking
Ischaemic heart disease	1	1	=13
Cerebrovascular disease	2	=2	=9
Dementia and Alzheimer disease	3	=5	=4
Trachea, bronchus and lung cancer	4	=5	1
Chronic lower respiratory diseases	5	4	8
Diabetes	6	=10	=16
Colon, sigmoid, rectum, anus cancer	7	=7	6
Blood and lymph cancer	8	=17	3
Heart failure	9	=2	11
Diseases of the urinary system	10	---	=16
Prostate cancer	11	=17	=9
Breast cancer	12	=15	=4
Influenza and pneumonia	13	=12	12
Pancreatic cancer	14	=15	2
Intentional self-harm	15	=17	=16
Skin cancers	16	=10	=13
Accidental falls	17	=7	=13
Hypertensive diseases	18	=12	---
Cardiac arrhythmias	19	9	---
Cirrhosis and other diseases of liver	20	=12	7

Table 6. Frequency ranking of causes of death, the actual frequency ranking according to the ABS, and respondents ranking of those conditions most suited to a palliative approach (= denotes conditions ranked equally by respondents, --- signifies no respondents selected this option)



## Discussion

This study suggests that paramedics have a sound grasp of some of the important aspects of palliative care. They expressed confidence in dealing with symptoms and with distressed patients and families, and understood the holistic nature of the palliative approach, encompassing physical, social, psychological and spiritual needs. Respondents believed that patients had a right to determine their own level of intervention but that active paramedic care could help in relieving pain and distress. Respondents did tend to equate palliative care with end-of-life and terminal care and cancer diagnoses. Such a focus and a lack of appreciation of the full spectrum of patients and diagnoses to which a palliative approach can be applied, has previously been reported by both emergency medicine clinicians (7) and paramedics (9,10). The greatest confidence was indicated in supporting the upset patient/family, reacting to reports of pain from the patient, and responding to and managing nausea and vomiting which are common and routine ambulance practice, irrespective of the patients underlying diagnosis and prognosis. Respondents over-estimated the frequency of certain causes of death, such as heart failure, trauma and cardiac arrhythmias, conditions commonly managed in ambulance practice.

Despite the small sample size, there are striking similarities in many of the responses to a study using a similar methodology among Australian ED medical and nursing staff (7). This is especially true of our study group's self-selected education needs, which focused on ethical issues, difficult end-of-life communication and the use of standardised patient care pathways. These higher ranking self-identified education needs in palliative care provision would form important parts of an education curriculum, where adult learners are known to learn most when they have already identified their own learning needs. Much of these areas are centred on the psychosocial needs of patients. This holistic approach to patient care is integral to contemporary palliative care practice and has recently been identified as a key issue in paramedic education (20,21).

The most obvious limitation of this study is the low response rate. This occurred despite a considered plan of study execution and anecdotal evidence that interest in this area was high among paramedic staff. While the response rate may represent a true lack of interest regarding this topic among paramedics, it is more likely that we chose a method of study promotion and enrolment that did not adequately capture our target population. Those who did respond are more likely to have a special interest or hold particular views about the paramedic practice/palliative care interface. The views our respondents hold are likely to be strong and this may be reflected in some of the polarised responses seen, such as those in regard to ethical issues and the patient's right to determine their own care.

## Conclusion

The research suggests that paramedics have some understanding of contemporary palliative care principles but that this can be further improved. The focus of educational initiatives for paramedics should be on understanding the common causes of death in, realising the potential broad applicability of a palliative approach, ethical issues and difficult end-of-life conversations. Emphasis should be given in educational initiatives to the applicability of palliative care in patient populations that paramedics might not otherwise identify as being suitable for such an approach.

## Acknowledgements

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## Conflict of interest

Ian Rogers is a member of the Board of St John Ambulance Western Australia and has been the (Acting) Clinical Director of St John Ambulance Western Australia since the death of Ian Jacobs. Judith Finn receives research funds providing partial salary support from St John Ambulance Western Australia. . Each author of this paper has completed the ICMJE conflict of interest statement.

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