

***The Thoughts and Opinions of Advanced Life Support
Providers in the South African Private Emergency
Medical Services Sector Concerning Pre-Hospital
Palliative Care***

by

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Abbreviations

AD: Advance Directive

AIDS: Acquired Immune Deficiency Syndrome

ALS: Advanced Life Support

CHF: Congestive Heart Failure

COPD: Chronic Obstructive Pulmonary Disease

COREQ: COnsolidated Criteria for Reporting Qualitative research

CPR: Cardio-Pulmonary Resuscitation

DNAR: Do Not Attempt Resuscitation

ECP: Emergency Care Practitioner

EMS: Emergency Medical Service

HE: Higher Education

HEMS: Helicopter Emergency Medical Service

HIC: High Income Country

HIV: Human Immunodeficiency Virus

HREC: Human Research Ethics Committee

ICU: Intensive Care Unit

LMIC: Low-to-Middle Income Country

MOLST: Medical Order for Life-Sustaining Treatment

NGO: Non-Governmental Organisation

RVD: Retro-Viral Disease

TB: Tuberculosis

UCT: University of Cape Town

UK: United Kingdom

USA: United States of America

WHO: World Health Organization

PART A: Literature Review

Background

The World Health Organisation (WHO) defines palliative care as *'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'*¹ This includes a wide variety of situations such as chronic illness and end-of-life care.²

Palliative care is usually performed in-hospital. However, emergency medical services (EMS) often encounter patients requiring palliative care as these patients may have acute exacerbations of illness, progress towards end-of-life or require transport to a medical facility.³⁻⁹ Thus, there is a role for palliative care in the pre-hospital setting. EMS providers are uniquely positioned to deliver this care in the pre-hospital setting as they are often the first point of medical contact.¹⁰ This has great potential benefit for patient comfort, early identification and relief of suffering and earlier referral to hospice care.^{10, 11}

Despite this unique position there is an overall lack of guidance within EMS systems to manage palliative patients.^{5, 6, 10} In the United States of America (USA), for example, only 5-6% of EMS systems have protocols for palliative care.^{6, 10} In addition, there is no specific pre-hospital emergency care curricula on the subject, resulting in a lack of education and training for EMS providers.^{3-5, 12, 13} This may stem from the historical focus of EMS training which primarily involves immediate measures to preserve life or limb until definitive care is reached.¹¹ This focus has resulted in an EMS ethos of 'saving lives.'^{5, 12} Palliative care, on the other hand, is not focussed on 'saving lives', but rather the prevention and relief of suffering.¹ Therefore, palliative care may seem to conflict with emergency care, placing EMS providers in difficult situations when confronted with palliative care patients.^{8, 12, 14}

South Africa itself faces what has been termed a "quadruple burden of disease" due to communicable diseases such as HIV/AIDS, high maternal and paediatric mortality rates, non-communicable disease as well as injury.¹⁵ The large number of patients suffering from these diseases and the life-limiting complications thereof, results in increased need for palliative care in the country as noted by the South African Minister of Health.¹⁶

Access to health care for patients suffering from these diseases is a further challenge in the Sub-Saharan African setting.^{17, 18, 19} In South Africa, EMS are often contacted

by those without access to transport to provide this service.²⁰ Thus, South African EMS providers may frequently encounter not only high acuity emergency patients, but many ill HIV/AIDS, cancer and other chronically ill patients requiring palliative care who are unable to access healthcare via alternative means.²¹ European studies have found that approximately 3-5% of all pre-hospital calls involve palliative care situations.^{2, 22,}²³ With the quadruple burden of disease and limited access in the South African setting, this percentage is likely higher as these factors result in increased frequency of contact between EMS providers and patients requiring palliative care.

Although EMS providers in South Africa manage palliative patients in the prehospital setting, to our knowledge, no research has been produced in the (South) African setting regarding prehospital palliative care. Outside of Africa literature has been produced but is limited. This literature review discusses paramedic perceptions of prehospital palliative care, prehospital palliative care patient management and legislation concerning prehospital palliative care. Finally, expert opinion pieces and recommendations are reviewed.

Objectives of Literature Review

The objectives for the literature review of this study are as follows:

- To identify literature relevant to the prehospital context regarding palliative care.
- To identify what literature has been produced within South Africa and abroad on the topic of prehospital palliative care.

Literature Search Strategy

The search strategy defined below is accurate as of 18 November 2019. The literature search was performed using various combinations of Boolean operators and medical subject heading (MeSH) terms as well as generic topic searches on PubMed as follows:

- String 1: (Emergency Medical Services [MeSH] OR Emergency Medical Technicians [MeSH]) AND (Palliative Care [MeSH] OR Palliative Medicine [MeSH])

- String 2: (Emergency Medical Services [MeSH] OR Emergency Medical Technicians [MeSH]) AND (Hospice Care [MeSH] OR Terminal Care [MeSH])
- String 3: PubMed search for '*prehospital palliative care*'
- String 4: PubMed search for '*paramedic palliative care*'

Filters activated for each search were language (English), year of publication (2000-2019) and studies performed with human subjects. Articles were selected for inclusion based on relevance of their titles. After review of the abstracts and full texts of these articles those which were irrelevant were excluded. Additional relevant articles were identified from the reference lists of included articles. Figure 1 outlines this process while Table 1 provides overviews of the selected articles.

Figure 1 – Search Strategy

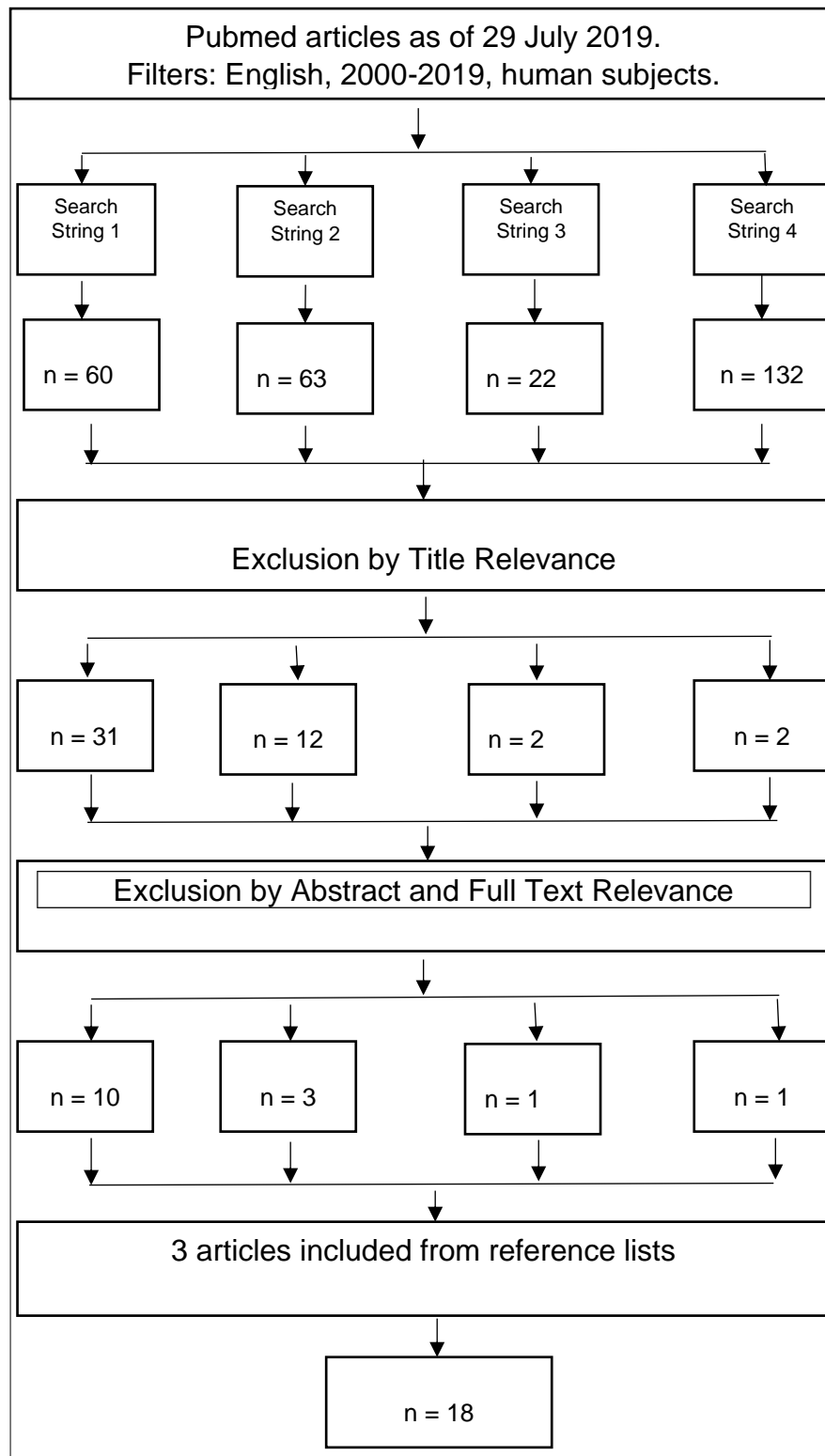


Table 1 – Article Overviews

Paramedic perceptions of prehospital palliative care				
Title	Study Type	Sample Size	Conclusions	Limitations
<i>Paramedics' Perceptions of Their Role in Palliative Care: Analysis of focus group transcripts</i> ¹²	Qualitative Focus Group Interviews	3 focus group interviews involving total of 26 paramedics	Key themes which arose: conflict in care goals, legal problems, lack of information, system problems. Further research suggested for education, guidelines and defining roles of paramedics in palliative care patient management.	Low response rate possibly resulting in an unrepresentative sample. Small sample size.
<i>Prehospital Providers' Perceptions of Emergency Calls Near Life's End</i> ⁵	Descriptive Cross-Sectional Survey	178 prehospital providers	There is synergy between prehospital and palliative medicine, however, further research is needed to develop and test prehospital end-of-life decision-making interventions as well as understand how prehospital providers operate when confronted with palliative situations.	Participant information recall and perception. The study as performed with a convenience sample at one institution.

<p><i>“We Are Strangers Walking Into Their Life-Changing Event”: How Prehospital Providers Manage Emergency Calls at the End of Life</i>⁷</p>	<p>Qualitative One-on-one Interviews</p>	<p>43 prehospital providers</p>	<p>Four main themes: multifocal assessment involving family, patient and surroundings, emotional family responses, conflict between family, patient and practitioner and management of the dying process. Results suggest need for increased ability of prehospital providers to uphold advance directives and patient wishes at end of life.</p>	<p>Participants from a single agency. Participants lacked diversity.</p>
<p><i>Paramedics’ perceptions and educational needs with respect to palliative care</i>¹³</p>	<p>Mixed Methods Survey</p>	<p>29 paramedics</p>	<p>Paramedics have a good grasp of what palliative care entails. They particularly identified terminal cancer patients as palliative. Paramedic education is needed in end-of-life communication practices, ethical issues and illnesses requiring palliation.</p>	<p>Low response rate and small sample size. Participants may be those with strong opinions/feelings.</p>
<p><i>Paramedics and their role in end-of-life care: perceptions and confidence</i>¹⁴</p>	<p>Descriptive Online Survey</p>	<p>182 paramedics</p>	<p>Paramedics saw end-of-life care as essential to their functions. Fear of litigation and conflict with patient</p>	<p>No way to verify participants’ experience and qualifications. Low response rate.</p>

			family members were identified as challenges in providing palliative care. Education needed for paramedic confidence in managing these cases.	
<i>Paramedics providing palliative care at home: A mixed-methods exploration of patient and family satisfaction and paramedic comfort and confidence</i> ²⁴	Mixed Methods Survey	Part A: 67 pre-paramedic encounter surveys and 18 post-paramedic encounter interviews from patients/families. Part B: 235 pre-implementation surveys and 267 post-implementation surveys.	After the implementation of the programme in this study, training and implementing of a new clinical guideline paramedic comfort and confidence in performing palliative care improved. In addition, paramedics found palliative care to be important and rewarding. Patient and family satisfaction with receiving palliative care from paramedics was high.	Small sample of two provinces in Canada. The possibility of self-selection bias exists.
Prehospital palliative care patient management				
<i>Palliative Care and Prehospital Emergency Medicine</i> ⁴	Retrospective Case Series Analysis	4 cases	Palliative and prehospital emergency care may be complimentary approaches. The cases analysed show the need for palliative care education for prehospital emergency	Limited review of only 4 cases. Findings and suggestions open to author biases and interpretations.

			teams and the need for improved collaboration between EMS and palliative care systems.	
<i>Treatment of oncology patients in the final stadium of disease by prehospital emergency physicians</i> ²³	Retrospective Observational	2765 EMS calls	2.5% of calls were for cancer patients requiring emergency assistance. Cooperation of emergency and palliative systems appears necessary in these situations. This would allow for patients to stay at home. Palliative and emergency medical curricula should be combined in relevant areas to implement palliative strategies in the prehospital field.	Prospective data needed. Findings may not apply to a paramedic-based prehospital system.
<i>Prehospital emergency treatment of palliative care patients with cardiac arrest: a retrolective investigation</i> ³	Retrospective Observational	88 patients	Approaches to prehospital palliative patients in cardiac arrest differ depending on EMS provider qualification. Many resuscitations initiated against patient wishes due to lack of advance directive or end-of-life protocol. Advance directives and 'do not	Small sample size. Limited due to retrospective nature.

			attempt resuscitation' orders should be more readily available and adhered to.	
<i>National Prevalence of Palliative Care Protocols in Emergency Medical Services</i> ⁶	Retrospective Observational Survey	121 EMS Agencies	5.8% of EMS Agencies have palliative care protocols. Thus, there is a lack of EMS palliative care protocols in the USA.	Only a 60.5% response rate. In addition, some protocols cover entire states and not just cities. Thus, EMS palliative care protocols may be more widespread than 5.8%. 'Palliative Care Protocol' was not defined.
<i>Quality of out-of-hospital palliative emergency care depends on the expertise of the emergency medical team – a prospective multi-centre analysis</i> ²²	Prospective Observational	361 emergency calls	Treatment of prehospital palliative care patients improves when prehospital physicians have palliative care expertise. Education in prehospital palliative care recommended.	Conclusions are specific to the German physician based EMS system and not necessarily paramedic based systems.
Prehospital palliative care legalities				
<i>Prehospital withholding and withdrawal of life-sustaining treatments. The French LATASAMU Survey</i> ²⁵	Retrospective Cross-Sectional	1069 prehospital physicians from 192 emergency mobile units	Withholding and withdrawing treatment common in French prehospital setting. This is controversial given the lack of information available	Results may be biased by low response rates. Respondents self-reported cases of end-of-life decision-making, however, no documents

			concerning patient and family wishes about end-of-life care.	were reviewed to confirm these cases.
<i>Prehospital emergency physicians' experiences with advance directives in Germany: A questionnaire-based multicenter study</i> ²⁶	Retrospective Mixed Methods Survey	104 emergency physicians	Majority of emergency physicians feel insecure about advance directives, report the need for defined end-of-life operating procedures and desire further educational training about prehospital palliative care.	Results may not apply to paramedic based systems. Lack of patient outcome data related to emergency physician decision-making. Survey answers rely on respondent memory, honesty and motivation for partaking in the study.
<i>Collaboration between prehospital emergency medical teams and palliative care networks allows better respect of a patient's will.</i> ²⁷	Retrospective Observational	40 patients	Collaboration between prehospital emergency teams and palliative care networks allows prehospital teams to information relative to their patients and, therefore, better respect the wishes of these patients.	No limitations listed by the authors of the study, however, sample size was small and data was analysed retrospectively.
<i>Paramedics experiences and expectations concerning advance directives: A prospective, questionnaire-based, bi-centre study</i> ²	Prospective Questionnaire-Based	728 paramedics	End-of-life decision-making challenging for paramedics. Paramedics desire guidelines for these situations. Advance directives should be made legally binding. Training in	No comparison of respondents vs. non-respondents. No follow-ups performed on respondents. Questionnaire was self-administered and its

			palliative care needed for paramedics.	validity has not been tested.
Expert opinion and recommendations				
<i>Palliative care and prehospital emergency medicine – apparently conflicting approaches?</i> ⁸	Editorial – Expert Opinion	No sample – 7 articles relating to prehospital palliative care cited	While palliative and emergency medical approaches seem to conflict, contact between emergency and palliative physicians provides opportunity to bring together the two different fields.	Opinion piece.
Challenges UK paramedics currently face in providing fully effective end-of-life care ²⁹	Expert Opinion	No sample – discussion of literature	Paramedics often care for patients at the end of life. There is a lack of research on this topic. Education in palliative care important for a paramedic led end-of-life care system.	Opinion piece.
<i>Integrating Palliative Care in the Out-of-Hospital Setting: Four Things to Jump-Start an EMS-Palliative Care Initiative</i> ¹⁰	Collaborative Plan of Action (IPAL-EM project)	No sample – plan of action to integrate palliative and prehospital care	Four steps to begin an EMS-palliative initiative: identify EMS ‘champions’, review protocols and literature, needs assessment, create action plan. Optimal palliative care begins out-of-hospital. This study provides a guideline to integrate	Requires implementation and study to determine effectiveness.

			palliative and prehospital medical care.	
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Paramedic perceptions of prehospital palliative care

As no research on prehospital palliative care has been produced in South Africa, a logical starting point is to identify the thoughts and opinions of South African EMS providers on the subject. Do they feel there is a need for prehospital palliative care? Do they manage palliative patients in their setting? Such questions are important to initiate research on the topic. Qualitative studies using interviews and/or focus groups are appropriate designs to answer these questions and have been performed elsewhere around the world. Notably, these qualitative studies seem to have been conducted exclusively in high income countries (HICs) such as Australia, the USA and Germany. As a low-to-middle income country (LMIC), South Africa may offer a unique perspective.

Lord, et al. performed a qualitative study aimed at identifying the knowledge, beliefs and attitudes of paramedics regarding palliative care patients.¹² This study was performed to inform larger future studies on the topic of paramedics and palliative care in the Australian setting.¹² Three focus groups as well as two one-on-one interviews were held with paramedics from two Australian states.¹² A total of 26 paramedics were involved.¹² Trigger questions used in the interviews involved paramedics' experiences with palliative patients, feelings about these experiences, preparedness to manage palliative patients, what policies and resources were in place and what they needed to improve their management of palliative patients.¹² Themes which emerged from the interviews were as follows: conflict concerning management goals between patient, family and paramedics; confusion surrounding legalities, lack of on-scene information, organisational policy limitations and lack of clinical guidelines.¹²

In discussing these themes, the authors concluded that further research is needed to improve palliative care education for paramedics, develop palliative protocols for paramedics, define the role of paramedics in palliative care and establish policies to uphold these developments.¹² This study would seem to support research on the topic in South Africa as similar needs, such as paramedic education, are likely present.

While thematic data saturation was achieved, the main limitation of the study was the possibility of an unrepresentative sample resulting in decreased transferability, particularly across countries.¹² Participants in the study were from two Australian EMS services.¹² EMS providers from other services in a LMIC country, such as South Africa, may offer further perspective.

Waldrop, et al. performed a cross-sectional, descriptive study which explored prehospital healthcare providers' thoughts around end-of-life calls, signs and symptoms of dying patients and medical orders for life sustaining treatment (MOLST).⁵ A survey instrument, which was pilot tested before administration and comprising of 36 questions, was given to 208 EMS providers from a single EMS agency.⁵ Of these, 178 surveys were completed and used in the study.⁵ The study found that end-of-life calls to nursing homes occur frequently; 47.8% of respondents saying they occur every shift and 50% of respondents indicated they are called to elderly patients with chronic illness one or more times per week.⁵ The most frequently encountered signs and symptoms of dying that prehospital healthcare providers indicated were apnoea, skin mottling, dyspnoea and hospice involvement in patient care.⁵ MOLST documentation was seen by providers infrequently; 57.9% saying they rarely or never see such orders.⁵ However, when MOLST documentation was available it primarily concerned decision-making around intubation, life-sustaining treatment and CPR.⁵

The findings of this study indicate the relatively high frequency with which EMS providers may encounter palliative patients in the USA.⁵ In addition, although MOLST documentation is in place to assist with EMS provider decision-making in these cases, they are often not available.⁵ In the South African setting MOLST documentation does not exist leading to a further lack of guidance for EMS providers in the country. In fact, in the South African prehospital setting, other legal documentation, such as do not attempt resuscitation (DNAR) orders and advance directives, is not recognized by legal statute.³⁰ While the Health Professions Council of South Africa (HPCSA) provides guidance on withholding and withdrawing treatment in the in-hospital setting, it does not provide guidance in the prehospital setting.³¹

The authors concluded that there is synergy between prehospital and palliative medicine, however, further research is needed to develop and test prehospital end-of-life decision-making interventions as well as understand how prehospital providers operate when confronted with palliative situations.⁵ Such further research may be useful in the South African setting given the higher burdens of communicable and non-communicable disease in the country when compared with the USA where this study was performed.

Limitations to this study include participant recall bias and the single-centre sample of the study.⁵ This may limit the generalisability and validity of the findings.

A further study conducted by Waldrop, et al. aimed to describe how EMS providers assess and manage end-of-life situations.⁷ A qualitative design using one-on-one

depth interviews was performed.⁷ Open-ended questions involving three topics were asked in the interviews: 1. Role of the family in assessment and intervention 2. Challenges surrounding end-of-life calls 3. Decision-making at the end-of-life.⁷ A total of 43 interviews were held (33 paramedics and 10 emergency medical technicians).⁷ Four themes arose from the interviews: 1. Multi-focal assessment – the assessment of end-of-life situations involves the patient, patient family members and the environment 2. Family responses – these are often emotionally challenging 3. Conflicts – missing legal documentation, family-patient conflicts 4. Management of the dying process – includes managing the patient as well as the family.⁷

This study emphasises the difficulties and challenges EMS providers face when managing end-of-life calls. The authors concluded that given these difficulties it is important to increase EMS providers' ability to uphold patient end-of-life wishes and deal with emotions of the process as well as support the families of the patient through palliative care education.⁷

Limitations of this study include limited diversity of participants as all participants were from a single agency.⁷ Thus, findings may lack transferability.

Rogers, et al. performed a mixed methods study to explore and measure paramedics' perceptions about their educational needs concerning palliative care.¹³ A previously validated online survey tool was administered to a single EMS agency in Australia.¹³ Quantitative data were reported using descriptive techniques while qualitative data (from open-ended questions) were analysed using content analysis.¹³ A total of 29 respondents completed the survey and were included in the study.¹³

The study found that with regards to palliative care, paramedics had a solid understanding of some important aspects such as the holistic (physical, psychological and spiritual) nature of palliative care.¹³ However, paramedics did tend to primarily focus on end-of-life care with terminal cancer patients, narrowing their view of where palliative care could be applied.¹³ Concerning their educational needs, paramedics identified the need for further training in palliative care ethics (i.e. use of advance directives and patient decision-making capacities), end-of-life communication and use of structured palliative patient care pathways.¹³ It is likely South African EMS providers would also identify palliative care education as a need given that palliative care does not form part of South African EMS curricula. However, their educational needs, as well as their understanding of palliative care, are yet to be explored.

The primary limitation to this study is the online nature of the survey tool as verification of participants is not possible.¹³ Furthermore, as a self-administered survey, the possibility of self-selection bias exists.¹³

A study by Kirk, et al. aimed to understand the confidence (comfort) and perceptions of paramedics regarding end-of-life patients and their families.¹⁴ An online survey with closed-ended questions was used.¹⁴ Invitation to partake in the study was sent to a single EMS agency in England.¹⁴ Completed surveys were received from 182 EMS providers.¹⁴ The study found that more experienced paramedics (those with greater length of service) were more confident when managing end-of-life patients.¹⁴ Concerns raised by paramedics in end-of-life situations were as follows: validity of legal documentation such as advance directives (70%), fear of litigation (46%) and conflict with patient family members (50%).¹⁴ Confidence levels and concerns among South African EMS providers is unknown and requires research.

The authors concluded that while paramedics perceive end-of-life care as important to their function, education for them is lacking and they face many challenges.¹⁴ Palliative care education is needed to increase paramedic confidence and give them support when dealing with end-of-life situations.¹⁴

This study is limited due to the nature of online surveys as there is no way to verify participants' experience and qualifications. In addition, the response rate was low and the possibility of self-selection bias exists.

A Canadian study performed by Carter, et al. aimed to evaluate two aspects of paramedics providing palliative care in patient homes using a mixed-methods approach: patient/family satisfaction (Part A) and paramedic comfort and confidence (Part B).²⁴ Quantitative data were reported descriptively and qualitative data was analysed using thematic content analysis.²⁴

The study was performed in two different Canadian provinces where a new palliative care programme was implemented: Paramedics Providing Palliative Care at home.²⁴ This programme included a new clinical practice guideline for paramedics delivering palliative care, new medications, allowed for treatment in the home without transport to a medical facility and provided paramedic training in these regards.²⁴ In Part A of the study, data was collected from patients/families who enrolled into the patient programme pre- and post-paramedic encounter by surveys and interviews respectively.²⁴ In total, 67 pre-paramedic encounter surveys and 18 post-paramedic encounter interviews were completed.²⁴ In Part B of the study, data was collected from paramedics who enrolled into the programme pre- and post-programme

implementation with the use of surveys. ²⁴ In total, 235 pre-implementation surveys and 267 post-implementation surveys. ²⁴

The study found that after programme implementation and training, paramedic comfort and confidence in performing palliative care improved. ²⁴ Paramedics also stated they found performance of palliative care both rewarding and important. ²⁴ It is possible these findings may be true of South African paramedics as well, however, this is yet to be explored. Furthermore, patient/family satisfaction with receiving palliative care from paramedics was high in this study. ²⁴ Therefore, the authors logically concluded that adding paramedics to the palliative care system improves paramedic, family and patient experience of palliative care. ²⁴ The study was limited by a poor response rate and possible self-selection bias. ²⁴

Based on these studies, which analysed EMS provider perception of prehospital palliative care, a common theme is apparent: EMS providers encounter palliative patients in the prehospital setting and therefore identify elements of palliative care as important to their roles. Furthermore, there is a perceived need for further education regarding palliative care as many challenges exist when treating palliative patients. If these findings are true in HICs, it is likely they are present in the South African LMIC context, though this is yet to be researched.

Prehospital palliative care patient management

Other literature which exists on the topic of prehospital palliative care focusses on the actual prehospital management of palliative patients by EMS providers. Existing literature is again minimal, and studies have been performed in HICs. However, it is interesting to note the frequency with which EMS providers encounter palliative patients in these countries as well as the problems they face in managing them. Similar problems may exist in the South African setting at a possibly increased frequency.

Carron, et al. performed a retrospective case series analysis to investigate palliative patients which were managed in the prehospital setting. ⁴ Four cases of palliative care situations were described and analysed. ⁴ Based on these case discussions, the authors found that EMS may encounter palliative patients when they deteriorate and display pulmonary and neurological symptomology, primarily in the context of cancer. ⁴ In addition, the cases present EMS providers with ethical and legal dilemmas. ⁴ These included respecting patient wishes, which was found to be difficult given on-scene information and time limitations, as well as applying advance directives in unexpected

situations.⁴ Furthermore, the cases cause EMS providers to rethink their roles in terms of 'life-saving' vs. supportive care.⁴

The authors concluded that EMS co-ordination with palliative networks is important to improve palliative patient management.⁴ They recommend formal training for prehospital staff in palliative care.⁴ Finally, they argue that EMS and palliative approaches may be complementary if used together.⁴ Due to the burden of disease in South Africa involving, in part, non-communicable diseases such as cancer, COPD and CHF, EMS providers may also commonly encounter palliative patients and be presented with the same dilemmas.¹⁵ South African burdens of disease including HIV, TB and resulting complications and comorbidities may further increase EMS provider encounters with palliative patients.¹⁵ As there is no collaboration between palliative and EMS networks in South Africa, this requires study.

This study is limited as it is a review of only 4 cases.⁴ Sample size was small as the study was performed over an 8-month period in a single Swiss state.⁴ Findings and suggestions are open to author biases and interpretations and may only apply to the authors specific setting.

A 2007 study by Wiese, et al. aimed to analyse the management of terminal cancer patients by prehospital emergency physicians.²³ Emergency cases from two EMS settings involving terminal cancer patients over a 12-month period were retrospectively reviewed.²³ Cases were analysed for call indications, prehospital management and involvement of palliative care teams.²³ During the 12-month period 2,765 emergency report forms were analysed, of which 2.5% were for cancer patients requiring emergency assistance.²³ These were included in the study.²³ The study found that calls were mostly made for cancer patients experiencing acute dyspnoea (42.7%).²³ After treatment, 61.8% of patients required hospital admission.²³ Palliative care teams were not involved in patient treatment in most cases (92.7%).²³

The authors concluded that co-operation of emergency and palliative systems appears necessary in these situations with the benefit of increased possibility of palliative patients staying at home.²³ Furthermore, palliative and emergency medical curricula should be combined in relevant areas to implement palliative strategies in the prehospital field.²³ Finally, they argued that palliative care teams should be more involved in the prehospital management of these patients.²³ Such co-operation, curricula and palliative care teams do not exist in the South African setting and require study to identify if similar conclusions may be drawn.

This study is limited by the lack of prospective data.²³ Also, as these findings were taken from a physician led prehospital system, findings may not apply to a paramedic-based system such as South Africa.²³

A further study by Wiese, et al. retrospectively investigated the prehospital paramedic and physician approach to palliative patients in cardiac arrest.³ Over a two-year period, all emergency calls involving palliative patients (advanced stage cancer where no curative approach could be applied) in cardiac arrest from four EMS agencies were analysed.³ A total of 88 palliative care patients in cardiac arrest were identified for the study.³ In 19 (22%) of the patients, resuscitation was not initiated.³ Paramedics initiated resuscitation in 61 (69%) cases and emergency physicians initiated resuscitation in 8 (9%) cases.³ Ten patients showed ROSC, however, no patients survived beyond two days.³ Advance directives were present in 43% of calls.³

The authors concluded that approaches to palliative patients in cardiac arrest differs according to EMS provider qualification.³ In addition, it was found that resuscitation was often initiated against patient and family wishes and that advance directives should be more readily available and used to assist EMS provider decision-making.³

Limitations of this study are the small sample size and retrospective nature of the study.³ In addition, this study was performed in a physician led EMS system and results may not be directly applied to paramedic-based systems such as in South Africa.³

Ausband, et al. performed a study to determine the prevalence of EMS palliative care protocols among EMS agencies in the USA.⁶ A survey was sent to 249 EMS agencies across the 200 most populous cities in the USA asking if a palliative care protocol (or similar) was in place.⁶ Of the 200 cities, responses were gained from 120 (60.5%).⁶ Of these, only 7 (5.8%) cities had an EMS agency with a palliative care protocol in place.⁶ These 7 cities had a combined population of 2.98 million which represented 6.3% of the population in the 120 cities responding to the survey (47.2 million).⁶

The authors concluded that since most of the USA population is not served by EMS agencies with palliative care protocols, EMS agencies should develop palliative care protocols where necessary.⁶ These results demonstrate that there is a lack of pre-hospital palliative care in an HIC country with highly developed EMS systems.⁶ In the LMIC setting of SA, where this data has not been researched, there is likely a further lack.

A limitation of this study was that 'palliative care protocols' were not pre-defined and each EMS agency was left to determine this.⁶ However, those that responded positively forwarded their palliative care protocol to the authors for analysis.⁶ While helpful to identify real palliative care protocols, the possibility of self-selection bias exists. Furthermore, the populations under study only included those in large urban environments and not rural or suburban areas.⁶ Thus, the exact percentages of the entire USA population served by EMS agencies with palliative care protocols is unknown.⁶

Another study by Wiese, et al. investigated the role of palliative care expertise in prehospital medical care.²² They prospectively examined prehospital emergency callouts involving advanced cancer palliative care situations over a 24-month period across four EMS agencies.²² Over these 24 months, 12,996 calls were responded to by the EMS agencies of which 361 (2.8%) fell into the advanced stage of cancer category (where no curative therapy could be applied).²² The differences in care given to these patients by prehospital emergency physicians was linked to the differing experience of these physicians regarding palliative care.²² Physician experience was divided into three categories: 1. expertise and experience with palliative care and emergency medicine, 2. expertise and experience with emergency medicine and not palliative care, 3. lack of experience and expertise in emergency medicine and palliative care.²² Of the 361 calls analysed 10% were treated by group 1, 42% by group 2 and 47% by group 3.²²

Statistically significant differences ($p < 0.01$) in terms of palliative patient care (transport, symptom management, end-of-life decision-making) were found between the groups.²² The best care, according to this study, was given by group 1: physicians with expertise and experience in both palliative care and emergency medicine.²² The authors concluded that the quality of prehospital palliative care depends on the expertise of the treating physician.²² They suggested that palliative and emergency medical care are complimentary and that palliative care principles should be incorporated into emergency medical care education.²² Thus, these findings highlight the positive impact of palliative care experience and training for EMS providers on palliative patient care.

The major limitation of this study is the specific German EMS context which is a physician-based system.²² Thus, results may not be directly applicable to paramedic-based EMS systems. However, it is reasonable to assume education in palliative care would be beneficial to paramedics.

As these studies demonstrate, EMS providers are frequently involved in palliative patient management. Despite this, there seems to be a lack of EMS palliative care protocols. To bridge this gap, a co-operative, multidisciplinary approach involving palliative care networks and EMS systems have been suggested. Currently in South Africa no EMS protocols or multidisciplinary approaches exist concerning palliative care in the prehospital setting and research is needed to identify their potential benefit.

Prehospital palliative care and legislation

Another aspect of prehospital palliative care which has been studied, albeit scarcely, is the ethico-legal framework. These studies primarily focus on the importance of respecting patient wishes, advance directives, ethical dilemmas and decision-making in the prehospital field. Respecting patient wishes is important to uphold their legal rights (i.e. to refuse care, choose what treatment they desire). Advance directives are helpful tools which can be used to this end. However, they often seem to cause confusion. In South Africa the same confusion exists as there is no legal guidance regarding advance directives in the pre-hospital setting.

Ferrand and Marty performed a survey aimed to investigate decision-making processes by emergency physicians in the pre-hospital setting regarding end-of-life care specifically with regards to withholding and withdrawing treatment.²⁵ Withdrawal of treatment was defined as discontinuation of life-sustaining treatment and withholding of treatment was defined as a decision to not use a life-sustaining treatment.²⁵ This retrospective cross-sectional study made use of a survey which was developed by using the results of semi-structured interviews with 15 physicians in the emergency medical centres of 2 French districts.²⁵ The physicians were asked to recall their most recent cases of life-sustaining decision-making processes.²⁵ From these interviews a 40-point survey was developed.²⁵ This survey was sent to 373 emergency centres (which run pre-hospital services in the French system).²⁵ In total 192 (51.4%) centres responded with 1069 (44.9%) physicians in participating centres involved.²⁵ Of these 816 (76.3%) physicians reported having made pre-hospital end-of-life decisions.²⁵ Patient family members were involved in 63.6% of these decisions.²⁵ Of conscious patients, 30.7% were involved in the decision-making process.²⁵ In 56.5% of cases, physicians consulted other physicians.²⁵ Withholding of treatment took place in 88% of cases while withdrawing of treatment took place in the remaining 12%.²⁵

The authors concluded that the withdrawal and withholding of treatment is common in the French prehospital setting and this is controversial as physicians in the prehospital

setting have limited knowledge of the patient's medical history and wishes concerning end-of-life management.²⁵ Training for prehospital physicians in palliative care and shared decision-making was recommended.²⁵ These results demonstrate the frequency with which prehospital emergency care and palliative/end-of-life patients come into contact and the difficulties of making end-of-life decisions in the prehospital setting given the lack of information available. As it is likely these difficulties exist in the South African setting, they should be studied. Current rates of prehospital withholding and withdrawing of treatment in the country are unknown.

The study was limited by a low response rate and failure to extrapolate data to non-respondents resulting in sampling bias.²⁵ In addition, information provided by respondents was not validated against patient care documentation and so results relied purely on physician memory.²⁵ Furthermore, the study was limited by its retrospective nature.

Another study conducted by Weise, et al. attempted to identify the knowledge of emergency physicians concerning legal and ethical issues with advance directives in end-of-life decisions.²⁶ Using a mixed-methods design, results from surveys sent to 150 emergency physicians were analysed.²⁶ Surveys included open-ended, binary and multiple-choice questions.²⁶ The survey including 14 questions to gather the following information: emergency physician demographic data, experience with advance directives and palliative care, and influence of advance directives on prehospital decision-making.²⁶ The physicians were divided into those with additional qualifications in palliative care, those with short training courses in palliative care and those with no training in palliative care.²⁶ In total, 104 (69%) completed surveys were returned.²⁶ Decisions made by experienced physicians were found to be more influenced by advance directives compared to inexperienced physicians.²⁶ Insecurity in dealing with advance directives was reported by 86 (82%) of physicians.²⁶ All 86 of these stated a need for training in this area.²⁶ A need for standard operating procedures concerning palliative care situations was reported by 90 (87%) of physicians.²⁶

Based on these findings, the authors concluded physician experience plays an important role in handling advance directives and end-of-life decisions.²⁶ Furthermore, there was a perceived need by prehospital emergency physicians for training in advanced directive use in end-of-life situations and standard operating procedures to assist in palliative care situations.²⁶ Thus, exposure to and training in palliative care decision-making and advance directive use seems warranted.

The lack of patient outcome data based on emergency physician decisions (i.e. complying with advance directives or not) represents a limitation of this study and a need for further research.²⁶ While some emergency physicians may feel uncomfortable with advance directive use and decide to follow or not follow them, it is unclear in terms of patient outcome if this is a real problem. Furthermore, this study is set in the context of a physician-based EMS system of Germany and thus, results may not be directly applicable to paramedic-based EMS systems.²⁶

Burnod, et al. performed a retrospective study which aimed to evaluate how well palliative care patients' wishes were respected by EMS providers after implementation of collaboration between the EMS system and a palliative care system.²⁷ A standardized process for this collaboration was developed and implemented.²⁷ Forty palliative patients within a community network whose wishes were known (in advance directives) were included in the study.²⁷ Wishes for maintaining home care were present in 14 (35%) cases, while transfer to hospital care was present in 26 (65%) cases.²⁷

This study found that when EMS providers made decisions for patient care in collaboration with the palliative network, patient wishes were respected in 83% of cases.²⁷ When decisions were made apart from collaboration with the palliative network, patient wishes were respected in only 40% of cases.²⁷ This was due to the lack of information available to the EMS providers without collaboration.²⁷ The authors concluded that collaboration between EMS systems and palliative networks allows for better respect of patient wishes.²⁷ This highlights the need for a multi-disciplinary approach to treating palliative patients in the prehospital setting.

It is worth noting that in the South African healthcare system, respect for patient wishes is regarded as highly important.²⁸ Patients possess the constitutional right to healthcare decision-making and autonomy.²⁸ How often these wishes are respected in prehospital palliative patients has not been studied. In addition, no collaboration currently exists between palliative and EMS systems. As a starting point for this research in the South African setting it would be valuable to identify the thoughts of South African EMS providers regarding prehospital palliative care patients and what would assist them in upholding their patients' wishes.

While no limitations to the study were listed by the authors, the sample size was small and data was analysed retrospectively.²⁷ Furthermore, no significance testing of results was performed.²⁷

Taghavi, et al. performed a prospective, questionnaire-based,) study in two German cities aimed at analysing the attitudes of paramedics towards end-of-life care and advance directives.² A self-administered survey tool was used involving 12 questions concerning end-of-life care and advance directives where answers were given a 5-point Likert scale.² While the survey tool was pilot tested with 5 paramedics beforehand, it was not previously validated.² Surveys were given to 900 paramedics, of which 728 (81%) returned completed surveys for inclusion in the study.² Most (71%) paramedics had experience in dealing with advance directives and end-of-life situations.² Most (84%) paramedics stated that CPR in end-of-life cases is of no value and 76% of paramedics said they would withhold CPR in these scenarios if it were legal to do so.² Many (54%) paramedics felt poorly to very poorly informed about advance directives while 80% fell into the category of satisfactory to very insecure about advance directives due to lack of education.² Paramedics mentioned that legal aspects of end-of-life care and advance directives should be included in their educational curricula.²

The authors concluded that end-of-life decision-making is challenging for paramedics due to legal insecurities and scope of practice limitations.² Bridging the gap between EMS and palliative care issues is needed and paramedics do not feel well equipped to handle end-of-life scenarios and advance directives.² Thus, training is needed for paramedics in these areas and should be included in EMS curricula.²

It remains unclear if this training should be at undergraduate or postgraduate level and what it should consist of. We suggest training should be included in undergraduate curricula to give a baseline understanding of palliative care, palliative patients and the palliative care approach. A postgraduate course should then be offered to elaborate on the intricacies of the topic and give greater understanding. This may be particularly useful for EMS providers involved in critical care retrieval and ICU transportation. Gaining the thoughts and opinions of EMS providers may be valuable here as a launching pad for the study of prehospital palliative care education.

This study was limited by self-selection bias.² In addition, the survey tool was not a validated tool and thus, results may be inaccurate.

The studies examining prehospital palliative care legalities appear to express one major theme: the difficulty EMS providers have in palliative care decision-making, specifically regarding end-of-life care and advance directive use. It is likely that similar challenges exist in the South African setting as no guidance regarding end-of-life decision-making and advance directive use exists in the prehospital setting. Gathering

the thoughts of South African EMS providers on their specific challenges will, therefore, be valuable.

Expert opinion and recommendations

The remainder of literature concerning prehospital palliative care includes editorials and an article making recommendations on how to implement prehospital palliative care. While expert opinion does not provide new data and represents the lowest level of evidence, it does provide thoughts with which to compare the opinions of EMS providers in our study. However, these opinions cannot currently be used in practice as they merely represent ideas which require research.

Duchateau, in a brief editorial, highlights the seemingly conflicting approaches of prehospital emergency care and palliative care.⁸ He stated the difficulties EMS providers face, their lack of training and their differences in focus regarding patient treatment when compared with the palliative care focus (i.e. 'saving lives' vs. relieving suffering).⁸ While this editorial does not provide new evidence, it does highlight common concerns in the literature concerning prehospital palliative patient care.⁸ Duchateau argues that although the approaches of palliative care and EMS care seem to be in conflict, they may actually work well together if used in collaboration to enhance the overall patient care plan.⁸ For example, EMS may be called to a palliative patient and contact a palliative physician who can give guidance on how to best manage the case.

A 2014 expert opinion paper by Brady underlined that UK paramedics often care for patients at the end of life.²⁹ Despite this, there is a lack of research on this topic. He argued that education in palliative care is important for a paramedic led end-of-life care system.²⁹ While this opinion-based paper does not provide new evidence, it does highlight common concerns in the literature concerning prehospital palliative patient care and is in line with Duchateau's paper.^{8, 29} Thus, this paper is a further call for research and education on the topic of prehospital palliative care. If these concerns are present in HIC countries within the UK, they are likely present in the LMIC setting of South Africa.

Lamba, et al. published a study based on a collaborative project (IPAL-EM project) aimed at providing a 'road-map' to start an EMS-palliative care initiative which would enhance prehospital palliative care.¹⁰ Four patient scenarios were reviewed to illustrate the need for prehospital palliative care.¹⁰ The authors then identified four steps to develop an EMS-palliative care initiative: 1. Identify EMS 'champions' 2.

Review protocols and literature 3. Perform a needs assessment 4. Create an action plan.¹⁰ The authors argued that optimal palliative care begins out-of-hospital and provided a guideline as to providing this care.¹⁰

These basic steps appear logical in any setting and this study provides ideas on how to overcome challenges with prehospital palliative care. Study is needed in the South African setting to determine if optimal palliative care would indeed begin in the prehospital setting, what challenges exist and how to overcome them. Furthermore, study is needed in South Africa to determine what steps EMS providers think would be appropriate in establishing prehospital palliative care, if any.

South African Palliative Care

To provide further context to our study, it is worth mentioning the current state of palliative care in South Africa. In South Africa, palliative care is recognised as a human right.³² The country is aligned with the WHO definition of palliative care and recommendations for palliative care practice.^{32, 33} Primarily, palliative care is provided by hospices and other non-governmental organizations (NGOs).^{32, 33} As of 2018, 150 hospices and 8 hospital palliative care services exist in the country.³² Palliative care provided by hospices mainly takes place in patients' homes.³² It is estimated that 0.52% of the population (286 000 people) require palliative care every year.³² However, this number is likely greater as these stats are based on mortality data alone.³² HIV infected patients represent the largest cohort of patients requiring palliative care.³²

Challenges to palliative care in South Africa include financial and resource constraints as well as a lack of education.^{32, 33} Due to these challenges, several hospices closed between 2011 and 2016 and historically, palliative care provision has relied on volunteers and donations.^{32, 33} Despite these challenges, progress is being made. The South African Minister of Health has recently shown attention to palliative care in the country and established a steering committee for palliative care in the country.³² Budget policies have also been planned to improve palliative care and government funding of hospices has increased.^{32, 33} Furthermore, education has improved as palliative care exposure has been introduced at undergraduate medical training level and world-renowned postgraduate studies in palliative care have been introduced.³²

While advancements are being made, there remains a large challenge in delivering palliative care in South Africa as access is often limited.³² As an LMIC, South Africa requires innovative ways of using its limited resources to meet these palliative care

needs. One possibility is use of EMS. Much of palliative care in South Africa already occurs in patient homes and this is often where EMS providers perform their function. In addition, EMS providers are in the unique position of delivering healthcare to the patient and bringing the patient to further healthcare.¹⁰ Integrating palliative care with EMS systems may, therefore, be of benefit.⁸ This requires study.

Summary

Existing literature on prehospital palliative care is scarce and has many limitations. What literature does exist highlights several important points regarding prehospital palliative care: EMS providers frequently come into contact with palliative care patients and experience many challenges, EMS providers lack education concerning management of these patients, EMS and palliative care approaches should be integrated and there is an overall need for further high-quality research on the topic of prehospital palliative care. Currently, in the South African LMIC setting, there is no research on this topic, palliative care is not included in EMS curricula and EMS systems are not integrated with palliative care systems. Therefore, a knowledge gap exists concerning prehospital palliative care in South Africa. Qualitative studies are useful to address these knowledge gaps by exploring ideas, giving meaning to lived experiences and generating knowledge. Thus, the aim of our qualitative study is to gather the thoughts and opinions of advanced life support (ALS) providers within the South African private EMS sector regarding pre-hospital palliative care in terms of its importance, feasibility and barriers to its practice.

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PART B: ARTICLE

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“To be picked up, wrapped in a blanket and held by your mom until you pass away,” South African Paramedic Perspectives on Prehospital Palliative Care

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Abstract

Introduction: Palliative care is typically performed in-hospital. However, EMS providers are uniquely positioned to deliver early palliative care as they are often the first point of medical contact. The aim of this study was to gather the thoughts and opinions of advanced life support (ALS) providers within the South African private EMS sector regarding pre-hospital palliative care in terms of its importance, feasibility and barriers to its practice.

Methods: A qualitative study design employing semi-structured one-on-one interviews was used. Content analysis, with an inductive-dominant approach, was performed to identify categories within verbatim transcripts of the interview audio-recordings.

Results: Four categories arose from analysis of six interviews: 1) need for pre-hospital palliative care, 2) function of pre-hospital healthcare providers concerning palliative care, 3) challenges to pre-hospital palliative care and 4) ideas for implementing pre-hospital palliative care. According to the interviewees of this study, pre-hospital palliative care in South Africa is needed and EMS providers can play a valuable role, however, many challenges such as a lack of education and EMS system and mindset barriers exist.

Conclusion: Challenges to pre-hospital palliative care may be overcome by development of guidelines, training, and a multi-disciplinary approach to pre-hospital palliative care.

African Relevance

- Limited resources are available to provide adequate palliative care.
- EMS providers frequently encounter palliative patients.
- No research has been produced on the topic of pre-hospital palliative care in Africa.

Background

The World Health Organisation (WHO) defines palliative care as *'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'* [1] This includes a wide variety of situations such as chronic illness and end-of-life care. [2]

Such treatment is typically performed by palliative care specialists who work in-hospital. However, emergency medical services (EMS) often encounter patients requiring palliative care as these patients may have acute exacerbations of illness, progress towards end-of-life or require transport to a medical facility. [3-9] As the first point of medical contact, EMS providers are thus uniquely positioned to deliver early palliative care in the home. [10] This has great potential benefit for patient comfort, early identification and relief of suffering and earlier referral to hospice care. [10, 11]

Despite this unique position there is an overall lack of guidance within EMS systems to manage palliative patients. [5, 6, 10] In the United States of America (USA) only 5-6% of EMS systems have protocols for palliative care. [6, 10] In addition, there is no specific pre-hospital emergency care curricula on the subject, resulting in a lack of education and training for EMS providers. [3-5,12, 13] This might stem from the historical focus of EMS training which primarily involves immediate measures to preserve life or limb until definitive care is reached. [11] This focus has resulted in an EMS ethos of 'saving lives.' [5, 12] Palliative care, on the other hand, is not focussed on 'saving lives', but rather the prevention and relief of suffering. [1] Therefore, palliative care may seem to conflict with emergency care, placing EMS providers in difficult situations when confronted with palliative care patients. [8, 12, 14]

The Sub-Saharan African region faces the world's most significant health crisis. [15] South Africa itself faces what has been termed a "quadruple burden of disease" due to communicable diseases such as HIV/AIDS, high maternal and paediatric mortality

rates, non-communicable disease as well as injury. [16] The large number of patients suffering from these diseases and the life-limiting complications thereof, results in increased need for palliative care in the country as noted by the South African Minister of Health. [17]

Access to health care for patients suffering from these diseases is a further challenge in the Sub-Saharan African setting. [15, 18, 19] In South Africa, EMS are often contacted by those without access to transport to provide this service. Thus, South African EMS providers may frequently encounter not only high acuity emergency patients, but many ill HIV/AIDS, cancer and other chronically ill patients requiring palliative care who are unable to access healthcare via alternative means. [20] European studies have found that approximately 3-5% of all pre-hospital calls involve palliative care situations. [2, 21, 22] With the quadruple burden of disease and limited access in the South African setting, this percentage is likely higher as these factors result in increased frequency of contact between EMS providers and patients requiring palliative care.

The aim of this study was to gather the thoughts and opinions of advanced life support (ALS) providers within the South African private EMS sector regarding pre-hospital palliative care in terms of its importance, feasibility and barriers to its practice. To our knowledge, no research has been produced in the (South) African setting regarding prehospital palliative care.

Methods

Design

A qualitative study design employing individual semi-structured interviews was used. Interviews were performed by the primary investigator, who was trained beforehand in qualitative interviewing. Prior to data collection a pilot interview was performed between the primary investigator and supervisor to ensure consistency and quality of interview technique. Data from this interview was not included in the final analysis. The theoretical orientation underpinning this study was phenomenology as it sought to describe and find meaning in the experiences of EMS providers regarding palliative care.

The interview schedule contained four questions referencing career background, importance of, concerns with, and opinions on palliative care feasibility in the South African pre-hospital environment. Pre-determined prompts and probes were included for each question to enhance data collection by thoroughly exploring the interviewees' thoughts and opinions. The interview schedule was jointly developed by CG and WS, based on the contextualisation of the limited available literature.

Setting

Each interview was held in a private setting agreed upon by the primary researcher and participant. To avoid interruptions, interviews were held with off-duty ALS providers.

ALS providers were chosen as the population of the study due to their broad scope of practice when compared to other cadres of provider. This scope of practice, although intended for emergency patients, includes the ability to perform certain palliative care interventions such as opioid administration.

The private South African EMS sector was chosen as the research team had greater access to the ALS providers within the private system. The private system was more suited to the inclusion and exclusion criteria of the study as it contained a greater number of ALS providers with higher education (HE) qualifications. For the purposes of this study the "private EMS sector" refers to non-governmental, for-profit EMS companies.

Data Collection

Six interviews were held from March to May 2018. Interviews lasted approximately 20-35 minutes. All six interviewees knew the interviewer from a mutual training institution. Participants were aware the study was part of the interviewer's post-graduate studies.

ALS providers were invited to participate in the study via email circulation within a local database of South African paramedics who have volunteered their names to be a part of the database. Three ALS providers indicated their willingness to participate and a further three providers were selected on a convenience basis.

Inclusion and exclusion criteria were as follows: Inclusion - Qualified ALS providers with HE qualifications (National Diploma, Bachelor of Technology and Bachelor of Health Sciences in Emergency Medical Care), currently working in, or with recent previous experience in, the South African private EMS sector with a minimum of two


years private sector operational experience. Recent previous experience referred to South African private sector operational experience, within the last 3 years if the ALS provider was not currently working in the private sector. Exclusion - ALS providers without pre-hospital, operational experience in the South African private EMS sector.

Analysis

Interview recordings, created with a recording application on a cellular device, were manually transcribed verbatim by CG. Transcriptions were identified by interview number and gender (e.g. Interview #1M).

Content analysis of transcribed data was performed using the framework of Braun and Clark. [23, 24] These techniques were conducted alongside data collection as field notes were made during interviews, and familiarisation with the data began. Transcription analysis was performed using an inductive-dominant approach. Meaning units were captured, condensed, coded and categorized (see figure 1) using NVivo version 12 software. [25] Data coding was performed by the interviewer alone. Researcher triangulation was performed between CG and WS where categories and codes were discussed, refined and finalised. Member checking of these categories and codes was performed hereafter.

Figure 1 Coding tree



	Example 1	Example 2
Category	Need for pre-hospital palliative care	Challenges
Code	Importance	EMS Mindset
Condensed Meaning Unit	Change in importance over time	Paramedics have mindset of changing lives
Meaning Unit	<i>“More important than I think most people realise. Especially when you first qualify. And especially after we did the topic last year, gave me a chance to think about it and reflect back on patients that I’ve seen where I could have managed them differently had I known then what I knew now, or at that point.”</i>	<i>“Cause like I said there’s very much this thing of we as paramedics need to save every single life, we need to get every single patient to hospital alive. So that’s why I say, it’s like we don’t want to accept that death is part of the natural process of patient outcomes. So I think it’s gonna be a big mindset change, yeah.”</i>

Data saturation, as detailed by Saunders, et al. was reached after six interviews. [26] This was evidenced by repetitive comments by interviewees and lack of additional data being gained after the sixth interview. Details of the interviewees and interviewer are presented in table 1.

Table 1 Interviewee and interviewer details

	Gender	Qualification	Post-Grad Experience	Areas of Experience
Interviewee #1	Male	ECP ^a	4 years	Operations: Road, HEMS ^b , Fixed Wing
Interviewee #2	Male	ECP	3 years	Operations: Road, HEMS, Fixed Wing Other: Psychology
Interviewee #3	Female	ECP	3 years	Operations: Road, HEMS, Fixed Wing, ICU ^c Ambulance
Interviewee #4	Female	ECP	6 years	Operations: Road, HEMS, Fixed Wing, ICU Ambulance Other: Nursing, Lecturing
Interviewee #5	Male	ECP	2 years	Operations: Road, ICU Ambulance
Interviewee #6	Female	ECP	3 years	Operations: Road, HEMS, ICU Ambulance
Interviewer (CG)	Male	ECP	5 years	Operations: Road, HEMS, Fixed Wing Other: Contract, Primary Health

^aECP = Emergency Care Practitioner. This equates to a 4-year bachelor's degree in Emergency Medical Care, ^bHEMS = Helicopter Emergency Service, ^cICU = Intensive Care Unit.

Reflexivity

I (CG) carried out the interviews and performed this study as part of the Master's degree in Emergency Medicine (UCT). During the study, I held positions as a paramedic working in primary healthcare in West Africa and as a helicopter EMS paramedic for a private company in South Africa. As I had no prior experience in qualitative research, I completed an online training course in qualitative research methodology before commencement of the study. [27] During the interviews I recognised my own personal biases (i.e. palliative care *should* be performed in the South African pre-hospital setting) and actively avoided these by refraining from asking leading questions and adhering closely to the discussion schedule. Throughout the

process I felt my interview technique improved. I also felt the discussion schedule was logical as answers to the pre-determined questions flowed naturally into the next questions during the interviews.

Trustworthiness

To ensure trustworthiness of the data the framework of Guba was used in seeking credibility, transferability, dependability and confirmability. [28] The following steps were taken to ensure these criteria in the study: [28]

- **Credibility:** Interview technique was practiced with a pilot interview. Participants were given the opportunity to refuse participation and participated voluntarily. During data collection and analysis frequent communication and debriefing sessions were held between the interviewer and study supervisors. Researcher triangulation was carried out and member checking was performed. A reflexive commentary is provided.
- **Transferability:** A thorough description of data collection methods is given. Interview duration and the data collection period are reported. Study results are further discussed in relation to available literature.
- **Dependability:** Full descriptions of research design and implementation, a reflexive commentary as well as the details of data gathering are presented.
- **Confirmability:** Preliminary hypotheses held by the research team which are not demonstrated in the data are discussed and reflected upon. Researcher triangulation and member checking were performed. In addition, verbatim transcriptions of the audio data were produced.

Ethical approval for the study was provided by the University of Cape Town's Human Research Ethics Committee (HREC Reference Number: 058/2018). This manuscript complies with the COnsolidated Criteria for Reporting Qualitative (COREQ) research checklist. [29]

Results discussion

Four categories emerged: 1) need for pre-hospital palliative care, 2) function of EMS providers concerning palliative care, 3) challenges to pre-hospital palliative care and 4) ideas for implementing pre-hospital palliative care.

Need for pre-hospital palliative care

Based on their experiences all participants stated there is a need for pre-hospital palliative care in South Africa. Reasons given were a) the opportunities to provide palliative care, neglect and importance of palliative care and b) ethics, patient rights and human dignity.

a) Opportunity, neglect and importance

“This is a huge, huge population we actually service that falls into that category: end-stage cancer, end-stage RVD [retroviral disease – HIV/AIDS]...” – Interview #5M

“...I think it’s actually more important than we realise.” – Interview #1M

“Opportunity [to perform palliation] yes, but I never took it.” – Interviewee #6

All interviewees detailed personal experiences regarding the opportunities they had to treat patients requiring palliative care. Specific populations of patients mentioned were those with terminal cancer, chronic mental and physical illnesses and the elderly. Several studies in High Income Countries (HICs) have noted similar palliative care patient populations to which EMS are called. [5, 21, 30] While these populations are served by South African EMS the opportunity to provide palliative care was seen to be neglected.

Participants detailed how experience played a role in their perception of pre-hospital palliative care’s importance. While early in their careers palliative care was not a focus, it became increasingly important with experience. Interviewees described palliative care in the South African pre-hospital setting as *“very”* and *“extremely important”*.

“...especially after we did the topic [palliative care] last year, gave me a chance to think about it and reflect back on patients that I’ve seen where I could have managed them differently had I known then what I know now...” – Interview #3F

Wiese, et al. have shown in several studies involving pre-hospital palliative care that EMS provider experience plays an important role in palliative situation decision-making. [9, 21, 31] They found that experienced EMS providers were both more comfortable and more confident in managing palliative situations. [9, 21, 31]

b) Ethics, patient rights and human dignity

One practitioner stated that ethically “we owe it” to patients to provide relief from suffering. This includes the provision of palliative care. Another interviewee mentioned the importance of treating end-of-life patients in a dignified manner by avoiding overtreatment. The concepts of dignity and autonomy are patient rights and integral to palliative care. [3, 9] These rights, however, may not always coincide with EMS therapeutic goals. [9] Thus, in the prehospital setting it is important to take these patient rights into account particularly when managing palliative patients. [3] Current literature suggests this can be attained through integration of emergency and palliative healthcare; something the interviewees of this study recognised as a need in South Africa. [7, 9, 32]

Another interviewee, taking the patient’s family into account, highlighted the danger of creating false hope in the case of overtreatment. This view is commensurate with the WHO position on palliative care. [1] Previous studies in which EMS providers have been interviewed concerning prehospital palliative care have demonstrated the consideration for family dynamics as an important part of managing palliative situations. [7, 12]

For the above reasons, participants felt there is a need for palliative care in the South African prehospital setting. While some felt it was “*appropriate in the South African setting*” and “*should be implemented*”, others felt that despite its importance, other shortcomings within the South African EMS system should be addressed first. These included areas such as primary health care provision, system development and improvement in current resuscitative practices. Likewise, in European studies, while many prehospital providers saw a need for developing prehospital palliative care, some did not consider this a priority given other pressing issues. [8, 9, 21] Further study is needed in the (South) African environment to identify top priorities and set a prehospital development agenda.

Function of pre-hospital healthcare providers concerning palliative care

Participants felt that EMS providers have an important role to play in providing palliative care. As Wiese, et al. stated, “...so long as there is no extensive outpatient care for palliative care patients, emergency medical teams must continue to play an important role...” [21] This includes the South African setting where both inpatient and outpatient palliative care is lacking. [17] According to participants, these roles are a) facilitation of care (including initiation of care, facilitation of further care and on-scene decision-making), b) improving quality of life and c) home-based care. Interviewees saw these roles as beneficial to both patient and family.

a) Facilitation of care

“What you do then determines what is going to happen for the rest of their course... So specifically pre-hospitally it’s such a big deal...” – Interview #3F

“...that liaising, that mediator between the two [treating doctor and patient] is, I think, one of the most important functions we have in those kinds of situations with palliation.”
– Interview #2M

These facilitative roles suggested by participants take advantage of the unique position of EMS as the first point of medical contact for pre-hospital patients requiring palliative care. EMS providers can assess the patient, “*take a step back*” and communicate with the patient and family members as to their desires for treatment and be a part of the decision-making process. As commonly described elsewhere, this initial pre-hospital decision-making sets the trajectory for subsequent palliative patient care. [5, 10, 13] In the German setting, it has been found that poor decision-making, by EMS providers inexperienced in palliative care, results in in-hospital treatments which are not desired by the patient or the patient’s family. [21]

Importantly one practitioner pointed out that while EMS providers can and should be a part of this decision-making process, it is not their place to make palliative care decisions in isolation.

“We can be part of the system that makes that decision, that executes the decision, but I don’t feel it’s our place to make that decision.” – Interview #4F

A Swiss prehospital palliative care study supports this viewpoint; the authors calling for collaboration between palliative care systems and EMS. [4] Likewise, an investigation, in which EMS providers were interviewed concerning palliative care emergencies, highlighted the desirable nature of a stronger integration between palliative and EMS systems. [9]

b) Improving quality of life

Interviewees identified improving quality of life as part of their role in palliation, consistent with the WHO definition of palliative care. [1] Describing an end-of-life situation where a baby has undergone palliative care and is at home with family, Interviewee #4F said, *“To be picked up, wrapped in a blanket and held by your mom until you pass away vs. lying in a hospital crib connected to vents and monitoring...you improve, in my opinion, the quality of life at the end because you can’t improve quality of life anymore with medical support...And then you also improve the quality of life for the family cause they get to have that experience.”* Thus, EMS providers could facilitate improved quality of life for both family and patient by means of relieving suffering in the prehospital environment.

c) Home-based care

One practitioner mentioned the value of home-based care and how EMS could play a role in its provision. She stated that palliative treatment could be administered in the patient’s home without subsequent transport to a healthcare facility which is current practice in the South African environment. Lord et al. found that Australian paramedics also felt their requirement to transport these patients to hospital inhibited their ability to provide palliative care. [12]

Home-based palliative care is supported practice in South Africa however, its implementation is lacking. [17] Current EMS practice in South Africa further adds to this problem in terms of mandated transport of patients to a medical facility should treatment have been administered. The hospitalisations which result increase demand on already strained palliative care resources in the LMIC-setting of South Africa. [17] Supported palliative care practices and EMS systems are therefore in conflict. However, EMS systems could be used to enhance home-based care as EMS already work in patient homes and are equipped for prehospital healthcare.

An interviewee felt EMS could play an important role in facilitating transport of patients to their homes to die in comfort rather than in a medical facility. While the use of EMS

to transport palliative patients from medical facilities to their home is not described in literature, the concept is worth researching as it could result in increased patient comfort, dignity and respect of patient and family wishes. These concepts are essential for the appropriate care of palliative patients. [6, 8, 9] However, this practice may strain EMS system resources, resulting in negative impact on service delivery to emergencies.

These suggested roles are not foreign to EMS providers. [10, 11] EMS providers are trained in decision-making processes, patient communication, handover processes, analgesic strategies and acting as mediators between the pre- and in-hospital healthcare services. [10, 11] EMS provider roles may, therefore, be well-suited to the provision of palliative care as they appear to fulfil the mandate of palliative care: to improve quality of life. [1]

Challenges to pre-hospital palliative care

When considering the implementation and practice of palliative care in the pre-hospital setting, participants identified numerous challenges which they felt needed to be addressed in order to implement prehospital palliative care programmes. Concerns were a) the current EMS mindset, b) lack of training, c) resource and scope of practice considerations, d) EMS system failures and e) difficulties specific to the pre-hospital field.

a) EMS mindset

Interviewees highlighted the need for a difference in approach to patients requiring palliation when compared to those suffering an emergency. The current EMS mindset, they explained, is to intervene and get the patient to hospital alive at all costs; 'saving lives' being the dominant EMS ethos in South Africa as it is in the USA and Europe. [5, 12] While this may be a major role of EMS providers, they argued that in end-of-life situations where medical treatment would be futile, this mindset would be inappropriate. According to them the paradigm would need to shift from a life-saving approach to a relief of suffering approach before prehospital palliative care could be effective.

"...there's very much this thing of we as paramedics need to save every single life. We need to get every single patient to hospital alive...So I think it's gonna be a big mindset change..." – Interview #1M

This is common elsewhere around the world, where EMS providers are forced to abandon their training when confronted with palliative situations. [4-6, 8, 12] While EMS and palliative mindsets seem to be in conflict, it has been suggested they may be complimentary if integrated. [4, 8, 21] This appears logical based on potential EMS provider functions regarding palliative patients.

Some participants felt pre-hospital palliative care would not be well-suited to every EMS provider; only specific providers with the “*capabilities and the will*” to perform palliation would be suitable.

“The number one criteria for me would be people that are actually passionate about it [palliative treatment] and interested in it.” – Interview #4F

This is the recommendation of Lamba, et al. who state the first step in integrating palliative care with EMS systems is identifying “*EMS-palliative care champions.*” [10]

b) Lack of training

The lack of training at undergraduate level in palliative care was identified as a challenge. No participants received training on the topic until after graduation, where even then most knowledge was self-gained. Even with knowledge and experience gained over time, participants lacked confidence to practice palliative care in the pre-hospital setting. One participant stated he would be “*hesitant*” without training while others expressed their need for further education on the correct approach to palliative patients.

“I know now that we need to do it [palliative care], it can be done safely and should be done for certain patients. And now it’s just to get more training in how to do it the correct way.” – Interview #1M

“I can’t actually remember having been introduced to the idea of palliative care at all in [undergraduate level].” – Interview #3F

Globally, EMS educational material on the subject is minimal and training has been called for in many studies. [3-5, 8, 13] This need for training is present in both physician and paramedic-based EMS systems. [3, 5, 8] A German study found that while 89% (n=93) of physicians had encountered palliative care patients, only 32% (n=33) were trained in palliative care. [9] While these data have not been researched in the South African setting, it is likely the need for training is greater due to the higher burdens of disease.

Two unique points regarding the need for training were raised by Interviewee #5M. He stated that education should be aimed at all levels of EMS providers, including BLS, as ALS providers do not respond to the majority of calls. According to him, this would make prehospital provision of palliative care more “*equitable*”. Secondly, he noted the need for patient and family education. They too should receive education on palliative care to improve communication with EMS providers about the management of such patients. This is consistent with views of American and Australian paramedics who likewise found the lack of family education challenging. [7, 12]

c) Resource and scope of practice considerations

Interviewee #4F provided an example from personal experience of how limited scope of practice fails palliative care patients: “...*there’s someone at home on a vent and you can hear there’s a bit of extra secretions, there’s a temperature... patient probably only needs a course of antibiotics. In reality, in normal life, the mom would put her kid in the car and go to the GP and get antibiotics. Because the child is ventilated she doesn’t have that freedom of movement. Now you must arrange a whole big transfer to hospital.*” She concluded by saying, “...*that function should be available to them at home*” suggesting antibiotics be included in ALS scope of practice.

While she and other participants felt scope of practice and resources were a limiting factor to the provision of pre-hospital palliative care, others felt these were adequate.

“... I think from a resource point of view in my current work setting there’s no reason why it [palliative care] cannot be implemented.” – Interview #1M

“...I do believe that we’re very limited from an analgesic...perspective.” – Interview #2M

Apart from medications, participants did express other limiting factors regarding palliative care management. They stated the following was not currently practiced, but would be useful: on-scene discharge, prescription of medications and changing of tracheostomies.

German paramedics also have scope of practice limitations which inhibit their ability to provide appropriate care to palliative patients. [2] In an end-of-life situation which has deteriorated to cardiac arrest they are forced to initiate mechanical and pharmacological resuscitative efforts in the absence of a physician. [2] While South African ECPs have more freedom in terms of when to withhold resuscitative efforts, they still lack in terms of procedural scope. While EMS provider scopes of practice may differ around the world, they all may experience limitations when facing palliative situations.

Resource limitations are not highlighted in prehospital palliative care studies in HICs. [9, 12] However, to integrate palliative care into EMS systems it is recommended a needs assessment be performed to identify required resources. [10] This is particularly relevant in the South African LMIC setting.

d) EMS system failures

Participants were concerned that when they do implement appropriate palliative care measures the system does not defend them and may discipline them. Other system problems noted were logistical difficulties (i.e. what hospital should these patients be transported to?), lack of communication amongst role players and questions surrounding documentation of palliative care management.

“I think we have a very valuable role to play, but it’s almost being limited by how things are structured...”– Interview #4F

“The family is telling me not to intubate this patient, but there was no legal document...so I was advised [by Medical Officer] to rather go the whole invasive treatment... So I intubated the patient and I knew that it was against her wishes and against the family’s wishes...”– Interview #6F

According to a study on prehospital palliative care protocols in the USA, EMS protocols are typically designed for patients requiring curative measures as opposed to comfort care. [6] This explains the dilemma highlighted by Interviewee #6F. EMS provider

discomfort around deviating from system protocol is well documented. [6, 12, 13] This has been found to limit their ability to manage palliative situations. [13] Participants in this study have similar limitations. The integration of palliative care into South African EMS systems, therefore, appears warranted to improve palliative patient management.

To further illustrate the dysfunction of the current system, one practitioner described a situation where she was called to a palliative healthcare facility to resuscitate a patient in cardiac arrest. *“Isn’t that where a patient should be left to die?”* she asked. This may be due to a failure of palliative care in South Africa. A study in France noted a similar problem revealing that emergency care was sought in end-of-life situations for patients already in palliative care in nearly 30% of cases. [30] The authors labelled this a *“disturbing finding”* highlighting the potential lack of training even among palliative care teams. [30]

Despite these system failures, some participants felt able to perform certain elements of palliative care, such as providing supportive care rather than full resuscitative care, in their current setting provided they were able to justify their management during clinical reviews. Others, however, feared the risk and felt unable to perform palliative care without repercussions from their employer.

e) Difficulties specific to the pre-hospital field

Further identified challenges result from unique pre-hospital patient management difficulties. The interviewees described difficulties in intervention decisions, dealing with patient family members, gathering information and with personal mental health. Determining when to initiate palliative care presented the potential for harm to both the practitioners and the patient. A patient requiring resuscitative treatment for survival could be mistaken as a terminally ill patient requiring palliation resulting in adverse outcome. According to participants, making these decisions is difficult in the prehospital setting as scene-time and information are limited. Furthermore, family and patient wishes may clash with each other or with practitioner clinical reasoning.

“...for me personally it was difficult making that decision [palliation vs ALS resuscitation] with 2 minutes’ worth of history on a patient you’ve never encountered and that you will never see again after the call’s over in 30 minutes.” – Interview #1M

“You might have family members that say yeah you have to do everything, even though you know this patient is more eligible for palliative care than resuscitation.” – Interview #6F

“I think from... an emotional welfare point of view ...you need to be comfortable then with the decision that you made.” – Interview #3F

The prehospital field is more challenging for healthcare providers than the controlled in-hospital setting. [29, 33, 34] Ferrand and Marty concur with the participants of this study that future quality of patient life is impossible to predict in the emergency pre-hospital setting and thus, viability decisions in palliative situations are challenging. [30] The lack of on-scene medical information available to EMS providers, particularly in palliative situations, has been highlighted as a challenge around the world. [10, 13, 32] This has been found to create conflict between EMS providers, palliative patients and patient family members as dilemmas develop over competing interests: patient wishes vs. family wishes vs. EMS protocols vs. legalities. [7, 10, 32]

Advance directives (ADs) and do not attempt resuscitation orders (DNARs) can be helpful to healthcare providers regarding decision making when managing palliative care patients as they give insight into patient wishes and legalities of treatment measures. [12] However, rather than assisting EMS providers in palliative situations, these documents have been shown to cause more confusion. [2-5, 7, 31] EMS providers are often unaware whether their patients have ADs or DNARs due to lack of available information. [5, 7, 10] Furthermore, when ADs and DNARs are presented, EMS providers are unsure of their legal implications in emergency settings as there are no clear guidelines for their use. [2, 12, 31] In South Africa the same confusion exists as there is no legal guidance regarding ADs or DNARs in the pre-hospital setting. [35]

Ideas for implementing pre-hospital palliative care

Despite the challenges of pre-hospital palliative care in South Africa, participants felt implementation was still necessary and possible. Their ideas for implementation were a) the creation of guidelines, b) a multi-disciplinary approach and c) the creation of pre-hospital palliative care specialists or teams.

a) Creation of guidelines

To overcome fear of practicing palliative care in their respective environments due to litigation or company repercussions, candidates stated guidelines should be developed and implemented. This would give them confidence by providing direction, system, legal and ethical backing when managing palliative patients.

“I think anybody would feel much more comfortable making those decisions if they knew that higher-up they would be backed-up.” – Interview #3F

“I think that [policy] will also just give the practitioner ease of mind to know they’re covered...” – Interview #1M

Calls for palliative care guidelines in EMS systems have been made previously. [2, 6, 10] A recent Canadian study found the introduction of one such guideline successful in improving paramedic comfort and confidence when performing prehospital palliative care. [36] As specific guidelines on this topic do not currently exist within South African EMS structures their development would be beneficial. This will require further research on what would constitute safe and effective practice of pre-hospital palliative care.

b) Multi-disciplinary approach

Along with guidelines, participants felt pre-hospital palliative care should involve a multidisciplinary approach with involvement of others. This would include family members, treating physicians and other specialists. The idea would be to ensure that correct investigations and treatment measures are performed before officially withdrawing treatment or declaring a patient for palliation. In so doing the decision-making regarding patient prognosis and management would not rest solely on the EMS providers. Thus, the risk of mistakenly performing palliation on a patient requiring more invasive treatment and vice versa would be reduced.

“There would’ve had to be a multi-disciplinary approach with counsellors, with the treating specialist, with everyone involved, making the decision to say ok it’s end-of-life, we are going to withdraw continuous care.” – Interview #4F

Palliative care itself makes use of a multi-disciplinary approach. [3] Thus, the integration of palliative care into EMS would result in EMS providers becoming role players. Many studies concerning prehospital palliative care have recommended a multi-disciplinary approach to provide the best possible care for palliative patients in all environments. [4, 8-10, 32] This should be considered in the South African prehospital setting.

c) Creation of pre-hospital palliative care specialists/teams

Participants mentioned the possibility of deploying specialised pre-hospital palliative care units which would “*fundamentally change the scope*” of prehospital healthcare influence. Candidates did not elaborate on what personnel the unit would consist of; however, a specialized unit would be able to incorporate not only EMS providers, but specialists from other medical disciplines, providing for a multi-disciplinary approach.

“In my view we might have to have pre-hospital specialists who have specialized in palliative medicine...I think it would be such an important additional component.” – Interview #2M

“I literally think you could have a specialised unit dedicated to palliative care. That’s how much of a need there is for it.” – Interview #4F

Quality of palliative care in the prehospital setting has been found to depend on the expertise of the healthcare providers present. [21] Thus, implementing specialist prehospital palliative care teams may improve quality of palliative patient care. While the use of specialist pre-hospital palliative care teams has not been researched in South Africa or abroad, Wiese, et al. have stated the necessity of integrating these specialist teams to support both the palliative patient as well as EMS providers faced with palliative situations. [3]

Limitations

The qualitative design of the study resulted in the ability to gather the thoughts and opinions of participants however, these may not be representative of other providers

within differing areas of South Africa or other countries. Furthermore, study participants all graduated from a single institution. While these limitations to transferability are apparent, the findings of this study correlate well with the findings of similar studies performed in other countries. The voluntary nature of participation in the study may mean only those with strong feelings about the topic participated, however, their opinions should be seen as no less valuable. Finally, a more varied sample may have resulted in more varied results. This is important for future study as cultural beliefs and practices vary concerning end-of-life situations.

Further research should be conducted within different South African settings, to further expand on the topic of prehospital palliative care, including the public sector which services different patient populations and may have more severe resource limitations. Research is needed to determine what effect prehospital palliative care would have on patients as well as develop guidelines and curricula for training purposes.

Conclusion

The aim of this study was to begin exploring the topic of South African prehospital palliative care by gathering the thoughts and opinions of ALS providers within the South African private EMS sector concerning prehospital palliative care importance, feasibility and barriers to practice. Four categories arose from interview analyses: 1) need for pre-hospital palliative care, 2) function of pre-hospital healthcare providers concerning palliative care, 3) challenges to pre-hospital palliative care and 4) ideas for implementing pre-hospital palliative care. According to the interviewees of this study, pre-hospital palliative care in South Africa is needed and EMS providers can play a valuable role. However, many challenges such as a lack of education and EMS system and mindset barriers exist. These barriers may be overcome by developing guidelines, training, and a multi-disciplinary approach. Given the paucity of research on the topic of prehospital palliative care in South Africa, the quadruple burden of disease described in literature and the personal experiences of the participants interviewed, the need for prehospital palliative care in the country is apparent and plans for implementation should be developed.

Conflicts of Interest

The authors declare no conflicts of interest.

Authors' Contributions

CG and WS conceptualized the idea for the study. CG performed data collection, analysis and drafted the manuscript. WS assisted in data analysis and acted as project supervisor alongside HG. All authors approved the final submitted version.

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PART C: ADDENDA

a. Journal Instructions

AUTHOR INFORMATION PACK

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DESCRIPTION

The *African Journal of Emergency Medicine* (AfJEM) is the official journal of the *African Federation for Emergency Medicine*. It is an Africa-centric, peer-reviewed journal aimed in particular at supporting emergency care across, you guessed it, Africa. AfJEM publishes original research, reviews, brief reports of scientific investigations, case reports as well as commentary and correspondence related to topics of scientific, ethical, social and economic importance to emergency care in Africa. Articles will be of direct importance to African emergency care, but may have originated from elsewhere in the world.

AfJEM publishes manuscripts of international quality. This is ensured through a process of rigorous peer-review (see below) where manuscripts are evaluated for accuracy, novelty and importance. It is however recognised that African researchers in emergency care are disadvantaged in the available range of journals into which they can publish their work. The editorial team is aware that this is due to many reasons, including that developing world topics are often considered too basic for western Emergency Medicine journals, or that topics are concerned with conditions which are largely irrelevant to those audiences. Furthermore, the quality of submitted manuscripts is often lower than acceptable international journal standards due to inadequate research training. AfJEM is dedicated to support all authors who wish to make an attempt at publication on an African Emergency care topic. In order to maintain and produce a high quality, international standard Emergency Medicine journal, AfJEM has devised *Author Assist*. For more detail go to <http://www.afjem.com/author-assistance.html>.

AfJEM is uniquely tailored to the needs and requirements of emergency care workers dedicated to improving emergency medicine in Africa. AfJEM specifically aims to address resource limitations as it pertains to the African continent. It will be ideal reading material for physicians, nurses and pre-hospital care workers wishing to improve their knowledge on general emergency medicine, trauma care, paediatrics, injury and disease prevention, service improvement, policy and ethics, disaster preparedness and response, and all other aspects of emergency care. In keeping with the *African Federation for Emergency Medicine*, it is our aim to be recognised as the international voice of quality emergency medical care in Africa.

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Details of publisher

GUIDE FOR AUTHORS

INTRODUCTION

The African Journal of Emergency Medicine (AfJEM, ISSN: 2211-419X) is the official journal of the [African Federation for Emergency Medicine](#). It is an international, peer-reviewed journal aimed in particular at supporting emergency care across Africa. AfJEM publishes original research, reviews, brief reports of scientific investigations, case reports as well as commentary and correspondence related to topics of scientific, ethical, social and economic importance to emergency care in Africa. Articles will be of direct importance to African emergency care, but may have originated from elsewhere in the world.

TYPES OF ARTICLES

Original Research: Original studies of basic or clinical investigations in areas relevant to emergency medicine. Reference to the relevance of the research in a resource poor setting is essential and should be alluded to in the discussion section. References and a structured abstract (see Preparation below) are required. Maximum length: 3,000 words, 5 tables and/or figures, plus the abstract (300 words) and references (max 50). The checklists found on the following websites should be used to structure your manuscript (a completed checklist showing that you adhered to the reporting format should be submitted with your manuscript):

- a. For randomised control trials: <http://www.consort-statement.org>
- b. For cohort, case-control, and cross-sectional studies: <http://www.strobe-statement.org/>
- c. All other studies: <http://www.equator-network.org/library/>

b. Interview Schedule

Interview Schedule

THE THOUGHTS AND OPINIONS OF ADVANCED LIFE SUPPORT PROVIDERS IN
THE SOUTH AFRICAN PRIVATE EMERGENCY MEDICAL SERVICES SECTOR
CONCERNING PRE-HOSPITAL PALLIATIVE CARE

NOTES TO INTERVIEWER: Statements in *ITALICS* are instructions to the interviewer. Questions and text to be read out are in **BOLD**. Prompts contained in textboxes may also be read out during the interview to encourage further dialogue or where questions require additional explanation.

FACILITATION: *Before the interview, refer to these notes to ensure familiarity with the content. All interviews should be run by the primary researcher. The primary researcher is to lead the discussion and take notes as well as operate the audio recording device. Each interview should lead to new thoughts, ideas and conclusions unless it is determined that theoretical saturation has been reached.*

PREPARATION: *Audio recording equipment and its sensitivity should be tested from various positions within the room before the interview. Ensure that participant consent forms and note-taking material is ready. Offer participant refreshments. Ensure the participant is as comfortable as possible before beginning the interview. Confirm that the participant has signed the consent form and that they consent to being audio recorded.*

CONFIDENTIALITY STATEMENT: **There are no right or wrong answers or opinions on the topic we will be discussing. We are here to gather your own personal and valuable thoughts. All your views, thoughts, opinions and answers will be kept confidential. I would also like to remind you that your consent can be withdrawn at any time, including during this process. (Give opportunity for questions on confidentiality)**

SESSION INTRODUCTION: *Start by briefly introducing yourself and the interview. Ask the participant to introduce themselves. You may start the session as follows:*

Identify participant on the recording by study number and gender

Thank you for taking the time to discuss the topic of pre-hospital, palliative, end-of-life care in South Africa. In essence, palliative care refers to the specialized treatment of terminally ill patients. Treatment is aimed at improving quality of life as well as relieving suffering. The purpose of this interview is to gather your thoughts and opinions on the importance of this care, concerns to performing this care and feasibility of performing this care specifically in the South African private pre-hospital setting.

I will start by briefly asking about yourself and your experience. I will then ask three questions on the topic which we can discuss. If, at any point, you have any questions or need clarification please feel free to ask whenever you would like.

Could you please begin by telling me about your career and background?

<i>PROBES AND PROMPTS</i>
<i>Demographics: Age, Gender, Qualification, Position.</i>
<i>Years of experience.</i>
<i>Previous experience/positions.</i>

How important would you say the practice of palliative care is in the pre-hospital setting?

<i>PROBES AND PROMPTS</i>
<i>Optional vs. Necessary.</i>
<i>Patient suffering (i.e. pain, dyspnoea, anxiety).</i>
<i>Opportunity to practice this care.</i>
<i>Number of patients requiring this care.</i>

Would you have any personal concerns with performing palliative care?

<i>PROBES AND PROMPTS</i>
<i>Legal concerns: current policies, fear of litigation, euthanasia, possibility of causing further harm, misdiagnosing end-of-life situation</i>
<i>Ethical concerns: EMS goal of saving life, euthanasia, hastening death, conscience</i>
<i>Technical concerns: lack of training/education, scope of practice</i>
<i>Note: Several of these may lead naturally into the next question.</i>

What do you think about the feasibility of palliative care in the specific South African private pre-hospital setting(s) which you are or have been in?

<i>PROBES AND PROMPTS</i>
<i>Resources: medications, procedural equipment</i>
<i>Finances</i>
<i>Lack of qualified personnel</i>
<i>Scope of practice</i>
<i>Lack of training/education</i>

SESSION CONCLUSION: *Once all the questions have been asked and answered you may conclude the session as follows:*

Thank you again for spending your time on discussing this topic and taking part in this study. Your thoughts and opinions are very valuable and I appreciate your contribution.

c. Participant Information and Consent Form

Participant Consent Form

Dear Participant,

This consent form provides the necessary information regarding our study. By signing this consent form you agree to participate in this study, the details of which are provided here. The study is entitled ‘The Thoughts and Opinions of Advanced Life Support Providers in the South African Private Emergency Medical Services Sector Concerning Pre-Hospital Palliative Care’. The aim of the study is, as the name implies, to gather the thoughts and opinions of ALS providers in the South African private EMS sector concerning pre-hospital palliative care to assist in determining whether such treatment can and should be performed in the South African private pre-hospital setting.

Should you choose to participate in this research project you will be required to participate in a 15-45min, one-on-one interview in which four questions will be asked. The interview will be audio recorded and transcribed for analysis at a later stage.

The data contained within the audio recordings and transcriptions are completely anonymous. At no stage will you be required to state your name or any other identifying information. In addition, this consent form will be kept separate from the audio recording and transcription to prevent identification and preserve anonymity.

Please note that your consent is completely voluntary. You may either decide to participate or not participate without any consequence to yourself.

No remunerations will be made to you if you participate in the study. Also, there are no direct benefits perceived. However, this research may lead to future benefits in the field of pre-hospital emergency care. A potential risk, which may occur during the interview, is the triggering of a ‘bad memory’. The questions in the interview are designed to avoid this, however, if it does occur help will be provided.

The researchers involved in this study are Caleb Gage (MPhil EM Student), Willem Stassen (MPhil EM) and Dr. Heike Geduld (MMed). Should you have any questions regarding the study please contact Caleb: email - caleb.gage@gmail.com cell – 083 799 4357.

I, _____, hereby confirm that I have read and understood the above information regarding this study and give my consent to being interviewed and audio-recorded during the interview as a part of this study.

Participant Signature: _____ Date: _____

Researcher Signature: _____ Date: _____

Supervisor Signature: _____

Date: _____

d. Technical Appendices

Counsellor Details

OLIVE BRANCH TRAUMA CENTRE

Olive Branch, 37 Wordsworth Avenue, Farrarmere, Benoni

Tel: 072 122 4766 / 011 849-7473.

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Dr. Barbara Wade, D Phil (Social work) MSc (Psychology), is an accredited member of SAASWIPP (The South African Association of Social Workers in Private Practice) and practices in the field of individual and family therapy, as well as specializing in all forms of trauma.

e. Acknowledgements

I am grateful to God for the opportunity to further my studies through this project and for His help in completing it.

I would like to thank my supervisors for this project, Dr. Willem Stassen and Dr, Heike Geduld, for their invaluable support and assistance during the course of this study. Thank you, not only for your help with the project, but for ensuring it was a valuable learning experience for me.

I am indebted to Dr. Barbara Wade for agreeing to provide counselling during this study to the interviewees should it have been needed.

I would also like to acknowledge and thank my wife, Nwabisa Gage, for her prayers, encouragement and support during this process.

Finally, I thank my parents, Jeffery and Deborah Gage, for their support not only in this project, but the Master's degree as a whole.

Thank you all.

f. Research Protocol

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ER24

Dr. Heike Geduld
MMed
University of Cape Town

This study is in partial fulfilment of the MPhil Emergency Medicine degree.

I, Caleb Hanson Gage, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I authorise the University to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Plagiarism Declaration:

1. I know that plagiarism is a serious form of academic dishonesty.
2. I have read the document about avoiding plagiarism, am familiar with its contents and have avoided all forms of plagiarism mentioned there.
3. Where I have used the words of others, I have indicated this by the use of quotation marks.
4. I have referenced all quotations and properly acknowledged other ideas borrowed from others.
5. I have not and shall not allow others to plagiarise my work.
6. I declare that this is my own work.
7. I am attaching the summary of the Turnitin match overview (when required to do so).

Signature:

Date:

1. Title:

The Thoughts and Opinions of Advanced Life Support Providers in the South African Private Emergency Medical Services Sector Concerning Pre-Hospital Palliative Care.

2. Purpose of Study:

Palliative care refers to the specialised treatment of life-threatening illness including terminal illness. ¹ Treatment is aimed at improving quality of life as well as relieving suffering. ¹ This treatment is typically performed by palliative care specialists who work in-hospital. However, pre-hospital emergency services are often the first point of medical contact for palliative care patients and frequently encounter end-of-life situations. Currently, palliative care is not common in pre-hospital emergency service systems around the world. This is particularly true in the South African pre-hospital context where no palliative care guidelines or policies on the subject exist. In addition, there is no pre-hospital emergency care curricula on the subject resulting in a lack of education and training for EMS personnel.

As the first point of medical contact, pre-hospital emergency service systems are uniquely positioned to deliver early palliative care. This is of great potential benefit to patients. Therefore, the purpose of this study is to explore this potential benefit by gathering the thoughts and opinions of advanced life support (ALS) providers regarding importance, concerns and feasibility of pre-hospital palliative care in South Africa.

3. Background:

The World Health Organisation (WHO) defines palliative care as ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’ ¹ This includes a wide variety of situations such as end-of-life care.

Pre-hospital EMS systems often encounter patients requiring palliative care. ² However, these same EMS systems do not have guidelines, protocols or procedures in place to provide palliative care. This stems from the historical focus of EMS training: acute medical management and the resulting ethos of ‘saving lives’. ³ Therefore, palliative care may be seen to conflict with emergency care specifically regarding end-of-life situations. ³

A 2010 study in Germany retrospectively analysed EMS calls involving palliative care cases.² The study found that 3% of all EMS calls involved emergent situations of palliative care patients.² Of these, 60% involved cardiac arrest.² Not only does this highlight the fact that EMS providers deal with palliative care cases, but that often those cases involve end-of-life care. In the South African context, with increased morbidity rates and burden of disease, these percentages are likely much greater.⁴

Another retrospective study of palliative care cases managed by EMS was performed in Switzerland.⁵ This study identified many ethical dilemmas which EMS providers face when dealing with palliative care cases and called for formal training in palliative care for EMS.⁵ These dilemmas included respecting patient autonomy as well as correctly applying legal documentation, such as advance directives, in a time-constrained emergency setting.⁵ The study stated that the ‘risk of not respecting the wishes of the patient and of aggressive and futile therapy is considerable’.⁵

A recent online survey in England sought to gather the thoughts of paramedics on end-of-life care in their environment.³ There were 182 respondents who identified several common areas of concern regarding end-of-life care including issues with documentation (70%), fear of litigation (46%) and conflict with patient family members (50%).³ The article concluded that while paramedics saw end-of-life care to be crucial to their role in EMS, specific education is needed for them to feel confident and supported.³

A 2015 Australian study used a mixed methods approach with a survey tool to gather the thoughts of paramedics regarding palliative care.⁶ There were a total of 29 respondents, all of whom identified 3 specific areas of education which were needed: ethical issues surrounding palliative care, end-of-life communication practices and structured palliative patient care pathways.⁶ The study concluded that paramedics have a sound grasp of palliative care, with a particular emphasis on end-of-life care, however, specific education was lacking.⁶

Interestingly, in the German physician led EMS, palliative care is provided in the pre-hospital setting to select patient groups (i.e. advanced neoplastic disease).⁷ This has proven valuable in keeping patients comfortable at home, as well as reducing the burden on the hospital system in Germany.⁷ Thus, pre-hospital palliative care has proven beneficial in that setting. Our study aims to explore these potential benefits and needs regarding pre-hospital palliative care in the South African paramedic led EMS by gathering the thoughts and opinions of the paramedics on the ground.

Together, these articles highlight a recently recognized need in the pre-hospital EMS setting for education in palliative care. EMS providers worldwide deal with palliative care cases while lacking essential guidance. The South African context is no different. While educational material on palliative care is available online, it is not currently used as part of EMS training, nor is it tailored to the pre-hospital setting.⁸ Developing pre-hospital palliative care guidelines also remains a challenge as research on palliative care as part of emergency medicine is scarce, particularly concerning the pre-hospital environment. To our knowledge, there has been no research produced in the South African context regarding pre-hospital palliative care.

4. Research Aim:

The aim of this study is to gather the thoughts and opinions of ALS providers in the South African private EMS sector concerning pre-hospital palliative care in terms of its importance and feasibility, as well as potential barriers to implementation.

5. Objectives:

- a) Gather the thoughts and opinions of ALS providers on the importance of palliative care in the South African pre-hospital context.
- b) Gather the thoughts and opinions of ALS providers on the feasibility of palliative care in the South African pre-hospital context.
- c) Identify concerns of ALS providers with regards to performing pre-hospital, palliative care and barriers to implementation.

6. Methodology:

6.1 Design:

The design of the proposed study will be qualitative using semi-structured, one-on-one, interviews.

6.2 Population:

A convenience sample of ALS providers within, or with prior experience in, the South African private EMS sector will be identified and interviews with 6-10 ALS providers will be conducted or up to the point of theoretical saturation. To prevent self-selection bias, ALS providers will be contacted via mass email through an ALS database. Those ALS who indicate their willingness to participate in the study will be contacted. To prevent gender bias, an equal number of male and female ALS providers will be interviewed.

Inclusion Criteria: Qualified ALS providers with higher education (HE) qualifications (National Diploma, Bachelor of Technology and Bachelor of Health Sciences in Emergency Medical Care), currently working in, or with recent previous experience in, the South African private EMS sector with a minimum of two years private sector operational experience. Recent previous experience refers to South African private sector operational experience, within the last 3 years should the ALS provider not currently be working in the private sector.

Exclusion Criteria: ALS providers without pre-hospital, operational experience in the South African private EMS sector.

ALS providers have been chosen as the population of the study due to their broad scope of practice when compared to other levels of training such as basic and intermediate life support providers. This scope of practice includes the ability to perform certain palliative, end-of-life care treatments. For example, opioids are commonly used in relieving the suffering of dying patients. The ALS scope in South Africa includes opioid use for acute pain management, however, current guidelines do not mention opioid use for palliative situations. Therefore, gathering ALS provider thoughts and opinions on this topic will be valuable.

The private South African EMS sector has been chosen as the research team has greater access to the ALS providers within the private system when compared to the public system. In addition, the private system is more suited to the inclusion and exclusion criteria of this study.

6.3 Recruitment:

ALS providers meeting the inclusion and exclusion criteria will be contacted via mass email about the study with use of an ALS database. The database which will be used is a locally formed database of South African paramedics who have volunteered their names to be a part of the database. Emails regarding job opportunities as well as research projects are regularly sent to this list of paramedics.

A brief description of the study will be given via email, and should ALS providers indicate their willingness to participate, an interview date, time and place will be agreed upon. Once at this meeting, the participant information and consent form and opportunity for questions will be given to the ALS provider. Once informed consent regarding the study has been gained, further consent will be gained regarding audio recording of the interview. The interview will then begin. Consent may, however, be withdrawn at any time before or during the interview or before transcription of the data and this will be explained to the participant.

6.4 Research Procedures and Data Collection Methods:

Interviews will be one on one and performed by the primary researcher, who has been trained in qualitative interviewing. Before interviews are performed for data collection, pilot interviews will be practiced by the interviewer and supervisor(s) to ensure consistency and quality of interview technique.

The interview schedule will contain 4 questions referencing career background, importance of, concerns around and opinions of end-of-life care in the South African private prehospital environment. In addition, pre-determined prompts and probes will be included for each question asked to gain more in-depth data (See Appendix A). These interviews will be recorded and transcribed for data analysis.

Each interview will be held in a private, comfortable setting agreed upon by the primary researcher and participant. Each interview will last approximately 25-35 minutes. To avoid potential interruptions, interviews will be held with off-duty ALS providers.

6.5 Data Safety and Monitoring:

After an interview, the audio recording device will be kept on the primary researcher's person until the audio file is copied onto the primary researcher's private, password protected laptop. This audio file will be backed up using Dropbox, a password controlled cloud storage system. The audio file on the recording device will then be deleted. At no time will the private laptop, email address, audio recording device and audio files be made available to anyone other than the research team. Transcribed copies of the audio files will be stored and backed up in the same manner and the research team will work with de-identified transcriptions. Thus, audio and transcribed data will be safely and privately secured.

6.6 Data Analysis:

Thematic analysis of transcribed data will be done using the framework of Braun and Clark in combination with the techniques described in '*A hands-on guide to doing content analysis*'.⁹

¹⁰ This will be done in 6 main steps: ^{9, 10}

Step 1: The researcher will familiarise himself with the transcribed data by reading and re-reading.

Step 2: Initial coding of the data will be performed.

Step 3: The various codes will be sorted into different categories and themes.

Step 4: Themes will be reviewed and refined.

Step 5: Themes will be named and defined.

Step 6: This data and analysis thereof will be written up as part of the discussion in the final report.

These steps of data analysis will begin alongside data collection as the primary researcher will make notes during interviews. These steps will also be flexible as the primary researcher will move back and forth between them to refine the data.

The research team will independently analyse the data; and develop and finalise the themes together.

To ensure trustworthiness of the data the framework of Guba will be used in seeking credibility, transferability, dependability and confirmability. ¹¹ The following are ways in which these four criteria will be ensured by the study: ¹¹

Credibility: Interviewing technique will be practiced before holding the actual interviews. Population sampling will be random through use of a database. Participants will be given the opportunity to refuse participation. During data collection and analysis frequent communication and debriefing sessions will be held between the interviewer and project supervisors.

Transferability: In the write-up, a thorough description of data collection methods will be given. This will include the number and length of data collection sessions as well as the total time-period over which data was collected.

Dependability: Full descriptions of research design and implementation as well as the details of data gathering will be presented in the write-up.

Confirmability: Preliminary hypotheses held by the research team which are not demonstrated in the data will be discussed in the write-up and reflected upon.

7. Ethical Considerations:

7.1 Risks and Benefits:

There will be no direct, immediate benefits to research participants.

A potential risk exists of the triggering of a personal, emotional memory during an interview. Should such an event occur, the interview will be stopped and access to counselling or any other resource necessary be offered and provided (See **7.5** and Appendix C). Participants will have access to their own institutional counselling resources. However, the research team will make an external counselling service available for the duration of the study.

7.2 Informed Consent Process:

Informed consent will be gained from all ALS providers for both participation in the study as well as recording and transcription. This will be done using an information sheet which will be read and signed by the potential candidate (See Appendix B). In addition, the researcher

will verbally explain the study as well as answer any questions the potential candidate may have. Participants will be free to withdraw their consent at any time as participation in the study is completely voluntary. However, due to the anonymous design of the study, consent cannot be withdrawn post-transcription of the data as there would be no way of connecting the interviewee with their transcribed interview.

7.3 Privacy and Confidentiality:

The gaining of informed consent and the performing of interviews will be done privately. The aim is to ensure no third party knows the participant is a part of this study unless informed by the participant.

The consent forms signed by the participants will be stored separately and will not be attached to the transcribed interviews. Furthermore, transcriptions will be edited to remove identifying data which may be stated during the interview. For example, should the interviewee mention their name, this will be removed from the transcript.

Storage of transcribed interviews will be secure. This will be done electronically using the primary researcher's private, password protected laptop computer. Back up of transcriptions will be done using Dropbox, a password controlled cloud storage system.

After transcription, audio recordings will be destroyed.

7.4 Reimbursement for Participation:

No reimbursement will be offered for participation. Participation will be completely voluntary.

7.5 Access to Care for Research Related Harm:

Should a personal, emotional memory during an interview be triggered the interview will immediately be stopped and contact details of a counsellor will be provided (See Appendix C). The interviewer will make any appropriate efforts to ensure the interviewee is assisted.

8. Dissemination of Findings Plan:

Findings of this study will be disseminated in the hope of stimulating further research on the topic. The research project, once complete will be disseminated in the following ways:

- a) Access to the study will be made freely available in PDF format via the UCT repository.
- b) The study will be published in a relevant journal which will ideally be free with open-access.
- c) Opportunities for research presentation will be sought.

9. Project Timeline:

EMDRC: November 2017

HREC (ethics): January-February 2018

WCG Health Application: January-February 2018

Data Collection: March-December 2018

Data Analysis: January-March 2019

Write-up: April-July 2019

Final Submission: August 2019

10. Resource Utilisation:

- a) Audio recording device for interviews.
- b) Laptop computer on which to transcribe audio recordings.
- c) Private email account for storage of transcriptions.
- d) Time.
- e) Transport costs. Interviews may be scheduled in a variety of places at the convenience of the participants.
- f) Transcription costs.

All the above resources are currently in place and in possession of the primary researcher.

11. Budget:

- a) Transcription costs: R4000-R6000
- b) Transport costs: R1000
- c) Total Budget: R7000

These costs are estimates. The primary researcher will cover all costs involved.

12. References:

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2. Wiese CHR, Bartels UE, Zausig YA, Pfirstinger J, Graf BM, Hanekop GG. Prehospital emergency treatment of palliative care patients with cardiac arrest: a retrolective investigation. *Support Care Cancer*. 2010;18:1287-1292.
3. Kirk A, Crompton PW, Knighting K, Kirton J, Jack B. Paramedics and their role in end-of-life care: perceptions and confidence. *Journal of Paramedic Practice*. 2017;9(2):71-79.

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http://www.who.int/healthinfo/global_burden_disease/en/. Accessed On: 07/10/17.
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7. Aguilara S, Cabanas JG, Machado A. Staffing of Ambulances. In: Tintinalli J, Cameron P, Holliman J, editors. *EMS : a practical global guidebook*. 1st ed. Shelton (CT): People's Medical Publishing House. 2010.
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11. Shenton AK. Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*. 2004;22:63–75.

13. Appendices:

Appendix A: Discussion Schedule

Appendix B: Participant Information and Consent Form

Appendix C: Counsellor Contact Details and Information

Discussion Schedule

THE THOUGHTS AND OPINIONS OF ADVANCED LIFE SUPPORT PROVIDERS IN THE SOUTH AFRICAN PRIVATE EMERGENCY MEDICAL SERVICES SECTOR CONCERNING PRE-HOSPITAL PALLIATIVE CARE

NOTES TO INTERVIEWER: Statements in *ITALICS* are instructions to the interviewer. Questions and text to be read out are in **BOLD**. Prompts contained in textboxes may also be read out during the interview to encourage further dialogue or where questions require additional explanation.

FACILITATION: *Before the interview, refer to these notes to ensure familiarity with the content. All interviews should be run by the primary researcher. The primary researcher is to lead the discussion and take notes as well as operate the audio recording device. Each interview should lead to new thoughts, ideas and conclusions unless it is determined that theoretical saturation has been reached.*

PREPARATION: *Audio recording equipment and its sensitivity should be tested from various positions within the room before the interview. Ensure that participant consent forms and note-taking material is ready. Offer participant refreshments. Ensure the participant is as comfortable as possible before beginning the interview. Confirm that the participant has signed the consent form and that they consent to being audio recorded.*

CONFIDENTIALITY STATEMENT: **There are no right or wrong answers or opinions on the topic we will be discussing. We are here to gather your own personal and valuable thoughts. All your views, thoughts, opinions and answers will be kept confidential. I would also like to remind you that your consent can be withdrawn at any time, including during this process. (Give opportunity for questions on confidentiality)**

SESSION INTRODUCTION: *Start by briefly introducing yourself and the interview. Ask the participant to introduce themselves. You may start the session as follows:*

Identify participant on the recording by study number and gender

Thank you for taking the time to discuss the topic of pre-hospital, palliative, end-of-life care in South Africa. In essence, palliative care refers to the specialized treatment of terminally ill patients. Treatment is aimed at improving quality of life as well as relieving suffering. The purpose of this interview is to gather your thoughts and opinions on the importance of this care, concerns to performing this care and feasibility of performing this care specifically in the South African private pre-hospital setting.

I will start by briefly asking about yourself and your experience. I will then ask three questions on the topic which we can discuss. If, at any point, you have any questions or need clarification please feel free to ask whenever you would like.

Could you please begin by telling me about your career and background? (*Reiterate that the interviewee should not state his/her name*)

<i>PROBES AND PROMPTS</i>
<i>Demographics: Age, Gender, Qualification, Position.</i>
<i>Years of experience.</i>
<i>Previous experience/positions.</i>

How important would you say the practice of palliative care is in the pre-hospital setting?

<i>PROBES AND PROMPTS</i>
<i>Optional vs. Necessary.</i>
<i>Patient suffering (i.e. pain, dyspnoea, anxiety).</i>
<i>Opportunity to practice this care.</i>
<i>Number of patients requiring this care.</i>

Would you have any personal concerns with performing palliative care?

<i>PROBES AND PROMPTS</i>
<i>Legal concerns: current policies, fear of litigation, euthanasia, possibility of causing further harm, misdiagnosing end-of-life situation</i>
<i>Ethical concerns: EMS goal of saving life, euthanasia, hastening death, conscience</i>
<i>Technical concerns: lack of training/education, scope of practice</i>
<i>Note: Several of these may lead naturally into the next question.</i>

What do you think about the feasibility of palliative care in the specific South African private pre-hospital setting(s) which you are or have been in?

<i>PROBES AND PROMPTS</i>
<i>Resources: medications, procedural equipment</i>
<i>Finances</i>
<i>Lack of qualified personnel</i>

Scope of practice

Lack of training/education

SESSION CONCLUSION: *Once all the questions have been asked and answered you may conclude the session as follows:*

Thank you again for spending your time on discussing this topic and taking part in this study. Your thoughts and opinions are very valuable and I appreciate your contribution.

Participant Consent Form

Dear Participant,

This consent form provides the necessary information regarding our study. By signing this consent form you agree to participate in this study, the details of which are provided here. The study is entitled ‘The Thoughts and Opinions of Advanced Life Support Providers in the South African Private Emergency Medical Services Sector Concerning Pre-Hospital Palliative Care’. The aim of the study is, as the name implies, to gather the thoughts and opinions of ALS providers in the South African private EMS sector concerning pre-hospital palliative care to assist in determining whether such treatment can and should be performed in the South African private pre-hospital setting.

Should you choose to participate in this research project you will be required to participate in a 15-45min, one-on-one interview in which four questions will be asked. The interview will be audio recorded and transcribed for analysis at a later stage.

The data contained within the audio recordings and transcriptions are completely anonymous. At no stage will you be required to state your name or any other identifying information. In addition, this consent form will be kept separate from the audio recording and transcription to prevent identification and preserve anonymity.

Please note that your consent is completely voluntary. You may either decide to participate or not participate without any consequence to yourself.

No remunerations will be made to you if you participate in the study. Also, there are no direct benefits perceived. However, this research may lead to future benefits in the field of pre-hospital emergency care. A potential risk, which may occur during the interview, is the triggering of a ‘bad memory’. The questions in the interview are designed to avoid this, however, if it does occur help will be provided.

The researchers involved in this study are Caleb Gage (MPhil EM Student), Willem Stassen (MPhil EM) and Dr. Heike Geduld (MMed). Should you have any questions regarding the study please contact Caleb: email - caleb.gage@gmail.com cell – 083 799 4357.

I, _____, hereby confirm that I have read and understood the above information regarding this study and give my consent to being interviewed and audio-recorded during the interview as a part of this study.

Participant Signature: _____ Date: _____

Researcher Signature: _____ Date: _____

Supervisor Signature: _____ Date: _____

Counsellor Details

OLIVE BRANCH TRAUMA CENTRE

Olive Branch, 37 Wordsworth Avenue, Farrarmere, Benoni

Tel: 072 122 4766 / 011 849-7473.

Email: drwade@olivebranch.co.za

Dr. Barbara Wade, D Phil (Social work) MSc (Psychology), is an accredited member of SAASWIPP (The South African Association of Social Workers in Private Practice) and practices in the field of individual and family therapy, as well as specializing in all forms of trauma.

g. HREC Approval Letter



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room **ES3-45** Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone (021) 406 6626
Email: shunika.thomas@uct.ac.za
Website: www.health.uct.ac.za/hrs/research/humanethics/forms

22 January 2018

HREC REF: 038/2018

Dr HI Geduld
Emergency Medicine
F51, Old Main Building

Dear Dr Geduld

PROJECT TITLE: THE THOUGHTS AND OPINIONS OF ADVANCED LIFE SUPPORT PROVIDERS IN THE SOUTH AFRICAN PRIVATE EMERGENCY MEDICAL SERVICES SECTOR CONCERNING PRE-HOSPITAL PALLIATIVE CARE (MPhil-candidate-Mr C Gage)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has formally approved the above-mentioned study.

Approval is granted for one year until the 30 January 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/hrs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator must obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledges that the student, Caleb Gage will also be involved in this study.

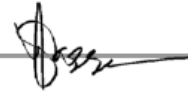
Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, THE HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

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