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The Development of Integrated Palliative Care and Emergency Medical Services in South Africa

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1) Gage CH, Stander C, Gwyther L, Stassen W. Emergency medical services and palliative care: a scoping review. BMJ Open. 2023;13:e071116.

2) Gage CH, Spies B, Crombie K, et al. The use of emergency medical services for palliative situations in Western Cape Province, South Africa: A retrospective, descriptive analysis of patient records. SAMJ. 2023;113(11):41-46.

3) Gage CH, Spies B, Crombie K, Slingsby T, Gwyther L, Stassen W. A Spatio-Temporal Analysis of Emergency Medical Services Use for Palliative Situations in Cape Town, South Africa. ***Accepted for Publication in South African Medical Journal.***

4) Gage CH, Gwyther L, Stassen W. South African palliative care provider perspectives on emergency medical services in palliative situations. AfJEM. 2024;14:231–239.

5) Gage CH, Gwyther L, Stassen W. The Dynamic of Control: Perspectives of Patients and Family Members With Palliative Care Needs on Emergency Medical Services. ***Under Peer Review: Sage Journals.***

6) Gage CH, Gwyther L, Ambler J, Burke J, Holmes L, Evans K, Krause R, Lachenicht K, Lincoln D, Payne K, Ratshikana-Moloko M, Stander C, Stassen W. Facilitating the Integration of Emergency Medical Services and Palliative Care in South Africa: A Nominal Group Technique. ***Accepted for Publication in African Journal of Primary Healthcare and Family Medicine.***

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Abstract

Background

The role of Emergency Medical Services in out-of-hospital patient management has evolved rapidly in recent years to include more intricate and integrated forms of healthcare beyond emergency care. For example, there has recently been recognition of the role Emergency Medical Services play in the provision of palliative care. The developing body of literature on this topic has recommended Emergency Medical Services and palliative care systems should integrate to improve palliative situation management in the out-of-hospital setting. In South Africa, however, these systems remain segregated. As a result, palliative situations are managed poorly by Emergency Medical Services providers due to disregard of patient autonomy and performance of aggressive, futile interventions. Potential benefits of integration between these systems include delivery of early palliative care, provision of home-based care, respect of patient autonomy, improved patient/family quality of life, increased patient and family satisfaction and confidence, decreased health care costs and appropriate trajectories of care. A further benefit in the low-to-middle income context of South Africa would be efficient use of limited resources.

Aim and Objectives

To develop a framework for the integration of palliative care and Emergency Medical Services systems in South Africa.

The research aim was pursued through the following objectives, each of which represented a study within the thesis:

Study 1: To review existing literature concerning the intersection of palliative care and Emergency Medical Services.

Study 2: To examine Emergency Medical Services use for palliative situations in South Africa.

Study 3: To gather the perspectives of palliative care providers on Emergency Medical Services use in palliative care in South Africa.

Study 4: To gather perspectives of South African patients and family members with palliative needs concerning Emergency Medical Services use in their care.

Study 5: To develop and prioritise approaches facilitating Emergency Medical Services and palliative care system integration within South Africa.

Methods

Study 1 was a scoping literature review performed with an *a priori* search strategy inclusive of grey literature. Empirical, English studies involving human populations published between 1 January 2000 and 24 November 2022 concerning EMS and palliative care were included. Extracted data underwent descriptive content analysis.

Study 2 was an observational, descriptive, retrospective patient record review employed at two hospitals with palliative care services in the Western Cape of South Africa. All patient records of those who arrived at the hospitals between 1 January 2020 and 31 December 2020 via EMS conveyance leading to palliative care provision were included in the study. Summary descriptive statistics (medians, ranges) were used to describe the numerical data (such as patient age). Clinical variables (such as patient chief complaint) were analysed as categorical data. Emergency Medical Services intersection with palliative situations according to time of day, working hours, day of week, and month of year were subjected to Chi-squared testing for temporal analysis. Geospatial data were investigated using cluster and proximity analyses. Spatio-temporal and clinical analyses were reported in separate articles.

Study 3 employed a qualitative design using individual semi-structured interviews with doctors and nurses holding post-graduate palliative medicine qualifications. Verbatim transcriptions of interviews were subjected to content analysis using an inductive-dominant approach to develop codes and categories.

Study 4 employed a qualitative design using individual semi-structured interviews with patients and family members with palliative needs. Verbatim transcriptions of interviews were subjected to thematic analysis using an inductive-dominant approach to develop categories and themes.

Study 5 was a nominal group technique, involving experts from both Emergency Medical Services and palliative care, who answered the question “what do you think should be done to most effectively integrate Emergency Medical Services and palliative care services in South Africa?” Answers were sorted into categories, awarded scores by participants, and ranked according to their impact and feasibility within SA.

Interviews with Emergency Medical Services providers were performed previously and are not repeated in this thesis. However, findings from this previous study are incorporated.

Results

Study 1 included 56 articles for review. Overall, these articles noted that EMS have a role to play in out-of-hospital palliative care, however, many challenges must be overcome. This study identified knowledge gaps and provided overall context for the thesis and subsequent studies.

In Study 2, 1 207 unique patients received palliative care services during the study period. Of these, 395 (33%) made use of Emergency Medical Services for hospital conveyance on 494 occasions. The median (range) patient age was 60 (20-93) years, and most transports involved male patients (54%, *n*=265). Family members were the primary caregivers in most instances (89%, *n*=440), dyspnoea was the most common chief complaint (36%, *n*=178) and cancer was the most frequent diagnosis (32%, *n*=159). The median length of hospital stay was 6 days, with most patients discharged home (60%, *n*=295). Most Emergency Medical Services transports occurred from peri-urban areas (78%, n=385), during the daytime (52%, n=257), out-of-office hours (53%, n=261), and weekdays (76%, n=375). Statistically significant variation in distribution was found according to time of day (p=<0.001), with 38% (n=188) of cases occurring between 13h00 and 19h00, and month of year (p=<0.001), with 36% (n=177) occurring in June, August and October. Proximity analysis revealed a mean driving time of 6.69min and distance of 3.65km to palliative care facilities. This study provided quantitative evidence of Emergency Medical Services intersection with palliative situations in South Africa as well as insight into palliative care access.

Study 3 found that palliative care providers maintained an overall positive view of integration with Emergency Medical Services, noting their beneficial impact and suggesting various methods of integration, while also highlighting challenges and concerns. In Study 4 patients and family members with palliative care needs described a loss of previous control they held over their lives and a subsequent longing to maintain what control remained. Emergency Medical Services care was viewed positively when this longing was satisfied and negatively when further control was seized. These studies allowed for the incorporation of primary stakeholder perspectives on the integration of Emergency Medical Services and palliative care.

In Study 5, fifty-two methods of Emergency Medical Services and palliative care integration were generated and ranked by the expert panel. These methods formed the following categories (listed in rank order from highest to lowest): Awareness, Education, Community Engagement, Communication and Information Sharing, Stakeholder Collaborations, Alternative Pathways and Approaches, Research, Funding, Policy Development, Governance.

Conclusions

This thesis identified and filled knowledge gaps concerning Emergency Medical Services and palliative care integration in the South African setting through review of contemporary literature, retrospective analysis of palliative situations involving Emergency Medical Services, gathering of primary stakeholder views, and expert panel development of integrative methods. While previously assumed, substantial intersection between Emergency Medical Services and palliative situations in South Africa has now been demonstrated, highlighting the significance of this topic within the country. Primary stakeholder perspectives offered support for Emergency Medical Services and palliative care integration, and novel insights into patient and family member experiences, necessitating a person-centred approach to care, have been provided. Guidance for the implementation of such integration, provided by experts from both Emergency Medical Services and palliative care systems, has been developed.

Based on this evidence, a conceptual framework for Emergency Medical Services and palliative care integration in South Africa was produced alongside guidance for practical use. The implementation of this framework will assist in the efficient use of limited healthcare resources in the country while simultaneously improving access to and quality of palliative care for those in need.

Though the framework presented here was developed for the South African context, it contains elements from the international literature as well as World Health Organization and health system integration frameworks. Thus, this framework may have applications outside of South Africa, particularly in other low-to-middle income countries with similar resource constraints. Future research should monitor the safety and efficacy of framework implementation, investigate the economic impact of EMS and palliative care integration through cost-effectiveness studies, develop curriculum for EMS education in palliative care, and involve pilot studies.

Table of Contents

List of Tables and Figures

Frequently Used Abbreviations

ACP	Advance Care Plans
AIDS	Acquired Immunodeficiency Syndrome
ALS	Advanced Life Support
APCC	Association of Palliative Care Centres
CAS	Complex Adaptive Systems
CFEPI	Conceptual Framework for EMS and Palliative Care Integration
CPD	Continual Professional Development
DNR	Do Not Resuscitate
ECP	Emergency Care Practitioner
ED	Emergency Department
EMS	Emergency Medical Services
EoL	End-of-Life
HE	Higher Education
HIC	High-Income Country
HIV	Human Immunodeficiency Virus
HPCSA	Health Professions Council of South Africa
HREC	Human Research Ethics Committee
IPCHS	Integrated People-Centred Health Services
LMIC	Low-to-Middle-Income Country
MOLST	Medical Orders for Life-Sustaining Treatment
NCD	Non-Communicable Disease
NGO	Non-Governmental Organizations
NGT	Nominal Group Technique
NHI	National Health Insurance
NHS	National Health Service
PALPRAC	Palliative Care Practitioners of South Africa
PC	Palliative Care
QoL	Quality of Life
SA	South Africa
SD	Standard Deviation
SDG	Sustainable Development Goal
UCT	University of Cape Town
UHC	Universal Health Coverage
WC	Western Cape
WHA	World Health Assembly
WHO	World Health Organisation

Definition of Key Terms

Emergency Medical Services: those systems and personnel providing medical care in the out-of-hospital setting using ambulance-based services.

Integrated Health Systems: the coordination of health services and the collaboration amongst provider organizations to establish an effective health system.

Out-of-Hospital Setting: All areas to which EMS may be called, from patient homes to any public space.

Palliative Care: an approach that improves the quality of life of patients and their families facing the problems 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.

Palliative Needs: needs arising from the pain, suffering and other problems (physical, psychosocial and spiritual) associated with life-threatening illness.

Palliative Situation: any event involving the care of a patient with palliative needs, including emergency, non-emergency, and end-of-life situations.

Person-Centred Care: an approach that consciously adopts the perspectives of individuals, families and communities, respects and responds to their needs, values, and preferences, and sees them as participants in their own healthcare rather than just beneficiaries.

Section 1

Introduction, Reflexivity, and Evidence Review

Section Introduction

Section 1 introduces the topic of EMS and palliative care, outlines the thesis structure, and provides contextual background for the remainder of the thesis. EMS and palliative care systems are discussed, and the problem of their segregation is highlighted. Contextual background is provided through a scoping literature review and personal reflexivity by the author aimed at improving trustworthiness.

This section consists of the following sub-sections:

- Chapter 1: Introduction
- Chapter 2: A Reflection on Personal Beliefs, the Research Journey and Thesis Outcomes
- Chapter 3: Gage CH, Stander C, Gwyther L, Stassen W. Emergency medical services and palliative care: a scoping review. BMJ Open. 2023;13:e071116.
- Section 1 Overview

The chapters which make up this section include one published article which is replicated *verbatim* but formatted and referenced appropriately for consistency throughout this thesis. This section concludes with an overview including additional considerations, key messages and how these contribute to thesis in its entirety.

Chapter 1: Introduction

Background

The role of emergency medical services (EMS) in out-of-hospital patient management has evolved rapidly in recent years to include more intricate and integrated forms of healthcare beyond emergency management. (1) For example, EMS systems have played increasingly important roles in the provision of community-based care. (2) As part of this community care, there has been a greater recognition of the role EMS systems play in the provision of palliative care. (2–5) The growing body of literature in this field has recommended integration between EMS and palliative care systems to improve palliative situation management in the out-of-hospital setting. (6–8) For the purposes of this thesis, 'palliative situation' is defined as any event involving the care of a patient with palliative needs, including emergency, non-emergency, and end-of-life situations.

The World Health Organisation (WHO) defines palliative care as *'an approach that improves the quality of life of patients and their families facing the problems 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.'* (9) Typically, existing literature involving EMS and palliative care focusses heavily on end-of-life (EoL) care. (10–13) Based on the WHO definition, however, palliative care includes a wide variety of situations such as chronic/life-limiting illnesses, EoL care and any condition (physical, psychosocial, spiritual) which may cause suffering. (9)

EMS systems are designed to manage patients in the out-of-hospital environment and provide transport to definitive care, as well as provide interfacility transfer services. (14,15) The purpose of EMS is to preserve life and limb in medical and traumatic emergencies. (16) EMS management of these emergencies involves application of immediate, 'life-saving', curative measures followed by conveyance to a medical facility for definitive care. (17,18)

Unlike EMS systems, however, palliative care is not primarily concerned with 'life-saving' interventions or medical facility-based definitive care. (16) Rather, palliative care is focussed on prevention and relief of suffering, thereby allowing patients to live, and die, with dignity. (9) It does not seek to shorten or prolong life but rather enhance its quality. (9,19) This involves psychosocial and spiritual care, management of symptoms (i.e. pain, dyspnoea), support for complex decision-making (i.e. advance care planning), respect of patient autonomy and co-ordination of care across multiple health settings making use of a multidisciplinary care team. (9,20,21)

South African Palliative Care

Currently, most palliative care in South Africa (SA) is provided by non-governmental organizations (NGOs) which provide hospice services, though there has been significant growth in state sector palliative care provision. (22,23) These NGOs are registered as charities and are reliant on donations and professional volunteers including doctors, nurses and social workers. (22) Despite the current available institutions, inequalities exist in distribution of these services and many areas of the country lack access to palliative care services. (22)

Progress has been made in SA palliative care education to integrate palliative care into multiple medical disciplines. (24) Palliative care training has been provided to nurses, doctors, correctional service facility workers and traditional healers in many areas of the country. (24–26) Furthermore, palliative care has been integrated into basic nursing and emergency medical curricula, and post-graduate palliative care qualifications have been developed (short course, diploma and degree programmes). (24) While large improvements have been made concerning education, the primary challenges to palliative care in SA remain limited human and financial capital, as well as inequitable access to services. (22)

The Disconnect

One area in SA where palliative care is yet to be integrated is EMS systems. (16) Currently, palliative care does not form part of SA EMS training or patient management, nor do palliative care systems make formal use of EMS to deliver palliative care. (16) This may be due to the apparent conflict between EMS and palliative care approaches. Although there is a disconnect between EMS and palliative care systems, the two frequently intersect. (5,6,8,12,16) EMS are called to assist palliative patients in emergency situations and transfer palliative patients between facilities. (5) This is particularly true after hours or during holidays when the usual patient caregivers are unavailable. (20,27,28)

As they progress towards EoL, patients with palliative care needs experience increasingly worse symptoms resulting in distress for themselves, family members and caregivers. (8,10,19) Thus, even in cases where advance care plans are in place and preparations have been made for a person to die at home, EMS are often called. (29,30) Frequently documented reasons for EMS calls in these cases are sudden, unexpected patient deterioration, caregiver exhaustion and alarming signs and symptoms such as dyspnoea, pain, convulsions and severe anxiety. (3,10,31)

SA Context

SA is a Low-to-Middle-Income Country (LMIC) which faces a 'quadruple burden of disease' due to communicable diseases such as human immunodeficiency virus (HIV), acquired immunodeficiency syndrome (AIDS), high maternal and paediatric mortality rates, non-communicable disease (NCD) and injury. (32) The large number of patients suffering from these diseases and the life-limiting complications thereof, has resulted in an increased need for palliative care in the country. (16)

Access to health care for patients suffering from these diseases is a further challenge within SA. (33–35) EMS are often contacted by those without access to transport to provide this service. (16) Thus, SA 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. (36) European studies have found that palliative care situations, including palliative emergencies and EoL situations, account for up to 10% of EMS calls. (8,31,37) No such data exists in SA. However, using mortality data alone, it has been estimated that 0.52% (n=286 000) of the SA population require palliative care annually. (24) With the quadruple burden of disease and limited access in the SA setting, the percentage of EMS calls to palliative situations is likely higher as these factors result in increased frequency of contact between EMS providers and patients requiring palliative care. (16)

Potential Integration Benefits

The problems arising from the lack of EMS and palliative care integration become evident when EMS are called to palliative situations. These include disregard of patient autonomy, performance of aggressive, futile interventions, and overall poor management of palliative patients by EMS providers. (11,20,28) While their respective care goals seem to clash, EMS and palliative care services may, in fact, complement one another if integrated. (28) Potential benefits noted in the literature are delivery of early palliative care, provision of home-based care, respect of patient autonomy, improved patient/family quality of life (QoL), increased patient/family satisfaction and confidence, decreased health care costs and setting of appropriate care trajectories. (3,6,16,38) In the LMIC context of SA, this may represent an efficient use of limited resources and decrease pressure on already overburdened emergency departments (ED).

EMS Provider Perceptions

EMS providers, internationally and in SA, view palliative care positively and see it as important to their role. (4,16) Despite this, EMS providers have identified several challenges when confronted with palliative situations (Table 1). (4,10,31) A previous SA study exploring the perspectives of SA EMS providers on palliative care found that EMS providers can play a valuable role in the provision of out-of-hospital palliative care and that plans for collaboration should be pursued. (16)

Table 1 EMS provider challenges in palliative situations (4,10,31)

Disposition	Out-of-Hospital Environment	EMS System	Education	Medico-legal Concerns	Conflicts
- Curative vs. palliative care. - Resulting inner conflicts.	- Lack of information. - Limited time. - Difficult decision-making.	- Mandated hospital transport. - Limited scope of practice. - Lack of alternative care pathways.	- Poor palliative patient management knowledge. - Lack of confidence.	- Advance Directives (ADs), Do Not Resuscitate (DNR) orders. - Deviation from protocols.	- Health care providers. - Family and patient. - Personal.

EMS=Emergency Medical Services

Considering these EMS challenges, several solutions have been proposed including EMS provider education, collaboration between palliative care and EMS systems, creation of palliative care guidelines and protocols, specialised out-of-hospital palliative care teams and further research. (6,8,16) According to several studies, these interventions would result in improved respect of patient autonomy, palliative patient management and EMS provider confidence. (3,6,16)

The following areas have been recommended as priorities for research concerning EMS and out-of-hospital palliative care: educational interventions, development of EMS palliative care protocols, defining the role of EMS in palliative situations, development of palliative care policies within EMS systems. (16,18,39) However, a paucity of literature exists on this topic within SA.

Summary

Given the paucity of evidence and the apparent need for EMS and palliative care integration in SA, research is required. This thesis reviews the topic of EMS and palliative care, identifies and fills knowledge gaps, and provides a novel body of literature in the country. From this new literature, a conceptual framework for EMS and palliative care integration in SA has been developed alongside guidance for practical implementation.

Thesis Aim

To develop a framework for the integration of palliative care and EMS systems in SA.

Objectives

The research aim was pursued through the following objectives:

1. To review existing literature concerning the intersection of palliative care and EMS.

2. To examine EMS use for palliative situations in SA.

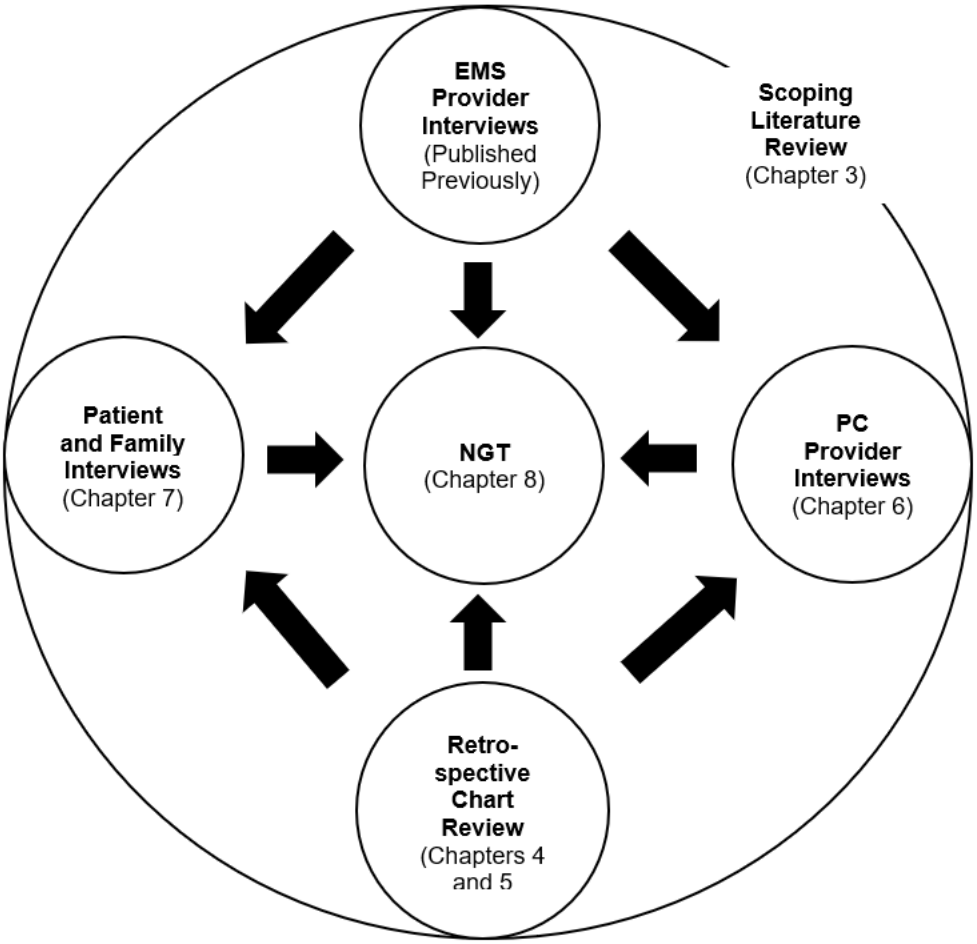
3. To gather the perspectives of palliative care providers on EMS use in palliative care in SA.

4. To gather perspectives of SA patients and family members with palliative needs concerning EMS use in their care.

5. To develop and prioritise approaches facilitating EMS and palliative care system integration within SA.

Research Procedures

The research aim and objectives were accomplished through the following studies which identified current evidence, collected quantitative data, gathered perspectives of primary stakeholders, and produced guidance through an expert panel: scoping literature review, retrospective chart review study, interview study of palliative care providers, interview study of patients and family members with palliative care needs, and a nominal group technique (NGT) (Figure 1).



The EMS provider interviews were previously published and do not represent a part of the thesis. Rather, the thesis took this study into account and built on it.

EMS=Emergency Medical Services, NGT=Nominal Group Technique, PC=Palliative Care

Figure 1 Diagram of Research Procedures

Justification of Research Procedures

EMS and palliative care systems are unintegrated in SA. (16) This is the fundamental problem the above studies aimed to address. Before these systems can be integrated, however, a body of evidence must be constructed. Given the paucity of literature in SA regarding EMS and palliative care, this framework is lacking, and many knowledge gaps exist (Table 2). The selected approach to this research aimed to fill knowledge gaps using methodological triangulation. For example, one knowledge gap this research attempts to fill is the reasons for EMS use in palliative situations. This gap is approached through a combination of a retrospective chart review, spatio-temporal analyses, and qualitative interviews.

Table 2 Evidence gaps identified from the EMS and palliative care literature

Evidence Gaps Include:	Addressed in this Thesis:
Map of current EMS and palliative care literature.	Scoping Literature Review (Chapter 3)
Extent of intersection between EMS and palliative situations.	Retrospective Chart Review – Clinical Analysis (Chapter 4)
Clinical reasons for EMS use in palliative situations.	Retrospective Chart Review – Clinical Analysis (Chapter 4)
Practical reasons for EMS use in palliative situations.	Retrospective Chart Review – Spatio-temporal Analysis (Chapter 5)
Palliative care provider perspectives on the use of EMS in palliative situations.	Palliative Care Provider Interviews (Chapter 6)
Patient and family member perspectives on the use of EMS in palliative situations.	Patient and Family Member Interviews (Chapter 7)
Patient and family member reasons for EMS use in palliative situations.	Patient and Family Member Interviews (Chapter 7)
Development and prioritisation of implementable approaches to EMS and palliative care integration.	Nominal Group Technique (Chapter 8)
Role of EMS in palliative situations.	Scoping Literature Review (Chapter 3), Retrospective Chart Review (Chapters 4 and 5), Palliative Care Provider Interviews (Chapter 6), Patient and Family Member Interviews (Chapter 7), Nominal Group Technique (Chapter 8)

Notes: These evidence gaps are addressed in the LMIC context of SA, thereby assisting in fulfilling the need for research in LMIC contexts. The scoping literature review (Chapter 3) contributes to each evidence gap through provision of contextual background.

EMS=Emergency Medical Services

To begin constructing this body of evidence, a logical starting point is to review current international literature on the topic. This will assist in contextualizing evidence and research in SA. The scoping literature review (Chapter 3) will achieve this starting point. The retrospective chart review, divided into analysis of clinical (Chapter 4) and spatio-temporal variables (Chapter 5) will then gather novel quantitative data in SA on the extent of EMS and palliative situation intersection and reasons for this intersection as these are currently unknown. Reasons for EMS and palliative situation intersection may involve both clinical factors, such as symptom management, and healthcare access factors which include spatio-temporal considerations such as geographic availability of care. (40) This has been demonstrated internationally as EMS are frequently called to manage alarming symptoms in palliative situations (3) and to provide palliative care access 24/7, even in rural areas, due to EMS mobility. (41,42) It has been argued theoretically that EMS frequently intersect with palliative situations in SA for these same reasons and, therefore, EMS and palliative care should integrate. (16) However, no quantitative evidence supporting these arguments exists in SA. The clinical and spatio-temporal analyses of the retrospective chart review study will assist in filling these knowledge gaps.

The scoping literature review and retrospective chart review studies will, in turn, provide context for the qualitative interview studies with palliative care providers (Chapter 6) and patients and family members with palliative needs (Chapter 7). Currently, the only information on EMS and palliative care in SA is the perspectives of EMS providers. (16) Thus, knowledge gaps exist concerning the perspectives of other primary stakeholders. The interview studies in this thesis will assist in filling these knowledge gaps. Qualitative methods are beneficial in generating ideas in new fields of research and are well suited to describe lived experiences and perspectives. (43) Furthermore, gaining stakeholder perspectives is a crucial element of the evidence-based approach to healthcare and is particularly relevant in new fields of study. (44)

Concerning the technique of interview interpretation, content analysis of the manifest data to the categorical level using an inductive dominant approach was planned for each study. This was likewise the approach employed in the previous EMS interview study. (16) Thus, three methodologically comparable qualitative studies could be produced with categories compared. An inductive dominant approach was chosen due to the novel nature of the topic under study. Having employed this analysis in the patient and family member interviews, it became evident further analysis to the latent, thematic level was required. Participants provided their perspectives through personal narratives which contained much underlying meaning and emotion. Exploring this underlying meaning would allow a deeper understanding of patient and family member needs in palliative situations. This would provide greater insight into the person-centred care they require. Furthermore, understanding these underlying needs aligns with palliative care which is holistic and includes, for example, meeting emotional needs. (9) Thus, thematic analysis was ultimately employed in the patient and family member interview study. As Olmos-Vega *et al* (45) have discussed, qualitative research is *"reactive to rich contexts"* and, therefore, methodological considerations must appropriately adapt to findings within these contexts.

The perspectives of EMS providers, palliative care providers and patients with palliative needs, together with quantitative data on EMS intersection with palliative situations will provide a clear picture of the problems to be addressed in SA. The NGT (Chapter 8) will then develop and prioritise approaches to these problems through expert consultation. Thus, a roadmap for the integration of EMS and palliative care systems in SA will be provided.

Together, these studies will provide context, fill knowledge gaps and address problems in SA concerning EMS and palliative care system integration. These studies will significantly increase SA specific literature on the topic and will be used to develop a conceptual framework (Chapter 9) for EMS and palliative care integration in SA.

Layout of this Doctoral Thesis

The studies contained within this thesis have been organized into several sections. Each section is built upon by subsequent sections, synthesizing in Section 5 where a conceptual framework is presented. Section 6 then discusses this framework and the thesis in its entirety. These sections are described below.

Section 1: Introduction, Reflexivity and Evidence Review

This section consists of three chapters. Chapter 1 contains the background to the topic of EMS and palliative care. Author reflexivity concerning personal beliefs, the research journey and thesis outcomes is presented in Chapter 2. Chapter 3 details the scoping literature review which identifies and discusses international evidence, thus providing context for each of the studies presented in this thesis.

Section 2: Retrospective Chart Review Study of Emergency Medical Services' Intersection with Palliative Situations

This section consists of two chapters, both of which present findings from the retrospective chart review study. Chapter 4 presents the clinical data of patients with palliative needs managed by EMS in the retrospective chart review. Chapter 5 presents the spatio-temporal data from the same study.

Section 3: Role-Player Perspectives on Emergency Medical Services in Palliative Situations

This section consists of two chapters reporting on the qualitative findings of the thesis. Chapter 6 presents the perspectives of palliative care providers on EMS use in palliative situations. Chapter 7 presents the perspectives of patients and family members with palliative needs on EMS use in their care. These studies were informed by the findings from the scoping literature review and retrospective chart review.

Section 4: Expert Panel Recommendations for Emergency Medical Services and Palliative Care Integration

This section consists of a single chapter. Chapter 8 details the NGT study in which an expert panel consisting of both EMS and palliative care providers developed and prioritised

approaches to EMS and palliative care system integration in SA. This study was informed by each of the previous studies contained within this thesis as well as the previously published EMS provider interview study. (16)

Section 5: Conceptual Framework

This section consists of a single chapter. Chapter 9 presents the developed conceptual framework for EMS and palliative care integration in SA and explains its construction. The conceptual framework was informed by findings from all studies involved in this thesis as well as the previously published EMS provider interview study.

Section 6: Discussion and Conclusions

This section consists of two chapters. Chapter 10 discusses the conceptual framework and thesis, making recommendations for next steps and proposing further areas for research and development. Chapter 11 presents conclusions based on the thesis and discussion thereof.

Included Papers and Approvals

Six original articles which have resulted from the studies in this thesis have been included with approval from the Doctoral Degree Board at the University of Cape Town (UCT) (Appendix 1). All studies were approved by the UCT Faculty of Health Sciences Human Research Ethics Committee (HREC). Approvals are included in Appendix 2.

Chapter 2: A Reflection on Personal Beliefs, the Research Journey and Thesis Outcomes

Chapter Introduction

The purpose of this chapter is to improve trustworthiness within this thesis by evaluating and embracing the effects of context and subjectivity upon the research which follows. (45) This is done by providing the reader with insights into the research team and a narrative autobiographical sketch of the author's personal background, beliefs, and development during the research journey. This chapter incorporates the personal, interpersonal, methodological and contextual domains of reflexivity as described by Olmos-Vega *et al*. (45). Given the focus on person-centred care in this thesis, the nature of this chapter, and in pursuit of genuine reflexivity, this chapter is written in a personal manner.

Research Team

The members of the research team involved in this thesis are Caleb Gage (student), Liz Gwyther (co-supervisor) and Willem Stassen (supervisor). This team was decided upon as it provided both EMS and palliative care expertise. I (CG) am an Emergency Care Practitioner (ECP) by profession with 11 years of experience. In the SA setting this equates to an Advanced Life Support (ALS) EMS provider with a four-year Bachelor's degree in Emergency Medical Care. I also hold a MPhil in Emergency Medicine and performed the studies within this thesis for a PhD in Emergency Medicine. During the compiling of this thesis, I worked as a lecturer and programme manager at a state-sector EMS college where I was involved in a range of short-courses and Higher Education (HE) training. I also continued to work part-time in the clinical environment both on the road and as a flight paramedic (rotor and fixed-wing). Over the past four-years as I have worked on this project, both my educational and clinical practices developed as I sought to both teach and treat patients from a more person-centred perspective.

LG is an emeritus Associate Professor at the University of Cape Town (UCT) where she established the Division of Interdisciplinary Palliative Care and Medicine. As a medical doctor she holds a MBChB, MMed Family Medicine, PGDip in Palliative Medicine, MSc in Palliative Medicine and a PhD in Palliative Medicine. She is a senior research scholar at UCT and recently completed a part-time consultancy position with the WHO, working on development of Primary Care Tools and tools to support the integration of palliative care into health systems. Her special interests are palliative care education, integration of palliative care into country health systems and strengthening primary care and human rights in health care. She

is a director of the African Palliative Care Association, past-chair of ehospice, a former CEO of Hospice Palliative Care Association of South Africa (HPCA), past-chair of the Worldwide Hospice Palliative Care Alliance (WHPCA), and past-director on the boards of the National Hospice Palliative Care organisation in the USA, and Pain Society of South Africa. Prior to this research I had not known LG, though I was familiar with some of her published work.

WS is likewise an ECP by profession and, in addition, holds a MPhil in Emergency Medicine, a PGDip in Applied Ethics and a PhD in Emergency Medicine. He has extensive experience in emergency care systems development and research, including in emergency medical dispatch. He is currently an Associate Professor at the UCT where he convenes the PhD in Emergency Medicine programme, and the Deputy Director of the WHO Collaborating Centre for Integrated Clinical Care at the university. I have known WS from undergraduate level as we studied at the same institution where he was a senior student and I a junior. WS also supervised my MPhil research (16) where the original idea behind this topic was formed.

Throughout this journey, our research team has maintained an excellent working relationship. Any disagreements, of which there were few, were argued in an academic and professional manner ultimately assisting in my own development. I remember at the beginning of the research journey I had a disagreement with WS concerning the proposal and he said, *"hold that thought, one day you'll become the expert."* Later, during the spatio-temporal study, he reminded me of this as we debated whether to include the category *"peri-urban".* Ultimately we did include that categorisation with WS saying, *"I'm convinced by all your argument."*

Both WS and LG provided invaluable insights based upon their experience within their respective fields. Together our collective experience shaped this thesis and each of us have benefitted from the work. While I may be the primary researcher, I recognise it would not have been possible without the supervisory support which I have been shaped by during this process.

Narrative Autobiography

Looking back, I have identified a connection between my childhood development and my present interest in both EMS and palliative care. Many events which took place during my childhood seem to have impacted me deeply, giving me a passion for this current area of study.

At 4 years of age, an elderly man and his wife, who were receiving hospice care at the time, lived with my family. This man was at the end-of-life and my family was assisting in caring for him. To this day I am unsure why, but I would often go sit on this man's bed attempting to comfort him by patting his head. Three years later I developed a keen interest in what could

be described as basic scientific observation. This primarily involved birds which I would actively study, charting my findings in various notebooks, comparing these findings with bird guides. In my schooling years this interest grew as I enjoyed scientific subjects such as chemistry, physics, and biology. Of these, I was particularly drawn to the study of human anatomy and physiology. My inclination was to take these interests further by studying in the medical field. It seemed natural to use these interests to ultimately help people; a simple concept which, in my estimation, is too often missing from modern healthcare.

While deciding which career path I was interested in I undertook basic first aid and ambulance assistant courses. Having enjoyed this training and the idea of out-of-hospital work, I investigated higher education EMS qualifications. The next year I enrolled into a Bachelor of Technology in Emergency Medical Care programme and never looked back. As a young and newly graduated Emergency Care Practitioner (ECP) there was one moment which greatly affected me, though at the time I thought little of it. I was transporting an elderly lady with dyspnoea to a local hospital. She was clearly at the end-of-life. I administered oxygen while literally mumbling to myself, *"there is nothing else I can do."*

It was only in my post-graduate studies in emergency medicine several years later that I recalled this moment. I was introduced to the topic of palliative care in a small two-week section of work. I was immediately drawn to this completely new approach to care. I had only ever known an emergency, lifesaving approach. In the EMS we often spoke of person-centred care, but we never seemed to employ it. And so, having found a branch of medicine dedicated to person-centred care, my research journey began, trying to incorporate palliative care within EMS. There was more I could have done for that elderly lady in the ambulance. I just didn't know it. These experiences during my personal development have resulted in my current heartfelt convictions for true, person-centred healthcare.

The Research Journey

When initially contemplating this research, the idea was simple: to improve EMS care of patients with palliative needs. As many students beginning their research journeys do, I envisioned large pilot projects to implement change, primarily at the patient-facing, clinical level. With the addition of supervisory wisdom, I was quickly (and gently) brought down to earth. Ultimately, the first study I performed on this topic, as a master's student, was an interview study with EMS providers to gather their perspectives on palliative care – a more logical starting point and one which the current thesis builds upon. (16)

The EMS participants in this study all viewed palliative care positively and shared their experiences of frequently encountering palliative situations. (16) This was encouraging to me as I began to realise in greater depth the relevance of the topic. This study also made me realise the extent of research required concerning EMS and palliative care which in turn led me to undertaking a PhD. While contemplating a research approach to the problem of segregated EMS and palliative care in SA at this level, I again realised a broader lens was needed. Improving patient care in palliative situations was still the primary aim, but achieving that aim involved systems, healthcare access, integration, frameworks, and so many other discussions beyond just 'making EMS better' in palliative situations. And so, even at the proposal stage, some personal and professional development was beginning, and each study forming part of this thesis taught me something new. In terms of methodologies, for example, the scoping literature review, retrospective chart review, and nominal group technique studies were new as I had only previously conducted the qualitative interview study.

Study 1 – Scoping Literature Review

During this study I discovered there was more literature concerning EMS and palliative care than I expected, though a relatively small amount compared to other bodies of literature. Most of the papers were fairly recent, so I was glad to see there was developing interest in this topic. There also appeared to be room for a comprehensive scoping review as other reviews were very narrow. Through this initial phase of the research, I was able to network with other authors engaged in similar research. This led to a side project which was later published as a discussion paper providing me with invaluable collaborating experience with international authors. (46)

Study 2 – Retrospective Chart Review

Based on the SA burden of disease and previous EMS provider interviews, I had presupposed there would be a fair amount of intersection between EMS and palliative situations in SA. However, no quantitative data existed and so this was an interesting opportunity to test my presuppositions and findings from the qualitative research. Having gathered the data for this study, I found the amount of intersection between EMS and palliative situations to be higher than I originally suspected. Personally, this further cemented the importance of EMS and palliative care integration in my mind, though how this should be done remained somewhat nebulous.

This study was particularly difficult to complete as data collection proved complicated. The hospitals used for the study maintained a mixture of electronic and physical patient records. As I was based in Johannesburg and the hospitals in Cape Town, it was not possible to access the necessary physical patient records myself. This obstacle was overcome by recruiting two data collectors within Cape Town to assist. While this was, at times, challenging to co-ordinate, it ultimately worked well, and I was able to gather the necessary data. This approach provided further collaboration experience and networking opportunities with other professionals for which I am thankful.

Study 3 – Interviews with Palliative Care Providers

It is always interesting to understand how other healthcare providers perceive one's own field of work and this study was no different. It was a fascinating experience to hear from palliative care experts and I learned much about the palliative care approach just from these conversations. As an aside, I was also feeling much more comfortable performing these interviews having had previous experience with EMS providers. Significant points of illumination for me in this study were the importance of stakeholder engagement and the fact that EMS, rather than performing palliative care in isolation, should form part of a team approach to palliative situations. Thus, my understanding of palliative care and its approach grew. During the write-up of this study, I was also challenged to begin developing specific recommendations. So, for example, rather than simply suggesting future research, also making recommendations for what that research should look like based on study findings. I believe this helped me strengthen my article writing and forced me to think deeper about study findings.

Study 4 – Interviews with Patients and Family Members

In many ways I consider this study to be the pinnacle of the project. If the purpose of this research was to improve patient care in palliative situations and shift EMS towards a more person-centred approach to care, then it was crucial to have the perspectives of patients and family members with palliative needs. Furthermore, I considered this study a true privilege as I was allowed to glimpse into very personal, often emotional, situations experienced by the participants. It was truly enlightening to see the needs and perspectives of these participants. I was left with an even greater desire to have these needs embedded in the final product of my research. Originally, the idea was to perform content analysis of the manifest data contained in the interviews, however, based on the nature of the findings, my supervisors and I agreed

thematic analysis would be more appropriate and impactful. I am grateful they encouraged me in this direction, not only for the richness of the findings, but for my own development as it required me to think at a higher level of abstraction.

A significant challenge encountered in this study was participant recruitment. Due to the vulnerable nature of patients and family members with palliative needs who are frequently unwell, it was difficult to find able and willing participants. At one point I recall discussing with my supervisors the possibility of completing this study with only five or six participants as it seemed I could no longer find any others. However, they encouraged my patience, and we expanded our search to additional contacts who could assist in recruitment. Thankfully, this expanded search resulted in several more willing participants which, in turn, strengthened the quality of the study. It seems one thing I needed to learn during this research journey was perseverance even when challenges appeared insurmountable.

Study 5 – Nominal Group Technique

By the beginning of this study, several concepts for inclusion in the final framework (person-centred approach, stakeholder collaborations, education, interventions at various levels: national to local) were becoming clear, however, what the final framework would look like, I did not know. While developing the NGT schedule and summarising the research to date, some further realisations occurred: flexibility was needed in the framework since local contexts within SA are diverse, entire literatures exist on health system integration and person-centred care. It was clear any framework developed in this research would need to draw upon these bodies of literature. Upon taking this literature into account, I realised a change in approach was required for the NGT.

Originally, the idea was to generate and rank solutions to the problem of segregated EMS and palliative care in SA. However, solutions imply a definitive, ‘one-size-fits-all’ approach within a simple system that will be responsive to such interventions as intended. Furthermore, solutions require enforcement (often from top-down) to have impact. Patient wellbeing, particularly in the palliative care setting, is far from simple. As a result, and rather appropriately, healthcare systems designed to enhance patient wellbeing are complex in nature. Examples of disastrous unintended consequences from ‘solutions’ abound in healthcare. And so, rather than generating solutions, the NGT sought to develop approaches which would facilitate integration efforts between EMS and palliative care. This would allow flexibility, considering local contexts and diverse patient needs while simultaneously empowering EMS and palliative care providers to adapt to ever changing local environments, rather than having strict solutions enforced. Within complex systems, it is the ability to adapt which is crucial. These reflections directly

influenced the conceptual framework developed in Chapter 9 through the inclusion of complex adaptive systems theory. Rather than a framework of interventions to integrate EMS and palliative care, a framework which cultivated a positive environment for integration was developed. Thus, the framework for EMS and palliative care integration began to take shape.

Although the above studies represent the methodological approach decided upon in this thesis, it was not arrived at instantaneously as seen in the discussion of content and thematic analysis. Many differing options were deliberated upon and other approaches could have been taken. In its infancy as a one-page concept document, the research procedures did not include patient and family member interviews. This likely reflects the personal approach I had unconsciously taken to healthcare which was not person-centred, but rather healthcare provider expertise focussed. I am thankful this subconscious approach was revealed during this process through the patient interviews which were included as it aligns with the person-centred, palliative approach to care.

Furthermore, concerning this study, family members were originally not included. Though a reviewer recommended their inclusion, I originally argued against it as the literature highlighted conflicts between patients and family members in palliative situations. (10) As a result, I argued, this population should be studied separately, but not as a part of this thesis as patients were the primary focus. Again, this likely reflected a subconscious approach I had unfortunately taken within the EMS: I am here to treat patients, not family members. Family members were only included in this study for practical purposes originally, as there were difficulties recruiting patients. Though this was admittedly unplanned, it became evident to me how important their inclusion was, not only as a part of true palliative care, but to enhance the quality of the study. This further developed my clinical practice to consider family members even within standard EMS work.

A further methodological discussion involved the final study and whether a NGT or Delphi would be more appropriate. Ultimately a NGT was decided upon as the research team decided this was best aligned with the purpose of generating and exploring ideas in response to question. (47) A NGT would also have the added advantage of allowing for prioritisation of ideas – an important consideration in resource-limited contexts such as SA.

Underpinning Belief

Dame Cicely Saunders, who is credited as the founder of the modern hospice movement and a pioneer in palliative care, once famously said, *"You matter because you are you, and you matter to the end of your life."* (48,49) She believed in compassionate, holistic patient care on

the basis that human life has inherent value and meaning. (48) It appears these beliefs were informed by her Christian worldview in which humanity is created in the *Imago Dei*, and therefore, is of intrinsically high value. (50)

I share this worldview and a belief in the value of human life. Ultimately, this belief underpins this thesis. It seems to me, that if human life is not of special value, healthcare, as well as this thesis, loses much of its meaning. However, if human life is of particular value, it is imperative healthcare systems and providers treat human life accordingly. Therefore, I agree with the approach taken by Dame Saunders, and truly believe in a holistic, person-centred approach to healthcare rooted in the objective value of human life.

Research Paradigm

With this belief in objective truth, I maintain a realist ontological stance. However, I also recognise the role my own biases play in my understanding of reality. I am fallible and, therefore, my understanding of reality and objective truth is fallible. As a result, I have attempted throughout this thesis to discuss my biases and the limitations of the research. Despite these limitations I believe that true, objective, and functional knowledge may be gained through research.

Based on these beliefs, my worldview is largely aligned with a critical realist approach. Critical realism is a philosophical approach which attempts to bridge the gap between positivism and interpretivism. (51) It asserts that an objective reality exists apart from our knowledge of it while also recognising that our understanding of reality is mediated through experiences, social contexts, and theories. (51,52) Consequently, knowledge is imperfect and subject to revision. Critical realism posits a 'stratified reality' consisting of the empirical (what is observed), actual (what occurs independent of its observation), and real (underlying causal mechanisms). (52) Scientific enquiry, in this approach, seeks not only to observe, but also uncover these deeper causal mechanisms. (52) Thus, this approach is beneficial for the study of complex phenomena through use of both quantitative and qualitative methods. (52)

As a critical realist approach aligns well with many of my personal beliefs and the topic of study in this thesis deals with complex themes (see Chapter 7 for example), critical realism is the dominant influential research paradigm of this thesis. Furthermore, this approach is suitable to the topic at hand as it allows for both quantitative and qualitative research which this thesis employs.

Conclusion

This research into EMS and palliative care began with the simple idea of improved EMS care for patients with palliative needs. While this idea remains central, the research has developed beyond just patient care into a conceptual framework for the integration of two distinct, yet complementary, systems. During this research journey, I have experienced both personal and professional growth from improved methodological understanding to greater degrees of critical thinking, for which I am grateful.

In the next several chapters many recommendations are made concerning EMS and palliative care integration based on the research performed. Whilst I firmly believe these recommendations are evidence-based and will be of benefit, I must also take responsibility for any shortcomings. In the spirit of genuine scientific investigation, I suggest these recommendations, rather than being definitive, are now to be tested to determine their relevance and efficacy.

I trust this work will be of benefit to all those involved in EMS and palliative care as well as the SA healthcare system in general. But most importantly, I trust the results of this thesis will accomplish in some way the very purpose of healthcare: to truly help people.

Chapter 3: Emergency Medical Services and Palliative Care: A Scoping Review

Chapter Introduction

The purpose of this chapter is to provide context for the remainder of the thesis through a scoping literature review. This review maps current literature and knowledge gaps requiring further research.

Declaration from author and co-authors

The following co-authors contributed to this publication: Stander C, Gwyther L, Stassen W.

Contributions of the authors were as follows: CHG, LG and WS designed the protocol. CHG and CS collected data. CHG drafted the manuscript with input from CS, LG and WS. All authors reviewed and gave final approval of the manuscript. CHG is the guarantor and accepts full responsibility for the study.

The extent of contributions from each person are as follows:

CHG 60%; CS 10%; LG 10%; WS; 20%

In accordance with the UCT Doctoral Degrees Board guideline titled, “GUIDELINES FOR THE INCLUSION OF PUBLICATIONS IN A DOCTORAL THESIS”, each author has signed below for approval to include this manuscript.

Signed by candidate

Caleb Gage — 16 January 2025 Date

Signed by candidate

Charnelle Standar — 16 January 2025 Date

Signed by candidate

Liz Gwyther — 16 January 2025 Date

Signed by candidate

Willem Stassen — 16 January 2025 Date

Emergency Medical Services and Palliative Care: A Scoping Review

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Abstract

Objectives: The aim of this study was to map existing emergency medical services (EMS) and palliative care literature by answering the question, what literature exists concerning EMS and palliative care? The sub-questions regarding this literature were, (1) what types of literature exist?, (2) what are the key findings? And (3) what knowledge gaps are present?

Design: A scoping review of literature was performed with an *a priori* search strategy.

Data sources: MEDLINE via Pubmed, Web of Science, CINAHL, Embase via Scopus, PsycINFO, the University of Cape Town Thesis Repository and Google Scholar were searched.

Eligibility criteria for selecting studies: Empirical, English studies involving human populations published between 1 January 2000 and 24 November 2022 concerning EMS and palliative care were included.

Data extraction and synthesis: Two independent reviewers screened titles, abstracts and full texts for inclusion. Extracted data underwent descriptive content analysis and were reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews guidelines.

Results: In total, 10 725 articles were identified. Following title and abstract screening, 10 634 studies were excluded. A further 35 studies were excluded on full-text screening. The remaining 56 articles were included for review. Four predominant domains arose from included studies: (1) EMS' palliative care role, (2) challenges faced by EMS in palliative situations, (3) EMS and palliative care integration benefits and (4) proposed recommendations for EMS and palliative care integration.

Conclusion: EMS have a role to play in out-of-hospital palliative care, however, many challenges must be overcome. EMS provider education, collaboration between EMS and palliative systems, creation of EMS palliative care guidelines/protocols, creation of specialised out-of-hospital palliative care teams and further research have been recommended as solutions. Future research should focus on the prioritisation, implementation and effectiveness of these solutions in various contexts.

Background

Emergency medical services (EMS) and palliative care function with unique respective aims. EMS are designed to preserve life and limb in out-of-hospital emergency situations by immediate intervention and hospital conveyance. (17,18) Palliative care is, according to the WHO, *'an approach that improves the quality of life (QoL) 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.'* (9) This includes a variety of situations such as chronic/life-limiting illnesses, end-of-life (EoL) care and any condition (physical, psychosocial, spiritual) causing suffering. (9) Thus, the EMS approach is curative, whereas the palliative approach is supportive.

Despite these seemingly conflicting approaches, EMS and palliative care often intersect. (5–7,12) As they progress towards EoL, patients with palliative needs experience worsening symptoms for which EMS are often contacted. (8,19) Furthermore, the role of EMS has expanded in recent years to include more intricate forms of healthcare beyond emergency care such as community-based primary care and palliative care. (2) Global ageing populations and subsequent increases in chronic non-communicable diseases are well-documented reasons for this expanded role as demand for palliative care rises and EMS are more frequently confronted with these patients. (41)

Contemporary EMS and palliative care literature recommends integration between the two fields to improve palliative care provision as their differing aims may, in fact, complement one another. (28) Nevertheless, a lack of integration persists. Typically, EMS are not trained in palliative care nor do palliative care systems make formal use of EMS to deliver care. (20) This results in disregarding of patient autonomy, performance of aggressive, futile interventions and overall poor management of those requiring a palliative approach to care by EMS providers. (11,20,28) However, should the two fields integrate, potential benefits include early palliative care delivery, provision of homecare, respect for patient autonomy, improved patient and family satisfaction, confidence and quality of life (QoL), decreased healthcare costs and setting correct trajectories of care. (3,6,16)

Given the growing body of EMS and palliative care literature, and potential integration benefits, a need exists to review current evidence. Previous reviews have focused on singular aspects such as specialised community paramedic roles in the provision of palliative care in patient homes, (41) however, a more extensive review of EMS in the broader out-of- hospital setting is lacking. Thus, this review aimed to map existing EMS and palliative care literature by answering the question, what literature exists concerning EMS and palliative care? The sub-

questions regarding this literature were (1) what types of literature exist?, (2) what are the key findings? And (3) what knowledge gaps are present? For the purposes of this study, EMS are defined as those systems and personnel providing medical care in the out-of-hospital setting using ambulance-based services. The out-of-hospital setting includes all areas to which EMS may be called, from patient homes to any public space.

Methods

Design

A scoping review of EMS and palliative care literature was performed, the protocol for which has been published previously, (53) detailing the methodological framework of Arksey and O'Malley used for this review. (54) The steps of this employed framework were (1) identifying the research question, (2) identifying relevant studies, (3) selecting eligible studies, (4) charting data and (5) collating, summarising and reporting results. (54) The optional sixth step of expert consultation was not included as this review forms the first part of an overarching investigation in which expert consultation will be subsequently performed. As this review aimed to simply map existing literature, in-depth quality appraisal of eligible studies was not performed, though limitations were noted.

Search strategy and eligibility criteria

An a priori search strategy, developed in line with the recommendations of Aromataris and Riitano, was used. (55) This strategy employed keyword combinations and their synonyms (see Appendix 3). The following databases were originally searched on 28 September 2021 with an updated search on 24 November 2022: MEDLINE via Pubmed, Web of Science, CINAHL, Embase via Scopus and PsycINFO. The University of Cape Town Thesis Repository and Google Scholar were searched to identify grey literature. These databases met the recommendation of Bramer *et al* for optimal database combinations. (56) Furthermore, Embase, CINAHL and PsycINFO provided access to unique palliative care literature not indexed in MEDLINE as highlighted by Tieman *et al*. (57) Additional articles were sought from hand-searching reference lists of eligible studies. This search strategy was piloted to ensure appropriateness of keyword combinations in the selected databases.

Eligible studies were selected based on the following criteria:

- Inclusion: empirical, English studies involving human populations published between 1 January 2000 and 24 November 2022 concerning EMS and palliative care. The EMS and palliative care interface was the primary focus for eligibility.
- Exclusion: studies involving the in-hospital setting, including emergency departments (EDs), those where the full text was unobtainable, editorial and discussion articles, opinion papers and studies involving exclusively EMS or palliative care.

Data Management

All identified studies were uploaded to Mendeley reference software (58) and duplicates removed. Remaining studies were exported to the Rayyan web application (59) where two authors (CHG, CS) independently screened titles and abstracts for inclusion. CHG and CS then screened the full texts of included studies for final inclusion in the review. Agreement achieved between authors was >99%. On discussion, complete agreement was reached for all studies. This process was overseen by LG and WS. All authors agreed on the final inclusion list.

Data extraction and analysis

An a priori data extraction matrix was used to gather the following data from each included study which were charted by CHG using Microsoft Word (Microsoft Corporation, Redmond, Washington, USA): title, authorship, publication year, setting, including country income status divided into high-income countries (HICs) and low-to-middle income countries (LMICs), aims, population and sample, EMS palliative care training, methodology, conclusions, significant findings, limitations. To ensure consistency in application of this extraction matrix, CS double coded 10% of included articles. In line with the recommendations of Arksey and O'Malley, extracted data underwent basic numerical analysis concerning the distribution of studies and descriptive content analysis where the literature was organised according to major domains. (54) These domains were identified through an inductive-dominant approach. Findings are presented in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews. (60,61)

Patient and public involvement

No patients were involved in this study.

Results

After duplication removal, 10 725 studies were identified. Following title and abstract screening, 10 634 studies were excluded. A further 35 studies were excluded on full-text screening. Of the full-text exclusions, 12 full texts were unavailable, the EMS and palliative care interface was not the primary focus in 11 studies, 8 studies presented non-empirical evidence and the remaining 4 studies were previously undetected duplicates. Hand-searching of included reference lists revealed no further studies. No grey literature fitting inclusion criteria was identified. In total, 56 studies were included for analysis. Figure 2 details the selection process while a summary of included studies is provided in Appendix 4.

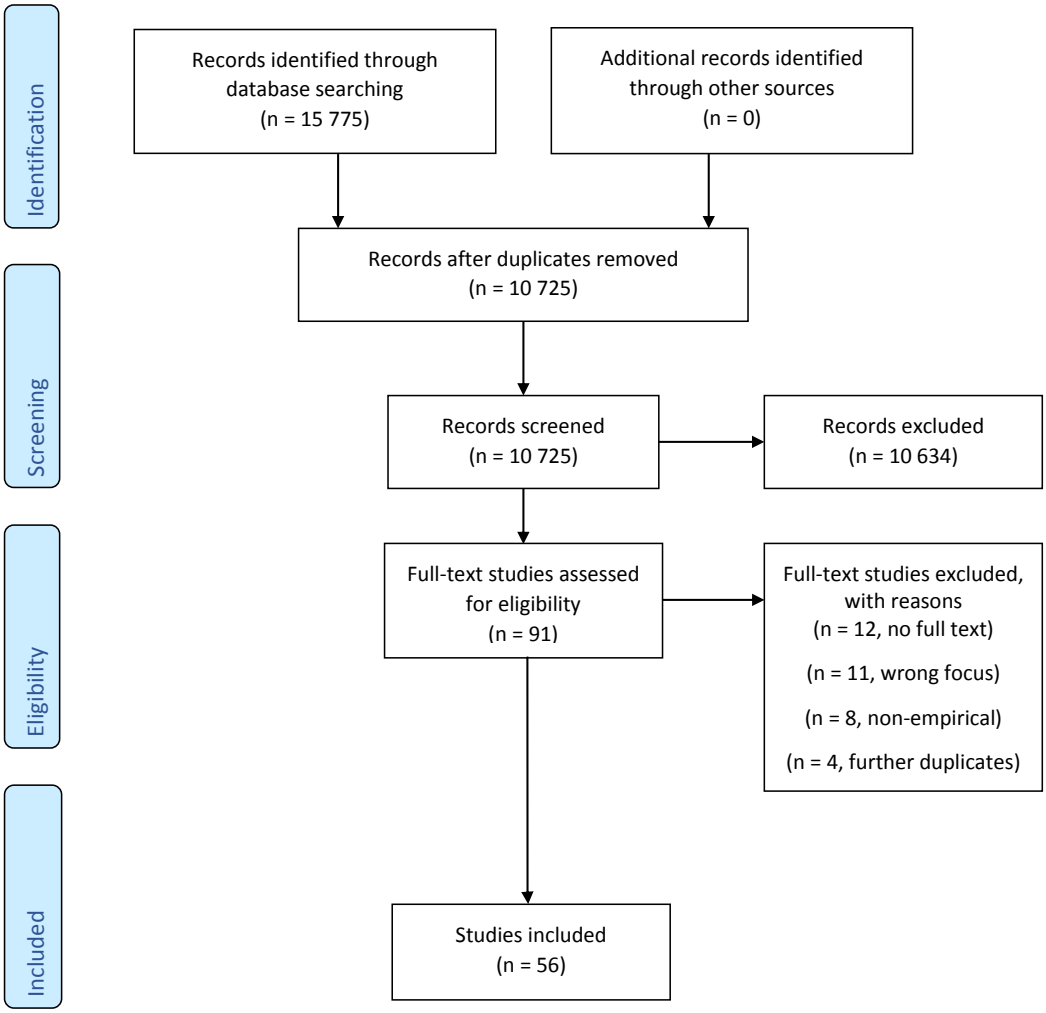

Figure 2 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) selection process flow diagram. (61)

Study characteristics

Included studies were performed in the USA (n=16), (7,10,17,29,62–73) the UK (n=9), (11,12,30,74–79) Germany (n=10), (8,13,31,37,80–85) Australia (n=8), (5,18,41,86–90) Canada (n=4), (3,91–93) France (n=1), (6) Switzerland (n=1), (20) New Zealand (n=2), (94,95) Finland (n=2), (42,96) Czech Republic (n=1), (97) Brazil (n=1) (98) and South Africa (n=1) (16) between 2002 and 2022. The majority of studies (96%, n=54) were performed in HICs with only Brazil and South Africa representing LMICs, and most (63%, n=35) were published between 2018 and 2022.

Methodologically, most studies were quantitative (55%, n=31) while the remainder used a qualitative (27%, n=15) or mixed-methods (18%, n=10) approach. Quantitative studies comprised of surveys (n=12), (8,17,66,71,73,75,77,80–82,86,88) retrospective cohorts (n=9), (6,13,42,62,63,74,84,85,87) literature reviews (n=5), (41,79,91,94,97) case series/reports (n=3), (7,20,64) a pre-intervention and post-intervention study (n=1) (70) and a prospective cohort (n=1). (8) Qualitative studies contained individual interviews (n=12), (10–12,16,30,31,68,69,72,76,95,98) focus group interviews (n=2) (18,93) and deliberative dialogues (n=1), (92) while the mixed-methods studies (3,5,29,37,65,67,78,89,90,96) made use of various survey and interview combinations.

EMS providers were the primary population in most studies (52%, n=29) (5,8,10–12,16–18,29–31,65–72,75,77,78,80–82,86,88,96,98) including paramedics, doctors and nurses involved in out-of-hospital emergency care dependant on EMS system model: paramedic-led (Anglo-American), physician-led (Franco-German). (41) Other investigations were performed using patient records (n=10), (6,8,13,42,62,63,74,84,85,87) published literature (n=5), (41,79,91,94,97) case reports/series (n=3), (7,20,64) stakeholders and experts (n=3), (37,76,92) mixed populations including patients, families, paramedics, caregivers, palliative providers and patient records (n=3), (3,89,93) EMS agencies (n=2) (73,98) and family caregivers (n=1). (95)

Study categories were EMS provider knowledge and perspectives (54%, n=30), (5,8,10–12,16–18,29–31,65–69,71,72,75–78,80–82,86,88,93,96,98) EMS– palliative integration (23%, n=13), (3,6,7,37,42,63,64,70,73,74,89,90,92) EMS–palliative intersection (14%, n=8) (8,13,20,62,84,85,87,95) and literature reviews (9%, n=5). (41,79,91,94,97) Studies concerning EMS provider knowledge and perspectives vis à vis palliative care focused on EMS management and decision making (n=9), (8,10,30,65,68,80–82,88) roles and barriers in palliative situations (n=11), (11,16,18,31,69,72,76–78,93,98) understanding and education (n=6), (5,17,66,67,71,96) identification of patients with palliative needs (n=2) (29,75) and potential solutions to overcome barriers (n=2). (12,86) Studies concerning EMS and palliative

care integration focused on effects of integration on patient transport, patient/family satisfaction and EMS provider confidence (n=7), (3,6,42,63,64,74,89) recommendations for integration (n=4) (7,37,70,92) and EMS palliative care protocols (n=2). (73,90) Studies concerning EMS and palliative care intersection focused on the characteristics and frequency of patients with palliative needs encountered by EMS providers (n=4), (8,62,85,87) EMS provider treatment of these patients (n=3) (13,20,84) and the experience of family caregivers. (95) Literature reviews focused on attitudes and perceptions of paramedics concerning EoL care (n=1), (79) EMS role in EoL care (n=1), (97) EMS palliative provision in community-based settings (n=1) (41) and rapid reviews of EMS and palliative care literature in Canada (n=1) (91) and New Zealand (n=1). (94)

Four predominant domains arose from included studies: (1) EMS' palliative care role, (2) challenges faced by EMS in palliative situations, (3) EMS and palliative care integration benefits and (4) proposed recommendations for EMS and palliative care integration.

EMS' palliative care role

Numerous studies (66%, n=37) (3,7,8,10,11,16–18,30,41,42,63–65,68,69,72,75–80,82–85,87,89–91,93–98) discussed the potential role of EMS in palliative care. Most EMS providers viewed palliative care positively, regarding it as important to their role as demonstrated in studies performed in the UK, (77) Australia, (89) Canada (3) and South Africa. (16) The EMS's palliative care role was frequently highlighted due to the intersection between EMS and patients with palliative needs. (8,84,87) For example, an Australian study found palliative situations comprised 0.5% (n=4348) of the annual EMS caseload. (87) Other studies, found palliative situations may represent up to 10% of caseload and most EMS providers had previously encountered palliative situations. (8,31) Commonly documented reasons for EMS calls to palliative situations were sudden, unexpected patient deterioration, caregiver exhaustion and alarming signs and symptoms: dyspnoea, pain, convulsions, severe anxiety. (3,10,31) These calls often occurred out-of-office hours or during holidays when the usual patient caregivers were unavailable. (20) Specific EMS palliative care roles included complex care provision, (97) adjusting patient trajectory, (16) decision-making within limited information environments, (11) therapeutic interventions, (84) 24/7 availability, provision of homecare (42) and improving patient and family QoL, comfort and confidence. (3)

Challenges faced by EMS in palliative situations

Most studies (63%, n=35) (7,8,10–13,16–18,20,29–31,41,62,65,66,68,71–75,77–79,81–84,88,91,96–98) highlighted various challenges EMS providers face in palliative situations. These challenges were EMS provider mindset, (17) the out-of-hospital environment, (16) EMS systems, (11) lack of education, (97) medico-legal confusion (81) and inter-personal conflicts. (18) The EMS provider mindset is to 'save lives' through a curative approach to care, whereas the palliative approach is primarily supportive through prevention and relief of suffering. (9,17,18) Other common challenges were related to the complex out-of-hospital environment: lack of information, limited time, consequent difficult decision-making. (31)

EMS system barriers to palliative provision were mandated hospital transport, (16) limited scope of practice (31) and lack of alternative care pathways. (11) Despite patient and family wishes and better clinical judgement, EMS providers often conveyed palliative patients to hospital due to system rigidity, fear of consequences and a lack of alternative care pathways. (11) Hospital transport was described as a safety net for EMS providers and, thus, their default decision in palliative situations. (30)

Many studies identified a lack of EMS provider education concerning palliative care (16,18,29,31,77) and only five studies mentioned EMS providers with additional palliative or hospice care training in their samples. (5,8,29,83,86) The additional palliative training ranged from short course to postgraduate diploma level. This lack of education was identified in both physician and paramedic-led EMS systems. (8,16)

Highlighted medico-legal challenges for EMS providers in palliative situations were fear of litigation (31) and confusion surrounding legal documentation such as advance directives. (20,66,81) EMS providers were sometimes unaware of the presence of legal documentation due to lack of available information at incidents. (7,10,68) Furthermore, where legal documentation was presented, EMS providers were uncertain of legal implications in emergencies. (18,81)

Finally, EMS providers described various conflicts requiring management in palliative situations. Conflicts arose with other healthcare providers, patients, families and within EMS providers themselves. (18) These conflicts were due to competing interests: patient wishes, family wishes, EMS protocols, EMS provider clinical judgement, medico-legal considerations. (10,16)

EMS and palliative care integration benefits

Many studies (36%, n=20) (3,6–8,16,31,41,42,63,64,70,74–76,83,84,89,91–93) described benefits of EMS and palliative care integration: early palliative provision, home-based care, respect of patient autonomy, improved patient and family QoL, increased patient and family satisfaction and confidence, improved EMS provider confidence and decreased healthcare costs. Conversely, the consequences of non-integration were disregard of patient autonomy, performance of aggressive or futile interventions and poor management of palliative patients by EMS. (11,20)

Provision of early, home-based palliative care by EMS was found to improve patient and family QoL, satisfaction and confidence as demonstrated by Carter *et al*. (3) This study found high patient and family satisfaction with palliative provision from EMS providers, observing their compassion and skill in symptom management. (3) Furthermore, knowledge of the 24/7 availability of EMS providers in this programme provided confidence and peace of mind. (3) Paramedic comfort and confidence in palliative provision likewise improved during the study. (3)

Collaboration between EMS and palliative care networks was found to improve respect of patient autonomy. (6) An example was provided in a case study by Clemency *et al* where a terminally ill patient was transported home from hospital, extubated and allowed to die at home according to her wishes. (64) This was facilitated by EMS under the guidance of palliative care specialists and in conjunction with a broader multidisciplinary team. (64)

Several studies discussed the potential decreased healthcare costs resulting from EMS and palliative integration. (42,75,89,91) The decreased costs would, theoretically, result from provision of homecare, thus avoiding expensive and unnecessary hospital admissions. (91) A Finnish study evaluating the integration of paramedics in EoL care argued that healthcare costs may be diminished through provision of homecare by paramedics in particular. (42)

Proposed recommendations for EMS and palliative care integration

All 56 included studies made recommendations for EMS and palliative care integration. These were EMS provider education, (5) EMS and palliative system collaboration, (6) EMS palliative care guideline/protocol creation, (16) specialised out-of- hospital palliative care teams (63) and further research. (87) The following topics were highlighted as areas for EMS provider education: identifying patients with palliative needs, (75) palliative therapeutic goals, (30) legal documentation and advance care planning, ethics, (20) withholding and withdrawing treatment, (66,82) patient and family communication (including caregiver support), (31) symptom

management, (84) interdisciplinary teamwork (89) and current palliative system structures. (88)

Lamba *et al* detailed four steps for EMS and palliative care integration: (1) identify EMS 'champions', (2) review protocols and literature, (3) perform a needs assessment and (4) create an action plan. (7) The authors argued that optimal palliative care begins out-of-hospital and, therefore, palliative and EMS systems should collaborate. (7) Such collaborations between palliative and EMS systems, making use of newly developed palliative care guidelines and protocols for EMS providers, were successfully deployed in Canada, (3) Finland (42) and the USA. (63)

Concerning further research, the following areas were recommended: educational interventions, (79) development of EMS palliative care protocols, (16) defining the role of EMS in palliative situations, (18) development of EMS palliative care policies and clarifying palliative care referral pathways, (18) cost-effectiveness of EMS and palliative care integration. (42,74,89)

Discussion

This scoping review aimed to map existing EMS and palliative literature by identifying study types, extracting key findings and noting limitations, thereby providing a summary of current evidence, context for EMS and palliative care integration and identifying knowledge gaps for future research.

The topic of EMS and palliative care has gathered momentum in recent years as the role of EMS systems in out-of-hospital care has expanded; most studies included in this review (63%, n=35) being published between 2018 and 2022. While the body of literature has grown, there remains a relative dearth of empirical evidence, with only 56 such studies identified here since the turn of the millennium. Many of these studies are small in scale, presenting limited findings. Common limitations include small sample sizes, limited external validity, use of unvalidated survey instruments, self-selection bias, recall bias and those resulting from retrospective approaches.

Despite these limitations, the literature, when aggregated, is consistent across various contexts. For example, similar challenges to EMS palliative provision, such as a lack of on-scene patient information, have been documented in both paramedic (10) and physician-led systems. (31) Moreover, findings regarding EMS role, challenges and integration benefits in palliative situations appear similar across HICs (97) and LMICs, (16) demonstrating the ubiquitous nature of the out-of-hospital environment.

Of importance, only two studies in this review (3.5%) were performed in LMICs, (16,98) revealing a significant knowledge gap. Due to disproportionately high burdens of disease and contemporaneous resource constraints, challenges and integration benefits in LMICs may be amplified when compared with HICs. (99,100) HICs have reported that 0.5%–10% of EMS caseload comprises palliative situations. (31,87) With their greater disease burdens, this proportion is likely much larger within LMICs. (16) LMICs require novel approaches to this problem given their resource constraints. The development of new, specialised out-of-hospital palliative care teams, for example, may not be feasible in LMICs. Capacitating already existing structures, EMS and palliative, to collaborate via alternative means may represent a more efficient use of scarce resources to achieve integration benefits. (89) Simply improving communication between the two systems may confer benefit as demonstrated by Dent *et al* where palliative telephonic advice provided to EMS resulted in decreased rates of hospital conveyance. (74) Similar integrative approaches have been successfully employed in HICs for mental health emergencies, linking mental healthcare workers with EMS and police to provide consult at point of care. (101)

The 1990 Commission on Health Research for Development affirmed that strengthening LMIC research capacity is 'one of the most powerful, cost-effective, and sustainable means of advancing health and development'. (102) Not only would LMICs benefit greatly from further research, but the cost-effective solutions developed would likewise benefit HICs where increasing healthcare costs remain a challenge. (103) Considering amplified LMIC problems, solutions and the need for contextually suitable approaches, the need for, and yet lack of, EMS palliative care LMIC research is striking.

While further research is needed, the existing literature supports, and indeed recommends, the integration of EMS and palliative care services whatever the context (paramedic vs physician-led, HIC vs LMIC). (6,16) Such integration would be congruous with the multidisciplinary approach espoused by palliative care (9) and recommended by the WHO. (104) The WHO has noted a growing demand for palliative care worldwide, with an insufficient corresponding supply of specialist palliative services. (104) Integration between palliative services and other disciplines is required to meet the need. Given the multidisciplinary requirement of palliative care and the significant EMS palliative care intersection, integration between the two appears essential.

Though a need for integration exists the question as to precise EMS roles in palliative situations remains. Whatever the specifics, several unique features of EMS may compliment palliative care provision: first-responder role, 24/7 availability, homecare provision and emergency capabilities. (2,7,105,106) The earlier palliative care is implemented, the greater its efficacy.

(21) EMS have the capability to both identify palliative needs and initiate palliative care immediately in their role as first responders. (7,105) Often patients with palliative needs wish to be treated at home but lack this option. (3) They may also suffer deleterious symptoms at any time of day or night requiring a hospital visit. (3) Out-of-hospital palliative care services frequently function exclusively during office hours leaving these patients without support. (20) The 24/7 availability of EMS, coupled with their homecare expertise, could ameliorate these gaps within palliative care provision and, in the not unlikely event of patient deterioration, EMS expertise in emergencies would be beneficial. (42)

Various recommendations to promote EMS and palliative care integration have been made. However, the priorities of these recommendations have not been established. It is likewise unclear from the literature whether EMS and palliative care integration itself is of high priority within individual countries or globally. Further research is required not only to prioritise recommendations for integration, but to prioritise EMS and palliative care integration within unique healthcare systems. Priorities will likely vary across disparate contexts; however, the literature suggests integration should be favourably considered as it has potential to be a low-cost, high impact intervention aligned with WHO priorities. Such integration would result in improved palliative care provision and access, (16) providing these vulnerable patients with dignity through protection of their autonomy and avoidance of non-beneficial treatment. In addition, EMS and palliative care integration may result in cost and resource savings by decreasing hospital burdens. (42,91) This in turn would free resources for additional healthcare interventions. Other causal-sequence benefits may result including a unified healthcare approach and bringing together of siloed systems (EMS, palliative, in-hospital), which would result in further improved patient experience across the healthcare spectrum.

A concern regarding this integration is that this expanded role would strain EMS resources by increasing caseload and time spent per incident. (106) Further investigation into this concern is needed across various contexts. However, existing evidence has shown no increased strain on caseload (42) and while time spent on scene does appear increased in certain palliative situations, these involve provision of homecare without conveyance. (42,105) Total time spent per incident appears to decrease in these situations due to time-saving from avoidance of transport, hospital handover, ambulance cleaning and restocking. (105)

Research priorities regarding palliative care in the ED setting have been established by Quest *et al* (39): (1) which patients are in greatest need of palliative care services in the ED?, (2) what is the optimal role of emergency clinicians in caring for patients along a chronic trajectory of illness?, (3) what are the educational priorities for emergency clinical providers in the domain

of palliative care? As EMS represent the out-of-hospital branch of emergency medicine, such priorities are germane.

Based on the included literature of this review, several specific EMS palliative care research gaps exist. There is a need for further epidemiological study, on a larger scale, across various contexts, particularly LMICs, to more accurately describe the impact of patients requiring palliative care on EMS systems. Further intervention-based studies are required to test the effectiveness of various forms of EMS and palliative care integration, including their cost-effectiveness. The potential benefit of decreased healthcare costs remains theoretical and requires investigation. Educational interventions require particular analysis as many questions remain unanswered: What EMS qualifications should be targeted? What content is most relevant? What level and type of intervention is required (ie, undergraduate vs postgraduate, informal vs formal)? Qualitative interview studies with palliative patients, family members and palliative specialists concerning EMS use in palliative care are largely lacking and would be beneficial as these are primary role players. Finally, both quantitative and qualitative data are needed from other stakeholders such as medical insurance companies which often cover the costs of both EMS and palliative services.

Limitations

This review is not without limitation. Some relevant studies, including grey literature, may have been missed due to the selection criteria, databases searched, search string employed and researcher finitude. Furthermore, only English studies were selected. However, it is unlikely many relevant studies were omitted as a comprehensive search string was developed, piloted and employed in conjunction with a broad database range, meeting recommendations for an optimal search strategy. Finally, the conclusions of this review should be observed with equipoise given the potential risk of bias, limited external validity of many included studies and the need for further contextual and empirical evidence.

Conclusion

Current literature suggests EMS and palliative care systems should integrate to improve palliative care provision. EMS have a role to play in out-of-hospital palliative care however, the specifics of this role require further investigation and are likely to differ across disparate contexts. Currently, when performing various functions in palliative situations, EMS providers are faced with several challenges which must be overcome to provide appropriate care. EMS provider education, collaboration between EMS and palliative systems, creation of EMS

palliative care guidelines/protocols, creation of specialised out-of-hospital palliative care teams and further research have been recommended as solutions. Future research should focus on the prioritisation, implementation and effectiveness of these solutions cross-contextually; particularly in LMICs where the need and potential impact are most significant.

Section 1 Overview

Additional Considerations

The scoping literature review presented here is the broadest to have been performed on the topic of EMS and palliative care to date. However, since the performance of this review, many further studies have been published (107–109) as the topic continues to develop, highlighting the growing importance of this topic internationally. Findings from these further studies have been incorporated into this thesis in addition to the context provided by the scoping review.

The reviewed literature identified shifting dynamics in patient populations and needs as the primary reason for the recent focus on EMS and palliative care integration.(41,110) Thus, the research concerning this integration is in response to a tangible need. According to the WHO, shifts in patient populations have occurred due to modern medical advances which have resulted in ageing populations, subsequent NCD proliferation and increased palliative care needs. (111) As rates of chronic illness and palliative care needs have increased, so too has EMS intersection with these patients. As a result, EMS systems have been forced to adapt to these changing requirements with a need for evidence to inform this adaptation.

While it is evident EMS are increasingly utilised in palliative situations, the reasons for such use, from a patient and family member perspective, remain unclear. Why do patients and family members with palliative needs utilise EMS to meet these needs? What are the needs EMS are used for? Is there a lack of palliative care access? Are EMS particularly suited to certain palliative care needs or are they utilised as a last resort? These, and many similar questions, require investigation as the answers inform another knowledge gap: What is the role of EMS in palliative care provision? While many roles in the reviewed literature were suggested, there remains a lack of consensus with further study suggested. (18) Throughout this thesis answers to these questions are investigated.

The scoping review revealed a relatively small body of literature concerning EMS and palliative care, being performed in several unique countries, and with many limitations, thus highlighting the current limited evidence base and need for further research. Specific evidence gaps requiring research are listed in Table 3 below. From the literature it is clear evidence is required not only in greater quantity, but in additional contexts (i.e. LMICs) which may have differing needs and resources. Furthermore, given the recommendation for EMS and palliative care integration, a need exists to develop an integrative framework to guide its implementation.

Section 1 Summary

Key Messages:

- Shifting global trends in patient populations and needs has resulted in a focus on EMS and palliative care as EMS are more frequently confronted with palliative care situations. Thus, EMS and palliative care research is based on a tangible need.
- Integration between EMS and palliative care systems is recommended and, therefore, an integrative framework to guide this process is required.
- There is a lack of evidence concerning EMS and palliative care integration and how this may be practically achieved, particularly in LMICs.
- Differing contexts have varying needs and resources available for EMS and palliative care integration (i.e. HIC vs. LMIC) and so, context-specific research should be performed.
- Various recommendations for integration have been made in the literature: Education, Stakeholder Collaborations, Alternative Pathways and Approaches, Policy Development, Research.

Table 3 Evidence gaps addressed in Section 1

Evidence Gaps Include:	Addressed in this Section:
Map of current EMS and palliative care literature.	Scoping Literature Review (Chapter 3)
Extent of intersection between EMS and palliative situations.	Retrospective Chart Review – Clinical Analysis (Chapter 4)
Clinical reasons for EMS use in palliative situations.	Retrospective Chart Review – Clinical Analysis (Chapter 4)
Practical reasons for EMS use in palliative situations.	Retrospective Chart Review – Spatio-temporal Analysis (Chapter 5)
Palliative care provider perspectives on the use of EMS in palliative situations.	Palliative Care Provider Interviews (Chapter 6)
Patient and family member perspectives on the use of EMS in palliative situations.	Patient and Family Member Interviews (Chapter 7)
Patient and family member reasons for EMS use in palliative situations.	Patient and Family Member Interviews (Chapter 7)
Development and prioritisation of implementable approaches to EMS and palliative care integration.	Nominal Group Technique (Chapter 8)
Role of EMS in palliative situations.	Scoping Literature Review (Chapter 3), Retrospective Chart Review (Chapters 4 and 5), Palliative Care Provider Interviews (Chapter 6), Patient and Family Member Interviews (Chapter 7), Nominal Group Technique (Chapter 8)

Evidence gaps addressed in this section and their corresponding studies are highlighted in green.
EMS=Emergency Medical Service

Section 2

Retrospective Chart Review Study of Emergency Medical Services' Intersection with Palliative Situations

Section Introduction

Section 2 provides quantitative data from a retrospective chart review study on the intersection between EMS and palliative situations in SA. This study was divided into two separate articles which investigated distinct variables from the same data set. One article analysed patient demographic and clinical variables, while the other analysed spatio-temporal variables. Together, these articles contribute to improved understanding of the extent of intersection between EMS and palliative situations, patient and family member reasons for EMS use in palliative situations, and the role of EMS in palliative situations.

This retrospective chart review study was informed by the scoping literature review in terms of the variables collected and, in turn, this study was used to inform the discussion schedules developed for the qualitative interview studies in Section 3 of this thesis.

This section consists of the following sub-sections:

- Chapter 4: Gage CH, Spies B, Crombie K, Gwyther L, Stassen W. The use of emergency medical services for palliative situations in Western Cape Province, South Africa: A retrospective, descriptive analysis of patient records. SAMJ. 2023;113(11):41-46.
- Chapter 5: Gage CH, Spies B, Crombie K, Slingsby T, Gwyther L, Stassen W. A Spatio-Temporal Analysis of Emergency Medical Services Use for Palliative Situations in Cape Town, South Africa. ***Accepted for Publication in South African Medical Journal.***
- Section 2 Overview

The chapters which make up this section include two published articles which are replicated verbatim but formatted and referenced appropriately for consistency throughout this thesis. This section concludes with an overview including additional considerations, key messages and how these contribute to the thesis in its entirety.

Chapter 4: The Use of Emergency Medical Services for Palliative Situations in Western Cape Province, South Africa: A Retrospective, Descriptive Analysis of Patient Records

Chapter Introduction

This chapter contains the first of two articles from the retrospective chart review study. This first article analysed patient demographic and clinical variables. The purpose of this analysis was to gather novel quantitative data on the extent of EMS and palliative care intersection within SA, as well as identify clinical reasons for EMS use in palliative care. Furthermore, this analysis contributes to improved understanding of the role EMS play in palliative situations.

Declaration from author and co-authors

The following co-authors contributed to this publication: Spies B, Crombie K, Gwyther L, Stassen W.

Contributions of the authors were as follows: CHG conceptualised the study, collected and analysed data, and drafted the manuscript. BS collected data and contributed to data interpretation. KC collected data and contributed to data interpretation. LG contributed to study design and data interpretation and acted as a co-supervisor for the project. WS conceptualised the study, contributed to data analysis and interpretation and acted as primary supervisor for the study. All authors critically reviewed the study and approved the final published version.

The extent of contributions from each person are as follows:

CHG 50%; BS 10%; KC 15%; LG 5%; WS 20%

Given the large number of co-authors, the principal investigator and the supervisor hereby sign for approval on behalf of the group, in accordance with the UCT Doctoral Degrees Board guideline titled, “GUIDELINES FOR THE INCLUSION OF PUBLICATIONS IN A DOCTORAL THESIS.”

Signed by candidate

Caleb Gage

16 January 2025
Date

Signed by candidate

Willem Stassen

16 January 2025
Date

The Use of Emergency Medical Services for Palliative Situations in the Western Cape of South Africa: A Retrospective, Descriptive Analysis of Patient Records

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Abstract

Background: An estimated 56.8 million people require palliative care annually, while only 14% receive such care. This imbalance is particularly acute in low-to middle-income countries (LMICs), where up to 80% of patients requiring palliative care reside. To correct this imbalance, integration between palliative services and other disciplines has been recommended. While improved palliative care integration is a priority in the South African (SA) LMIC context, emergency medical services (EMS) and palliative care remain non-integrated. This has resulted in poor palliative situation management by EMS and a lack of research concerning their intersection.

Objective: To examine EMS use for palliative situations in the Western Cape (WC) Province of SA by describing frequency of intersection, patient characteristics and outcomes.

Methods: An observational, descriptive, retrospective patient record review was employed at two hospitals with palliative care services in the WC. All patient records of those who arrived at the hospitals between 1 January 2020 and 31 December 2020 via EMS conveyance leading to palliative care provision were included in the study.

Results: In total, 1 207 unique patients received palliative care services at both hospitals during the study period. Of these, 395 (33%) made use of EMS for hospital conveyance on 494 occasions. The median (range) patient age was 60 (20-93) years, and most transports involved male patients (54%, *n*=265). Family members were the primary caregivers in most instances (89%, *n*=440), dyspnoea was the chief complaint (36%, *n*=178) and cancer was the most frequent diagnosis (32%, *n*=159). The median length of hospital stay was 6 days, with most patients discharged home (60%, *n*=295).

Conclusion: EMS in SA frequently encounter palliative situations for symptoms that may be managed within their scope of practice. Consequently, it appears that EMS have an important role to fulfil in the care of patients with palliative needs. Integrating EMS and palliative care may result in improved palliative care provision and, therefore, EMS and palliative care integration would be beneficial in SA.

Background

The World Health Organization (WHO) has noted an increasing global demand for palliative care owing to ageing populations and consequent increasing rates of non-communicable disease. (41,104) Despite this growing demand, there has been an inadequate corresponding supply of palliative care services. (104) Estimates indicate that 56.8 million people require palliative care annually, while only 14% receive such care. (112) This imbalance is particularly acute in low-to middle-income countries (LMICs), where up to 80% of patients requiring palliative care reside. (112,113) These increased LMIC palliative needs result from greater disease burdens, resource limitations and underdeveloped palliative care provision. (112,113) To correct this imbalance, integration between palliative services and other disciplines has been recommended. (114) One such developing area of integration is between palliative care and emergency medical services (EMS). (53,110) The limited existing data suggest that up to 10% of EMS call-outs may involve palliative situations and, given this intersection, palliative care should be integrated within EMS systems. (31)

Taking LMIC challenges, recommendations for cross-disciplinary palliative care integration and the intersection between EMS and palliative situations into account, the South African (SA) setting is pertinent. SA falls into the LMIC category and suffers a 'quadruple burden of disease' due to communicable diseases, particularly HIV and AIDS, high maternal and paediatric mortality rates, non-communicable disease and injury. (32) The ensuing chronic, life-limiting illnesses have resulted in an increased need for palliative care in the country, as noted by the SA Ministry of Health. (115) Using mortality data alone, an estimated 0.52% (*n*=286 000) of the SA population require palliative care annually. (24) Palliative care literature in the country has stated, 'to meet this need, additional services within the public health sector, including community and home-based care will need to be developed.' (24)

SA previously supported a World Health Assembly (WHA) resolution to strengthen palliative care systems, making palliative care development a priority in the country. (116,117) Accordingly, palliative care has been included as an essential service in the new National Health Insurance (NHI) proposal and is considered a human right. (117) Furthermore, progress has recently been made in SA palliative care integration, with cross-disciplinary training in some locations being provided to nurses, doctors, correctional service facility workers and traditional healers. (24,116) One area in SA where palliative care remains non-integrated is within EMS systems. (16) Currently, palliative care does not form part of SA EMS training, protocols or patient management, nor do palliative care systems make formal use of EMS to assist in palliative care provision. (16) This results in poor management of palliative situations by EMS and represents an opportunity for enhanced palliative care provision within the

country. (16) Moreover, there is a dearth of SA-specific research concerning EMS and palliative care. Therefore, the characteristics of patients managed in palliative situations by SA EMS are unclear, as is the extent of intersection between the two. The aim of this study, therefore, was to examine EMS use for palliative situations in the Western Cape (WC) Province of SA by describing the frequency of intersection, patient characteristics and outcomes. For the purposes of this study, 'palliative situation' refers to any incident involving the care of a patient with palliative needs.

Methods

Design

An observational, descriptive, retrospective patient record review was employed. This study was compiled according to the Reporting of studies Conducted using Observational Routinely-collected health Data (RECORD) extension of the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) checklist. (118)

Setting

The WC province of SA has a population of 7.3 million, (119) accounting for ~12% of the total SA population. (120) Like the rest of the country, the WC maintains two distinct healthcare systems: private and state. (121) State healthcare is supplied by the government to all citizens, while private healthcare is accessible only to those with healthcare insurance. Currently, only 17% of the SA population (24% in the WC) hold healthcare insurance. (122) State hospitals are divided into varying levels: district (level 1), regional (level 2) and tertiary (level 3). (123) District hospitals are frequently the entry point into the healthcare system, as regional and tertiary facilities are often geographically distant. They offer 24-hour emergency departments (EDs) and basic outpatient, inpatient, diagnostic and therapeutic services. Patients requiring care beyond the capabilities of district hospitals are referred to regional or tertiary hospitals, which are larger and capable of more complex, specialist diagnostic and therapeutic procedures. Patient records from two state hospitals, one district and one tertiary, within the WC were used in the present study. Both facilities have established palliative care services.

Within the EMS sector, both private and state, out-of-hospital emergency care is provided using a paramedic-led rather than physician-led system. (16) Currently, formal training at a higher education (HE) institute is required to register as an EMS provider. However, this was a relatively recent change and many providers with basic short-course qualifications remain

registered. (124) The HE courses range from 1 (basic) to 4 (advanced) years in duration. Owing to the relatively low number and unequal distribution of advanced EMS providers in the country, ambulances are largely staffed with basic providers, while advanced providers frequently operate alone in rapid response vehicles.

Sample and sampling

All patient records of those who arrived at the district and tertiary hospitals between 1 January 2020 and 31 December 2020 via EMS conveyance leading to palliative care provision were included in the study. Illegible patient records, duplicates and those missing data pertaining to the mode of hospital arrival were excluded. Patient records of those who were not both conveyed by EMS and recipients of palliative care were likewise excluded.

Patient variables were extracted from a combination of EMS, hospital palliative service and ED records, all of which were included within individual patient files at both hospitals. Patient files at the district hospital were available in a digital database to which CHG was granted access. Patient files at the tertiary hospital were physically stored in the facility's records department; however, the palliative service and ED maintained digital databases. BS and KC were granted access to both the physical and digital records. They linked patients across the platforms with a heuristic that included unique hospital numbers, folder numbers, patient names and dates of birth.

Data were collected from November 2022 to February 2023 by CHG at the district hospital and BS and KC at the tertiary hospital. This was performed according to the recommendations of Gilbert *et al*. (125) to improve accuracy and minimise inconsistencies:

• Training: data collectors were trained in the study aims, objectives and data extraction tool prior to the study.

• Case selection: well-defined protocols and inclusion and exclusion criteria were developed and applied to the patient records.

• Definitions: all variables analysed were precisely defined.

• Extraction tool: a standardised extraction tool was used to guide data collection and uniformly handle data that were conflicting, ambiguous or missing.

• Meetings: throughout the data collection process, frequent meetings were held among the research team to ensure consistency in data handling.

• Monitoring: LG, WS and CHG closely monitored data-extracting performance.

• Testing of inter-rater agreement: CHG re-extracted data from a random sample of tertiary hospital patient care records (10%), blinded to the extracted data of BS and KC. Findings were compared, and an inter-rater reliability (IRR) of 1.0, calculated using Cohen's kappa (κ), was achieved. Furthermore, the data extraction tool was piloted by CHG and BS prior to the study to enhance consistency.

Data were recorded and cleaned using Excel (Microsoft Corp., USA). No missing data techniques were employed.

Data analysis

An *a priori* data extraction tool developed by the research team, based on previous international studies, (3,42) was used to extract the following variables: patient characteristics: age, sex, primary home caregiver, chief complaint, diagnosis outcome: length of stay, disposition.

Patient age was recorded in years. Sex was classified as male or female. Primary caregiver referred to the person(s) who mostly cared for the patient at home (e.g. family members or home palliative services).

Chief complaint referred to a patient's primary symptom upon EMS arrival. Diagnosis was the primary documented reason in the hospitals for the patient receiving palliative care. This was linked to the categories into which the palliative centres divided diagnoses: cancer, cardiovascular, respiratory, renal, hepatic, neurological, frailty/dementia, HIV/AIDS and other.

Length of stay was calculated from the time of hospital arrival to the time of final disposition, and was recorded in days. Disposition referred to patient outcome in terms of the following: discharged home, discharged to hospice, death or other.

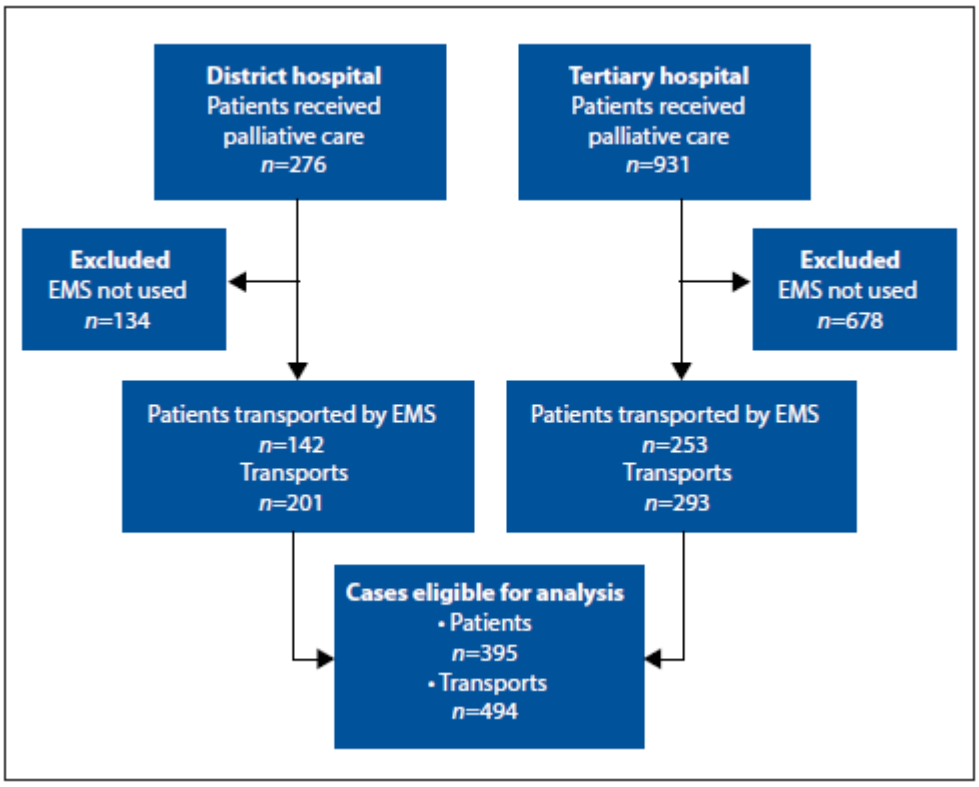
Summary descriptive statistics (medians, ranges) were used to describe the numerical data: patient age, frequencies and length of stay. The remaining variables were analysed as categorical data. Data were analysed using SPSS Statistics for Windows version 28.0 (IBM Corp., USA).

Ethical approval

Ethical approval, including a waiver of informed consent, was gained from the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee (ref. no. 589/2021). Institutional approvals were gained from both the district and the tertiary hospital.

Results

In total, 1 207 unique patients received palliative care at both hospitals from 1 January 2020 to 31 December 2020. Of these, 395 (33%) made use of EMS for hospital conveyance and were included in the study. During the course of the year, these patients were transported on 494 occasions, resulting in an average of 41 EMS transports of patients with palliative needs per month. Fig. 3 demonstrates case selection.



EMS=Emergency Medical Services

Figure 3 Case Selection

Table 4 summarises the characteristics of the palliative situations managed by EMS. The characteristics were calculated based on number of EMS transports, unless otherwise specified, as the aim of the study was to examine EMS use for all palliative situations, which included repeat patient presentations. The median (range) patient age was 60 (20-93) years, and most transports involved male patients (54%, *n*=265). Family members were the primary caregivers in most instances (89%, *n*=440). Dyspnoea was the most common chief complaint (36%, *n*=178), and cancer was the most frequent diagnosis (32%, *n*=159). The median length of hospital stay was 6 days, with most (60%, *n*=295) patients ultimately discharged home.

Table 4 Characteristics of palliative situations managed by EMS

		District n=201	Tertiary n=293	Total n=494
Age, median (IQR)		60 (25)	61 (21)	60 (22)
Sex, n (%)	Male	103 (51%)	162 (55%)	265 (54%)
	Female	98 (49%)	131 (45%)	229 (46%)
Primary Caregiver, n (%)	Family	158 (79%)	282 (96%)	440 (89%)
	Home Palliative Service	4 (2%)	0 (0%)	4 (1%)
	Other[1]	39 (19%)	11 (4%)	50 (10%)
Chief Complaint, n (%)[2]	Pain	47 (23%)	33 (11%)	80 (16%)
	Dyspnoea	98 (49%)	80 (27%)	178 (36%)
	Seizures	2 (1%)	7 (2%)	9 (2%)
	Trauma	2 (1%)	2 (1%)	4 (1%)
	Loss of Consciousness	18 (9%)	15 (5%)	33 (7%)
	Cough	4 (2%)	4 (1%)	8 (2%)
	Body Weakness	6 (3%)	6 (2%)	12 (2%)
	Vomiting	8 (4%)	5 (2 %)	13 (3%)
	Other	16 (8%)	50 (17%)	66 (13%)
	Missing Data	0 (0%)	91 (31%)	91 (18%)
Length of Stay, median (IQR)		5 (6)	9 (11)	6 (10)
	Missing Data	0 (0%)	13 (4%)	13 (3%)
Diagnosis, n (%)	Cancer	68 (34%)	91 (31%)	159 (32%)
	Cardiovascular	41 (20%)	19 (6%)	60 (12%)
	Respiratory	25 (12%)	20 (7%)	45 (9%)
	Renal	9 (4%)	56 (19%)	65 (13%)
	Hepatic	4 (2%)	4 (1%)	8 (2%)
	Neurological	11 (5%)	28 (10%)	39 (8%)
	Frailty/Dementia	7 (3%)	5 (2%)	12 (2%)
	HIV/AIDS	21 (10%)	6 (2%)	27 (5%)
	COVID	6 (3%)	44 (15%)	50 (10%)
	Other	9 (4%)	20 (7%)	29 (6%)
Disposition, n (%)	Discharged home	145 (72%)	150 (51%)	295 (60%)
	Discharged hospice	1 (0.005%)	26 (9%)	27 (5%)
	Death[3]	43 (21%)	99 (34%)	142 (29%)
	Other	12 (6%)	6 (2%)	18 (4%)
	Missing Data	0 (0%)	12 (4%)	12 (2%)

IQR=Interquartile Range, HIV=Human Immunodeficiency Virus, AIDS=Acquired Immunodeficiency Syndrome, COVID=Coronavirus Disease.

[1] Patients with 'other' primary caregivers include those with no specified caregiver and those with caregivers other than family or palliative care workers such as a neighbour.

[2] Patients with 'other' chief complaints presented with a broad constellation of symptoms including, headache, dizziness, diarrhoea, constipation, anasarca and hypoglycaemia. The chief complaint 'trauma' refers to those who received palliative care after sustaining an injury (e.g. a fall).

[3] Death represents a 'final outcome' and, therefore, percentages are higher when calculated based on unique patient numbers rather than EMS transports: District 43 (30%), Tertiary 99 (39%), Total 142 (36%).

Discussion

This study aimed to examine EMS use for palliative situations in the WC Province of SA by describing the frequency of intersection, patient characteristics and outcomes. This was to assist in filling the knowledge gap of EMS and palliative care intersection within SA. To our knowledge, this is the largest study to gather quantitative data on the subject in the country.

A previous qualitative study in SA gathered the perspectives of EMS providers on palliative care and found that these providers reported frequently encountering palliative situations. (16) Because of this intersection, the providers viewed EMS and palliative care integration positively, elaborating on the role of EMS in palliative situations. (16) The current study supports these findings as it indicates substantial and frequent intersection between EMS and palliative situations in the WC, with one-third of patients who received palliative care at the two hospitals in 2020 conveyed by EMS on 494 occasions throughout the year. High-income countries (HICs) have, likewise, found substantial intersection between EMS and palliative situations. A German study found palliative situations may represent up to 10% of EMS caseload. (8) In Australia, a study found palliative situations comprised 0.5% (*n*=4 348) of annual EMS caseload. (87) Within LMICs, and SA in particular, it has been argued that these percentages are likely higher owing to their increased burdens of disease. (16) A further contributing factor within SA may be a lack of personal transport options for patients, resulting in increased reliance on EMS to meet this need. Future research could quantify annual EMS palliative situation caseload in SA, including proportions of conveyance and non-conveyance.

Frequently documented chief complaints of patients with palliative needs for which EMS are called include dyspnoea, pain, convulsions and severe anxiety. (10,31,46) We found dyspnoea (36%, *n*=178) and pain (16%, *n*=80) to be the most common chief complaints, while convulsions accounted for only a small percentage of cases (2%, *n*=9). While no cases of anxiety as a chief complaint were found, it may be that where such cases occurred, EMS providers were able to provide relief and these patients were not conveyed. Our findings are in line with several HIC studies in which dyspnoea and pain were likewise the most frequent chief complaints of palliative situations where EMS were called. (3,42,87) Although this may indicate that EMS encounter similar palliative situations in both LMIC and HIC settings, variance in symptom aetiology and patient socioeconomic status is likely present, representing an area for further study.

Significantly, the management of dyspnoea and pain falls well within the scope of practice of EMS providers, who are trained in the management of these symptoms, including in SA. However, EMS providers are trained to manage dyspnoea and pain in emergency situations rather than palliative contexts. For example, while morphine, an essential palliative medication, (126) is included in the scope of practice for advanced EMS providers in SA, it is not used in the management of severe dyspnoea in palliative situations. EMS providers are not trained in this application, and this indication does not explicitly form part of their scope of practice. Wiese *et al*. (84) have recommended opioids be used for this purpose, demonstrating that dyspnoea in this population is significantly relieved with opioid administration by EMS providers. To achieve this benefit, EMS providers would require training not only in opioid administration for dyspnoea, but also in identifying which situations require a palliative approach to care, including family support and the use of non-pharmacological approaches.

A further benefit of EMS and palliative care integration described in the literature is the provision of home-based care without medical facility conveyance. (74) Carter *et al*. (3) demonstrated that provision of home-based palliative care by EMS improved patient and family quality of life, satisfaction and confidence. This in turn has potential to decrease overall healthcare system costs by avoiding unnecessary hospital admission. (42,75,89,91) Such integration may, likewise, enhance respect for patient autonomy, as the majority of patients with palliative needs may wish to die in the comfort of their homes rather than in a medical facility. (127) Within SA, a study in Soweto found home to be the preferred place of death in 67% (*n*=126) of advanced cancer patients. (128) These benefits would be valuable within the WC context as most hospital transports in our study ultimately resulted in discharge home (60%, *n*=295), many after only a brief 0-3-day stay in hospital (27%, *n*=129). With EMS and palliative care integration, many of these hospital transports may have been avoided.

Of concern in our study, 36% (*n*=142) of patients with palliative needs conveyed by EMS died in hospital, with an even higher proportion present in the tertiary hospital (39%). Clinicians in district hospitals may be more likely to discharge patients home owing to greater knowledge of local home-care services and limited space in their facilities, whereas clinicians in tertiary hospitals may be more intervention focused and slower to refer patients to palliative care services. Several factors may have contributed to these high percentages of hospital deaths. Not all patients and their family members desire death in their home, and some may have chosen hospital conveyance regardless of outcome. (128,129) Inadequate home-care resources in the area may contribute to these decisions, as a local medical facility may be the only place to receive care. Our data support this, with only 4 (1%) cases of palliative home care services identified as the primary source of care. Alternatively, insufficient patient, family or EMS knowledge of available home-care resources may likewise impact decision-making.

From the EMS perspective, to a medical facility, regardless of their wishes, particularly once medications have been administered or other care rendered. (16) While the advanced EMS provider scope of practice within SA allows for the performance of an on-scene discharge to avoid unnecessary conveyance and keep patients at home, it is not currently used, as no policies or guidelines for its use exist. Whatever factors are involved, integration between EMS and palliative care would improve respect for patient autonomy, enhance homecare provision and avoid in-hospital deaths where patients wish to stay home. Such integration could make use of the existing SA EMS scope of practice, for example, opioid administration and on-scene discharge.

Healthcare in SA, as in other LMICs, suffers from budget and resource constraints in addition to its quadruple burden of disease. (32) Consequently, medical facilities within the country, particularly state hospitals, regularly operate with patient numbers well above their capacity while being under-resourced. Avoiding unnecessary admissions and in-hospital deaths, and decreasing costs through EMS and palliative care integration, may represent an effective intervention to assist in alleviating these problems. In the USA, such integration has been successfully implemented with the use of specialist mobile hospice units working alongside EMS. (63) Given the resource constraints of SA and other LMICs, the development of new systems may be too costly, and the integration of two existing systems (EMS and palliative), which frequently intersect, represents a logical and more efficient use of scarce resources. Simply improving communication between the two systems through telephonic consultations may be a cost-effective intervention. (74,110) Alternative models of care, such as the community paramedic in Canada (3) or extended care paramedic in Australia, (41) which integrate palliative care, may be also more feasible within SA, and should be researched.

Limitations

This study is limited by its retrospective design. Furthermore, as this study was performed with patient records at two state hospitals in a single province of SA, its external validity is restricted both within SA and internationally. However, within SA it is likely that provinces share a similar intersection between EMS and palliative situations, as the quadruple burden of disease is ubiquitous. In addition, the real intersection across all provinces is likely greater, as our study only focused on two state hospitals and primarily involved state EMS. The private healthcare sector and those patients not conveyed by EMS, or with unmet palliative needs, were not observed. Owing to the COVID-19 pandemic, data collected in the year 2020 may be atypical, though only 10% of cases in this study involved a COVID-19 diagnosis. While the pandemic may have increased the number of patients with palliative needs conveyed by EMS, it is more

likely the associated national ‘lockdowns’ resulted in fewer overall cases, as many patients avoided medical facilities.

Conclusion

SA suffers from a quadruple burden of disease resulting in an increased need for palliative care. While this need has been prioritised and palliative care is recognised as a human right, there are insufficient resources to adequately meet the demand, necessitating palliative integration with other services. While progress has been made integrating palliative care in SA with nurses, doctors and other allied healthcare workers, no integration exists with EMS systems. From our findings, EMS in SA frequently encounter palliative situations for symptoms that may be managed within their scope of practice. Therefore, it appears that EMS have an important role to fulfil in the care of patients with palliative needs. Integrating EMS and palliative care may result in improved palliative care provision, respect for patient autonomy, decreased rates of unnecessary hospital admission and in-hospital death, and reduced overall healthcare system costs. These benefits are particularly germane to the SA context and, therefore, EMS and palliative care integration would be beneficial to the country.

Chapter 5: A Spatio-Temporal Analysis of Emergency Medical Services Use for Palliative Situations in Cape Town, South Africa

Chapter Introduction

This chapter contains the second of two articles from the retrospective chart review study. This second article analysed patient spatio-temporal variables. The purpose of this analysis was to identify reasons for EMS use in palliative care regarding healthcare access. In addition, this analysis contributes to improved understanding of the role EMS play in palliative situations.

Declaration from author and co-authors

The following co-authors contributed to this publication: Spies B, Crombie K, Slingsby T, Gwyther L, Stassen W.

Contributions of the authors were as follows: CHG conceptualised the study, collected and analysed data and drafted the manuscript. BS collected data and contributed to data interpretation. KC collected data and contributed to data interpretation. TS contributed data analysis and interpretation. LG contributed to study design and data interpretation and acted as a co-supervisor for the project. WS conceptualised the study, contributed to data analysis and interpretation and acted as primary supervisor for the study. All authors critically reviewed the study and approved the final published version.

The extent of contributions from each person are as follows:

CHG 50%; BS 5%; KC 5%; TS 20%; LG 5%; WS 15%

Given the large number of co-authors, the principal investigator and the supervisor hereby sign for approval on behalf of the group, in accordance with the UCT Doctoral Degrees Board guideline titled, “GUIDELINES FOR THE INCLUSION OF PUBLICATIONS IN A DOCTORAL THESIS.”

Signed by candidate

Caleb Gage

16 January 2025
Date

Signed by candidate

Willem Stassen

16 January 2025
Date

A Spatio-Temporal Analysis of Emergency Medical Services Use for Palliative Situations in Cape Town, South Africa

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Abstract

Background: Approximately 56.8 million people worldwide require palliative care annually, while only 14% receive such care. Within low-to-middle income countries (LMICs) this imbalance is prominent as these countries contain up to 80% of these patients. To correct this imbalance, palliative care integration with other disciplines has been recommended. One developing area of integration in the South African (SA) LMIC context, involves Emergency Medical Services (EMS).

Objectives: The aim of this study was to describe the geographic and temporal distribution of EMS and palliative situation intersection in Cape Town, SA.

Methods: A descriptive, retrospective patient record review was employed at two hospitals in Cape Town. Records of patients who received palliative care at the hospitals after EMS transport between 1 January 2020 and 31 December 2020 were included. EMS intersection with palliative situations according to time of day, working hours, day of week and month of year were subjected to Chi-squared testing for temporal analysis. Geospatial data were investigated using cluster and proximity analyses.

Results: Overall, 494 instances of EMS palliative situation transport were identified. Most occurred from peri-urban areas (78%, n=385), during the daytime (52%, n=257), out-of-office hours (53%, n=261) and weekdays (76%, n=375). Statistically significant variation in distribution was found according to time of day (p=<0.001), with 38% (n=188) of cases occurring between 13h00 and 19h00, and month of year (p=<0.001), with 36% (n=177) occurring in June, August and October. Proximity analysis revealed a mean driving time of 6.69min and distance of 3.65km to palliative care facilities.

Conclusion: EMS are frequently used for access to palliative care during any time of the day, week or year, particularly in peri-urban areas. EMS may further improve access through integration with palliative care. This efficient use of constrained resources should be pursued in SA, focussing on areas of increased demand.

Introduction

Palliative care is an approach that improves the quality of life of patients and their family members experiencing the problems associated with life-threatening illness, through the prevention and relief of suffering. (112) Approximately 56.8 million people worldwide require palliative care annually, while only 14% receive such care. (112) Within low-to-middle income countries (LMICs), which contain greater disease burdens relative to high-income countries (HICs), this disparity is prominent as they contain up to 80% of patients requiring palliative care. (112,113) Despite the disproportionate need for palliative care within LMICs, access to such care is limited due to scarce resources and underdeveloped palliative care services. (112,113) An example of this imbalance between palliative care supply and demand, may be found in the LMIC context of South Africa (SA). SA suffers a "quadruple burden of disease" due to communicable diseases, non-communicable diseases, elevated maternal and paediatric mortality rates, and injury. (32) Subsequent life-limiting illnesses have resulted in increased palliative care needs. (117) Mortality data alone indicate 0.52% (n=286 000) of the SA population require palliative care annually. (24) To meet these high demands, the World Health Organization (WHO) has recommended palliative care integration with other healthcare disciplines. (104)

One developing area of palliative care integration involves Emergency Medical Services (EMS). (97,110) It has been demonstrated within HICs that EMS and palliative care integration improves palliative care access, particularly in rural areas. (42,74) While much progress has recently been made integrating palliative care in SA within various health and allied health sectors, palliative care access challenges remain and EMS segregation persists. (16,24,116,130) However, positive conditions for integration are present in the country as palliative care has been included as an essential service in the National Health Insurance (NHI) bill. (117) Furthermore, access to palliative care is recognised as a human right in SA. (117)

To benefit from these positive conditions, SA specific research, *vis à vis* palliative care and EMS, is essential. One area requiring investigation is the spatio-temporal distribution of EMS intersection with palliative situations. Given their limited resources, LMICs require targeted, efficient interventions. Within various areas of SA, identifying locations of high EMS and palliative situation intersection may allow the development of such interventions within the context of local resources. Furthermore, these analyses may identify methods by which EMS may improve palliative care access. The aim of this study, therefore, was to describe the geographic and temporal distribution of EMS and palliative situation intersection in Cape Town, SA. The term 'palliative situation' refers to any incident involving the care of a patient with palliative needs.

Methods

Design

A descriptive, retrospective patient record review was employed to gather clinical, spatial, and temporal data. The clinical data were published previously (130) and the current study presents the spatio-temporal analysis of the dataset. This report has been compiled according to the Reporting of studies Conducted using Observational Routinely-collected health Data (RECORD) extension of the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) checklist. (118)

Setting

The Western Cape (WC) province of SA, in which Cape Town is situated, has a population of approximately 7.3 million; (119) representing 12% of the SA population. (120) Around 64% of the WC population reside in Cape Town. (119) As in the rest of SA, the WC maintains two healthcare sectors: private and state. State healthcare is supplied by the government to all citizens while private healthcare is restricted to those with medical insurance or adequate financial means. Currently, only 17% of the SA population (24% in the WC) hold medical insurance. (122) State hospitals are categorized into three levels: district, regional and tertiary. (123) District hospitals are frequently the entry-point into the healthcare system offering 24-hour emergency departments (EDs), basic outpatient and inpatient care. Patients requiring advanced care are referred to larger regional or tertiary hospitals which are capable of more complex, specialist interventions. Patient records from two state hospitals within Cape Town, one district and one tertiary, were used in this study. Each of these facilities provides a palliative care service.

In both private and state EMS sectors, out-of-hospital emergency care is provided using a paramedic-led rather than physician-led model. (16) Formal training at a higher education (HE) institute is required to register as an EMS provider, however, this requirement was recent, and many providers with vocational training, remain registered and practicing. (124) HE courses range from one (assistant) to four years (practitioner) in duration.

Sample and Sampling

Patient records of those who arrived at the two hospitals between 1 January 2020 and 31 December 2020 using EMS transport leading to palliative care provision were included. Patients who received palliative care at the hospitals were, therefore, equated with having

palliative needs at the time of EMS interaction. Thus, for the purposes of this study, palliative care needs were viewed broadly and may have included any situation for which palliative care was deemed necessary by the hospital palliative care providers: emergencies, non-emergencies, end-of-life care, pre-existing, or newly identified palliative care situations. Illegible patient records, duplicates and those missing data relating to the mode of hospital conveyance were excluded.

Variables were extracted from a combination of hospital palliative service, ED and EMS records, which were all included within individual patient files. District hospital patient files were available on a digital database to which CG was given access. Tertiary hospital patient files were physically stored in the facility, however, the ED and palliative service maintained digital databases. BS and KC were given access to both physical and digital records at the tertiary facility and linked patients across the platforms with a heuristic inclusive of unique hospital numbers, folder numbers, patient names and birth dates.

Data were collected from November 2022 to February 2023. To ensure accuracy and minimise inconsistencies the recommendations of Gilbert et al. were followed: (125) Data collectors were trained beforehand in the study aims and data extraction tool. Carefully defined protocols, inclusion and exclusion criteria were developed and applied to all patient records. Analysed variables were precisely defined. A standardized extraction tool was used to uniformly handle missing, conflicting, or unclear data. Throughout data collection, frequent meetings were held to ensure consistency in approach. LG, WS and CG monitored data extracting performance. CG re-extracted data from a random sample (10%) of tertiary hospital patient care records, blinded to the extracted data of BS and KC. An interrater reliability (IRR) of 1.0, calculated using Cohen's kappa (κ), was achieved. The data extraction tool was piloted by CG and BS prior to the study.

Missing data techniques were not employed. Data was recorded and cleaned using Microsoft Excel (Microsoft Corporation, Redmond, Washington, U.S.A.).

Data Analysis

An *a priori* data extraction tool, based on previous international studies, was used to extract the following spatio-temporal variables: Area, Time of Day, Working Hours, Day of Week, Month of Year.

Area referred to the location where EMS were called to a patient. These were divided into urban and peri-urban based on socio-economic status, economic activity, infrastructure, and geography. For the purposes of this study urban refers to cities and towns with extensive infrastructure, and large-scale economic activities including trade, finance, and commerce. (131) Peri-urban refers to adjacent areas which mark the interface between urban and rural environments. (131,132) Despite their urban locales, peri-urban areas are characterised by poor infrastructure, decreased socio-economic status relative to urban areas, and mixed urban and rural economic activity including small-scale agriculture and industry. (131,132) Day time was defined as 6am to 6pm. Office hours were defined as 8am to 5pm. Weekday was defined as Monday to Friday.

Summary descriptive statistics were used to describe frequencies, proportions, distances, and times. Chi-square goodness of fit testing, assuming equal distributions, was used to analyse the temporal data: distribution of EMS calls to palliative situations by time of day, day of week and month of year. A p-value <0.05 was set for statistical significance. Data were analysed using IBM SPSS Statistics for Windows version 29.0 (IBM Corporation, Armonk, New York, United States of America).

Geospatial data were analysed with the ESRI World Geocoder from ArcGIS (Esri, California, United States of America). Data were geocoded and aggregated at suburb level to preserve patient confidentiality. To correct for potential biases in data distribution due to the varying sizes of Cape Town suburbs, a cluster analysis was performed to identify areas of statistically significant higher or lower incidence.

Proximity analysis was performed to identify projected driving times and distances from cases of EMS and palliative situation intersection to the closest palliative care capable facility. These facilities were WC Department of Health clinics within the City of Cape Town and hospitals which offer palliative services. The clinics offer generalist palliative care services and may refer patients to hospitals for specialist palliative care where necessary. ArcGIS proximity analysis uses typical traffic trends determined by averaging historic driving speeds in five-minute intervals over the period of one week for each road.

Ethics

Ethical approval, including a waiver of informed consent, was granted by the University of Cape Town (UCT) Faculty of Health Sciences (FHS) Human Research Ethics Committee (HREC): 589/2021. Institutional approvals were granted from each hospital.

Results

From 1 January 2020 – 31 December 2020, a combined 1207 patients received palliative care from the two hospitals. Of these, 395 (33%) used EMS for hospital conveyance on 494 occasions. This resulted in an average of 41 EMS transports of patients with palliative needs per month. The majority of transports occurred from peri-urban areas (78%, n=385). Most occurred during the daytime (52%, n=257), out-of-office hours (53%, n=261) and weekdays (76%, n=375). Table 5 provides a summary of the spatio-temporal characteristics.

Table 5 Spatio-Temporal Characteristics

		District n=201	**Tertiary n=293**	**Total n=494**
Area, n (%)	Peri-Urban	201 (100%)	184 (63%)	385 (78%)
	Urban	0 (0%)	85 (29%)	85 (17%)
	Missing Data	0 (0%)	24 (8%)	24 (5%)
Time of Day, n (%)	Day	112 (56%)	145 (49%)	257 (52%)
	Night	89 (44%)	131 (45%)	220 (45%)
	Missing Data	0 (0%)	17 (6%)	17 (3%)
Working Hours, n (%)	Office Hours	99 (49%)	117 (40%)	216 (44%)
	Out of Office Hours	102 (51%)	159 (54%)	261 (53%)
	Missing Data	0 (0%)	17 (6%)	17 (3%)
Time of Week, n (%)	Weekday	152 (76%)	223 (76%)	375 (76%)
	Weekend	49 (24%)	70 (24%)	119 (24%)

Figures 4-6 demonstrate the distribution of EMS palliative situations according to time of day (Figure 4), day of week (Figure 5) and month of year (Figure 6). Statistically significant variation in distribution was found according to time of day (χ^2=105.792; df=23; p=<0.001) with 38% (n=188) of cases occurring between 13h00 and 19h00, and month of year (χ^2=44.251; df=11; p=<0.001) with 54% (n=267) of cases occurring from June to October 2020. No significant variation was found according to day of week (χ^2=7.393; df=6; p=0.286).

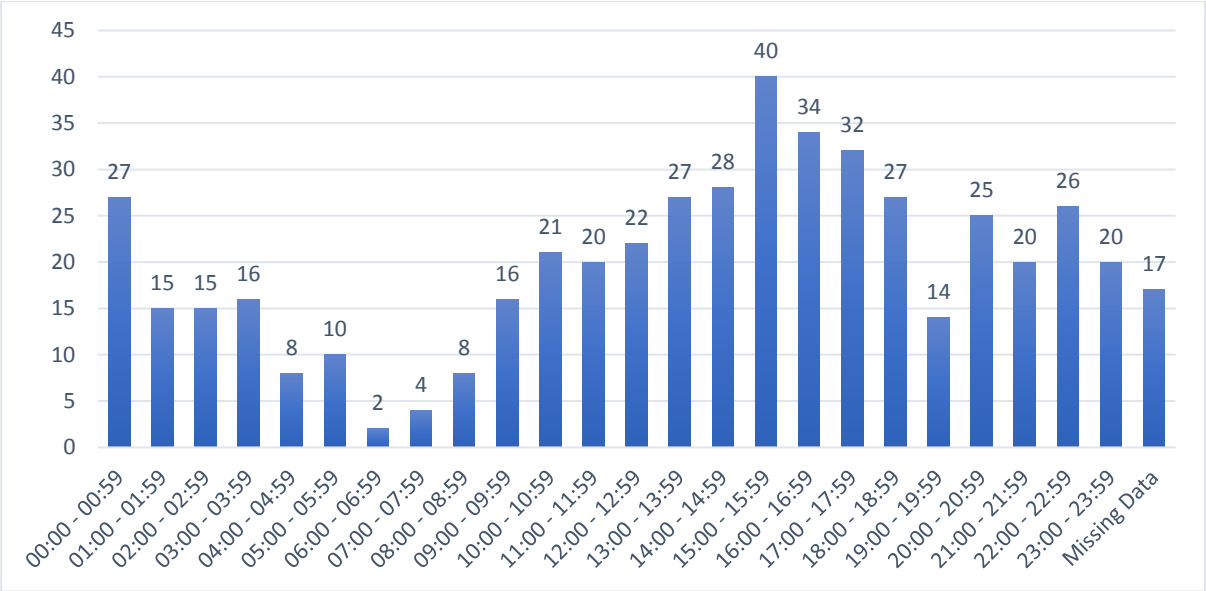


Figure 4 Distribution of EMS palliative situations by time of day

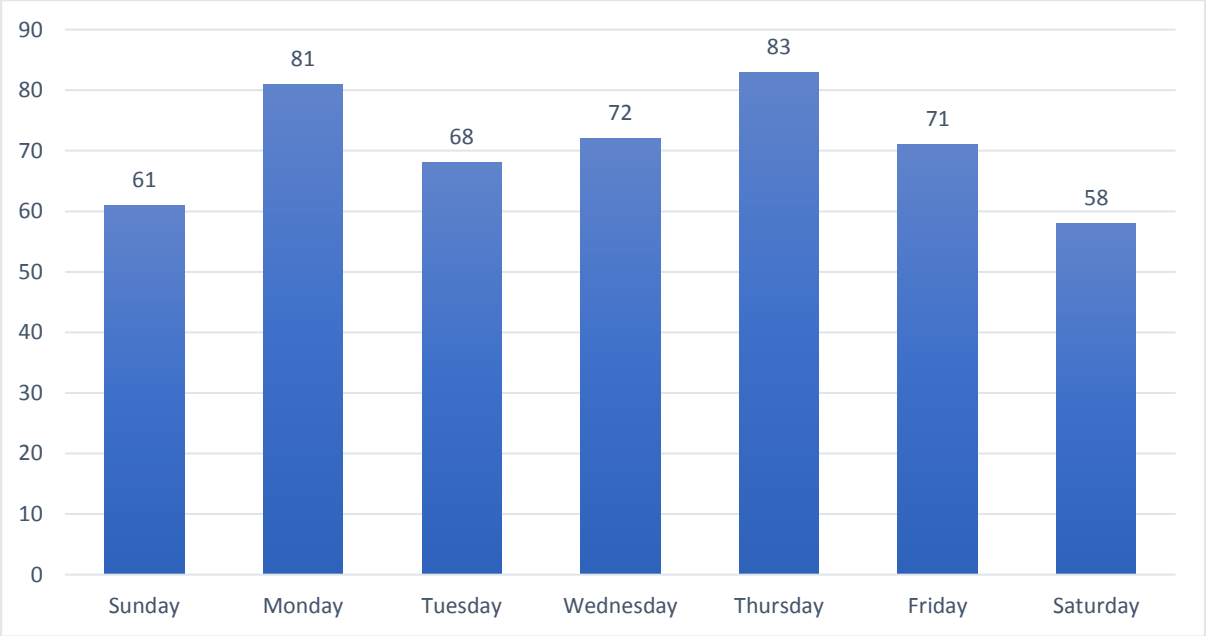


Figure 5 Distribution of EMS palliative situations by day of week

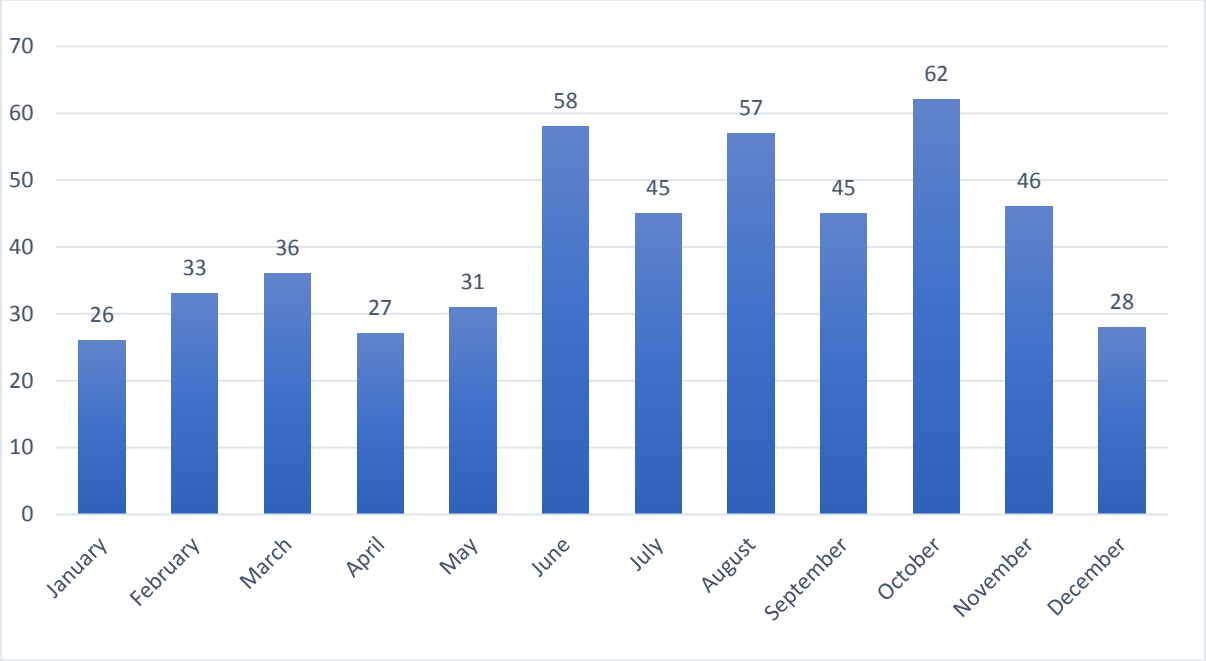
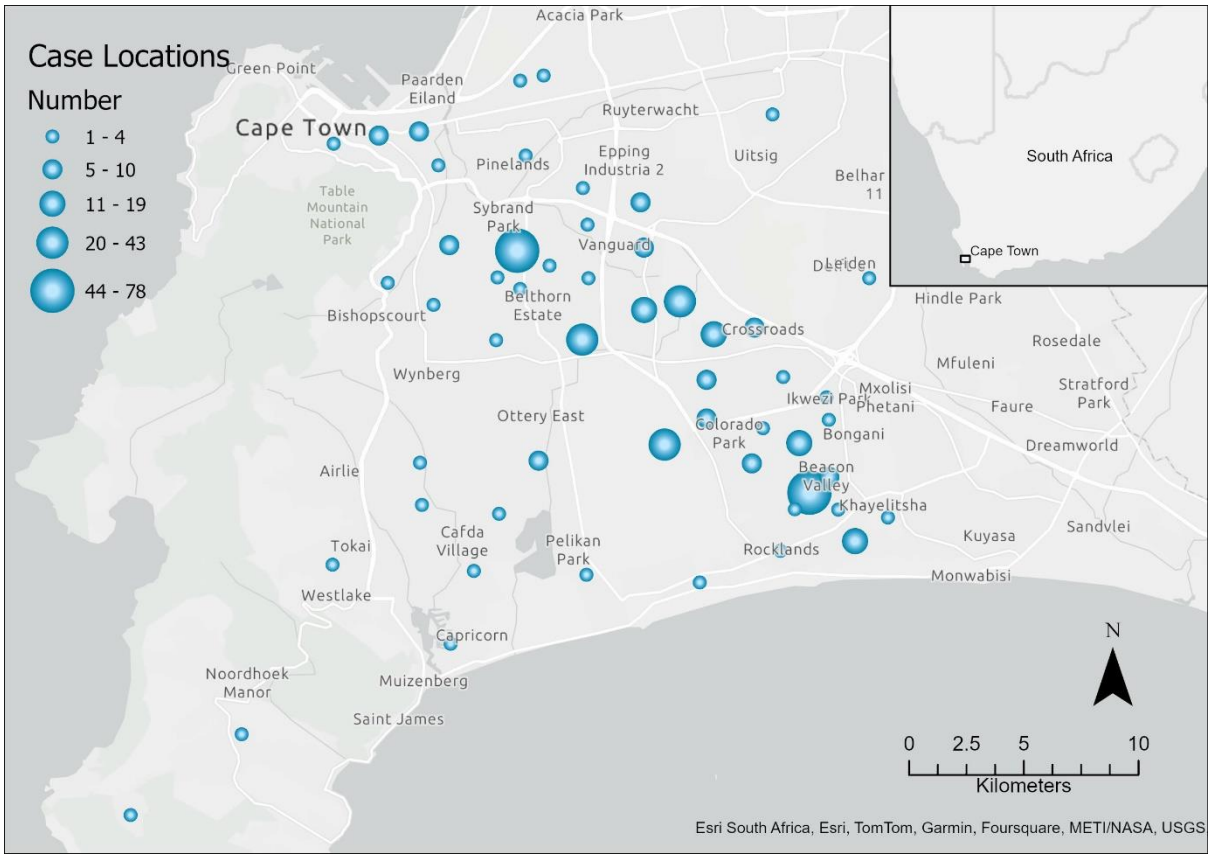
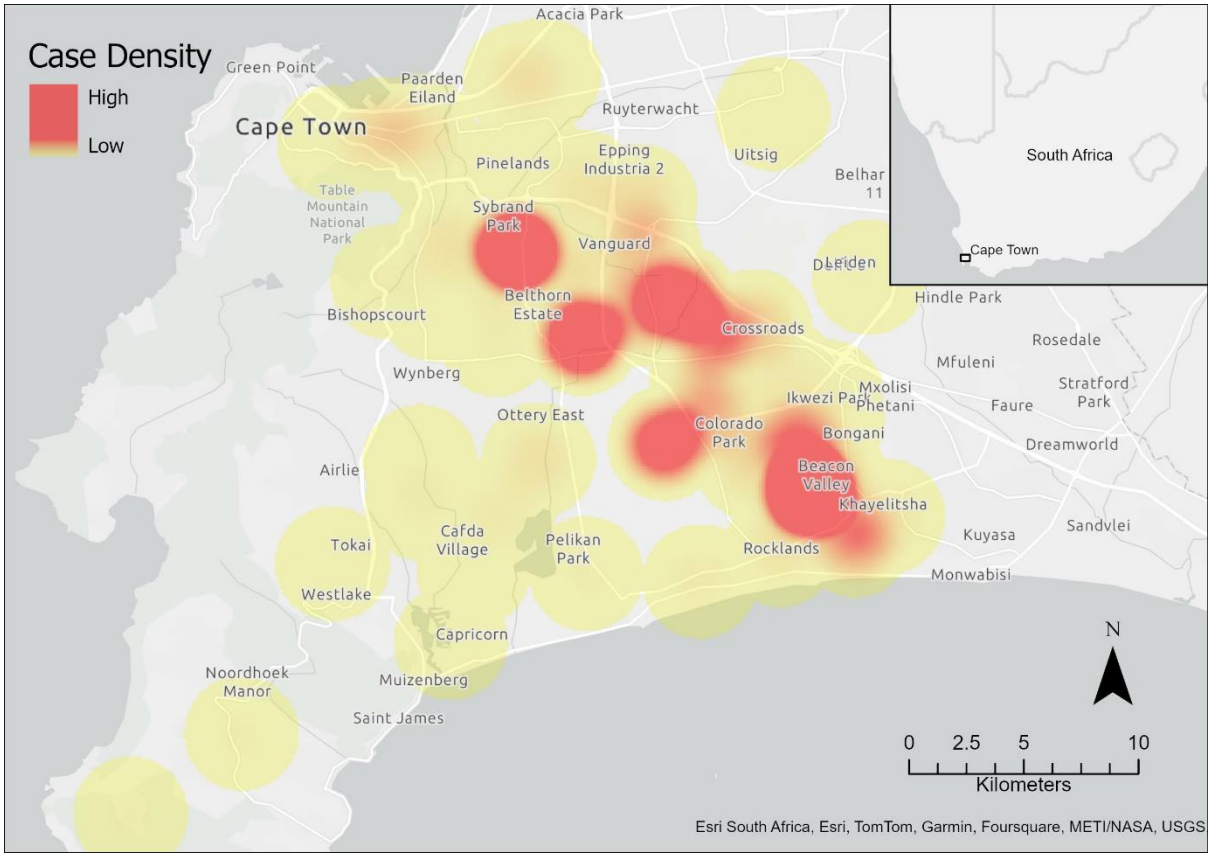


Figure 6 Distribution of EMS palliative situations by month of year

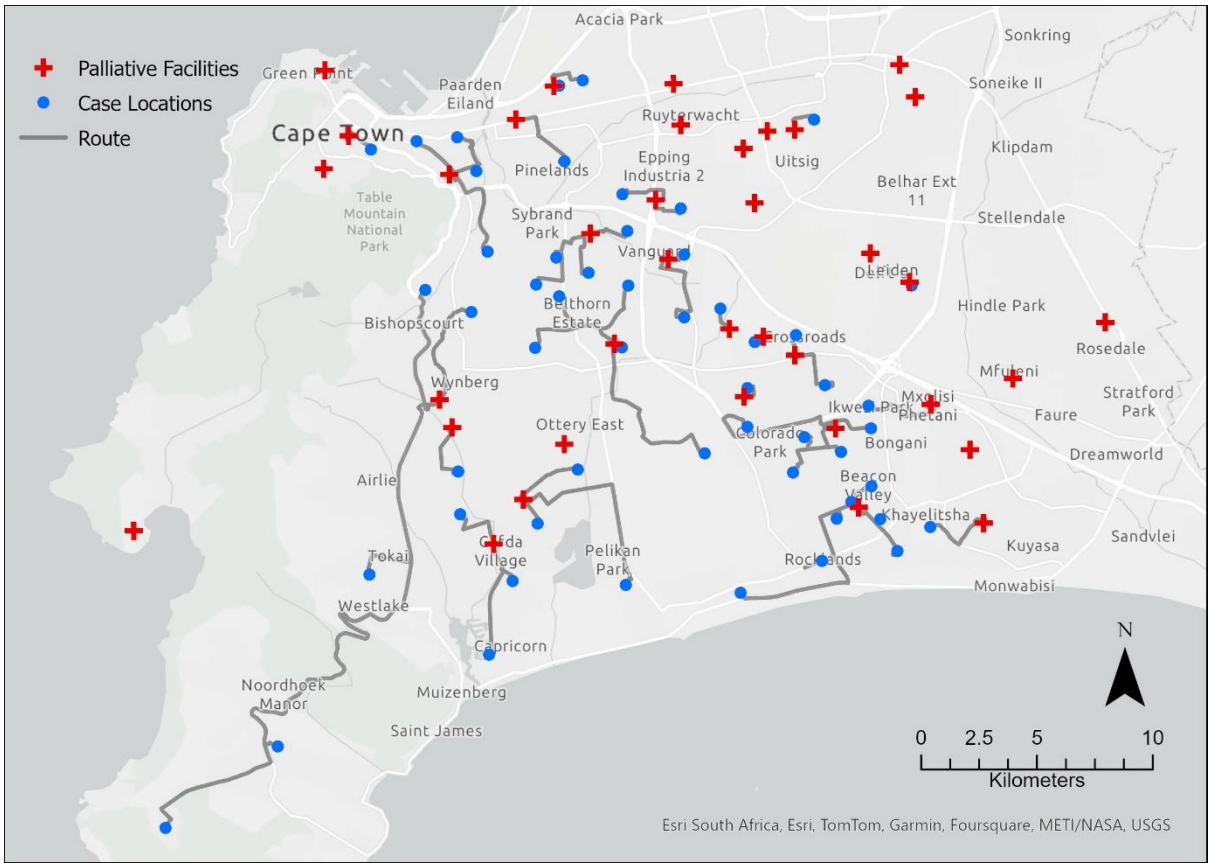
Figure 7 demonstrates the geospatial distribution of EMS palliative situation intersection and available palliative care facilities. No statistically significant variations in distribution were found after cluster analysis. Distribution was explained by suburb size with larger suburbs containing greater case numbers. Proximity analysis revealed a mean (range, standard deviation) driving time of 6.69min (1.12 – 29.75, 4.69) and distance of 3.65km (0.23 – 26.45, 4.47) from cases of EMS and palliative situation intersection to palliative care capable facilities.



Map 1: A graduated symbol map indicating locations of EMS intersection with palliative situations.



Map 2: A heat map indicating EMS and palliative situation case density.



Map 3: Visualisation of proximity analysis. Palliative facilities refer to WC government clinics and hospitals with palliative care capabilities. The path to the nearest palliative care facility is indicated by the Route.

Figure 7 Geospatial distribution of EMS and palliative situation cases

Discussion

The aim of this study was to describe the geographic and temporal distribution of EMS and palliative situation intersection in Cape Town, SA for the purposes of developing targeted, efficient interventions within the context of locally available resources and to identify areas in which EMS may contribute to palliative care access. To our knowledge, this is the first such study concerning EMS and palliative care.

The majority (78%, n=385) of EMS intersection with palliative situations occurred in peri-urban areas. Despite its location in an urban environment, most EMS transports to the tertiary hospital were likewise from peri-urban areas (63%, n=184). These areas are adjacent to urban centres but maintain rural characteristics such as poor infrastructure and decreased socio-economic status. (131–133) As a result, they frequently suffer from difficulties accessing even basic healthcare. (133) Within SA, it has been noted that many such areas developed as a consequence, not necessarily of urban sprawl, as documented elsewhere in the world, (134) but historical discrimination. (135,136) After the abolition of apartheid, urban economic centres,

previously reserved for 'whites', were opened to all South Africans resulting in a massive influx of the population from outlying rural areas to these urban centres in search of better opportunities. (135,136) The peri-urban areas surrounding these centres sustained the primary impact of this rapid population increase resulting in uncontrolled growth and service delivery challenges. (135) Despite these negative historical consequences and ongoing challenges, peri-urban areas contain tremendous potential for development. Discussing the historical context of this rural-urban integration in SA, Sadiki and Ramutsindela stated, *'…the acknowledgement of the rural-urban divide should be the first step towards meaningful peri-urban transformation.'* (136) We suggest EMS and palliative care integration would form a valuable part of this transformation.

Our findings indicate a heightened reliance on EMS in peri-urban environments for patients with palliative needs despite the close proximity of palliative care capable facilities in most cases (mean distance 3.65km). This may be due to the frequently high burdens of illness in such areas and lacking alternative transport options. However, regardless of alternative transport availability, patients with palliative needs may remain reliant upon EMS as their conditions frequently render them immobile, precluding typical vehicular transport. Furthermore, these findings may indicate a lack of access to palliative homecare services, which would prevent the need for medical facility transport. Findings from the clinical data support this as home palliative services were the primary source of care in only 1% (n=4) of cases in this study. (130)

Within HICs, EMS have been successfully deployed not only to meet palliative care transport needs, but also homecare needs through community paramedic models in which dedicated EMS providers function as part of a broader palliative care team. (41,63) One potential benefit of palliative homecare is decreased healthcare system costs through avoidance of unnecessary hospital admissions. (38,137) As previously reported, most hospital transports in the current study ultimately resulted in discharge home (60%, *n*=295), many after only a brief 0-3-day hospital stay (27%, *n*=129), potentially indicating unnecessary hospital transports. (130) While the cost-effectiveness of EMS use for this purpose remains an area for investigation, particularly in SA, several studies have postulated this benefit. (42,75,89,91) Given the resource limitations of SA and other LMICs, novel system development, such as specialist out-of-hospital palliative care teams, may be costly and the integration of two existing systems (EMS and palliative), may represent more judicious use of constrained resources. (130) Community paramedic models, in particular, may be of substantial cost-benefit (91) and should be explored in SA.

While EMS use for palliative situations may prove cost-effective, their safety in some peri-urban areas represents a challenge. High crime rates are strongly associated with areas of increased socio-economic inequality (138–140) which, in turn, may negatively impact EMS ability to perform their various functions. Within Cape Town itself attacks on EMS have been frequently reported, resulting in certain areas requiring an escort by the South African Police Services before entering the area. (141) In addition to negatively affecting EMS care provision, this may likewise contribute to a lack of palliative homecare services as nurses, who frequently travel alone, are not permitted to travel in these areas due to safety concerns. Should EMS be integrated with palliative care in SA for its provision in patient homes, mechanisms for safety will be required.

Some studies have noted that, due to their 24/7 availability, EMS are frequently called to patients with palliative needs out-of-office hours, during the night or other times when palliative services are unavailable. (20,42) We found that while most cases of EMS intersection with palliative situations occurred out-of-office hours (53%, n=261), they were relatively evenly distributed across office and out-of-office hours and variance was not explained by day of week. While cases during the night were frequent, daytime hours were slightly more common (52%, n=257). The more even distribution of our findings across office and out-of-office hours, day and night, when compared with the literature, may be explained by a relative lack of homecare services in SA, including during office hours. However, statistically significant variance was found regarding hour of the day with 38% (n=188) of cases occurring between 13h00 and 19h00. Case numbers appeared to rise throughout the morning and into the afternoon, which may be explained by worsening patient symptoms or caregiver distress as a day progressed. Peak case numbers occurred between 15h00 and 18h00. As the majority of primary caregivers in this study were family members, (130) this may be explained by caregivers returning home from work and finding their loved ones in distress. Furthermore, statistically significant variance was noted according to month of the year with 54% (n=267) of cases occurring from June to October. These represent colder winter and spring months which, in addition to seasonal viral infections, may exacerbate the conditions of those with palliative needs, many of whom are immunocompromised.

Though numerous facilities offering palliative care services exist within Cape Town, it appears access to these facilities requires assistance. EMS were frequently used for this purpose particularly in areas of decreased socio-economic status and during any time of the day, week or year. Penchansky and Thomas described five dimensions of access to healthcare: 1) Availability: the supply of services in relation to demand, 2) Accessibility: the location of services in relation to clients, accounting for transportation resources, 3) Accommodation: the manner in which available services facilitate clients, 4) Affordability: the cost of services in

relation to clients' purchasing power, 5) Acceptability: clients' attitudes concerning available services and healthcare workers, and healthcare worker attitudes towards clients. (40) Currently, in palliative situations, patients and their caregivers make use of EMS for improved accessibility, provided by EMS conveyance, and accommodation as EMS are available 24/7.

Through integration with palliative care, EMS may improve access in all dimensions. Equipping EMS to recognise palliative care needs and provide this care in patient homes would improve both the availability and acceptability of palliative care. This has been demonstrated in Canada where palliative homecare provided by EMS improved patient and family satisfaction. (3) While the limited existing evidence suggests EMS and palliative care integration may be cost-effective from a healthcare system perspective, improvements in affordability from a patient standpoint may also result. EMS use for palliative homecare without conveyance may avoid unnecessary personal transport and other costs associated with hospital admissions. This would not only improve the affordability of immediate care needs but also increase patient purchasing power for future needs through relief of high opportunity costs associated with hospital admission. Affordability improvements would mostly benefit those within areas of decreased socio-economic status (i.e. peri-urban areas) who lack resources and concomitantly suffer the greatest disease burdens. (142) In this manner, EMS and palliative care integration may play a role in decreasing healthcare access inequalities which is the overarching goal of the NHI in SA. Therefore, EMS and palliative care integration should be considered within the NHI framework.

Limitations

This study is limited by its retrospective design. Due to the keeping of physical records at the tertiary facility, some data were missing ($\leq$5%), however, this small proportion is unlikely to significantly affect the results. The true intersection between EMS and palliative situations is likely underreported in this study as only two state hospitals, involving primarily state EMS, were used. The private sector, patients not transported by EMS, and patients with unmet palliative needs, were not observed. In addition, as this study was performed at only two state hospitals within Cape Town, the geographical findings are restricted primarily to the drainage areas of these hospitals. Nevertheless, the reliance of patients upon EMS for access to palliative care in these areas is worthy of attention. This study reveals the need for larger scale spatial analyses within SA to compare more diverse areas. Furthermore, as areas were aggregated at suburb level, rather than specific address, some accuracy in proximity analysis may have been lost; however, this effect is likely minimal. Due to the COVID-19 pandemic data collected in the year 2020 may be atypical. The pandemic may have increased the frequency

of EMS and palliative situation intersection due to greater patient numbers and preferential use of EMS over public transport. However, it is more likely the enforced national 'lockdowns' resulted in decreased frequency as many patients avoided medical facilities and were encouraged to remain home. Furthermore, only 10% of cases in this study involved a COVID-19 diagnosis. (130) Concerning the temporal data, hospital arrival times were used in lieu of EMS call times as these were largely missing from patient hospital files. As large discrepancies may exist between these times, findings of this study may be more reflective of EMS interaction with palliative situations than patient need in some cases. However, these findings remain important and likely do not affect the relatively even distribution of times across office and out-of-office hours, day and night, nor the 24/7 use of EMS in palliative situations.

Conclusion

While numerous facilities within Cape Town, SA offer palliative care services, it appears assistance accessing these facilities is required. From our findings, EMS are frequently used for this purpose at any time of the day, week or year, particularly in areas of decreased socio-economic status and during the colder winter months, despite the close proximity of patients to palliative care facilities. EMS currently provide access to palliative care through their 24/7 availability and patient conveyance. Should EMS and palliative care integration occur, EMS may further improve access through the provision of homecare, thereby enhancing availability, acceptability, and affordability of care. Moreover, this integration would represent an efficient intervention as it would synergise existing EMS and palliative care resources. As an efficient use of constrained resources, with the potential to greatly improve palliative care access among those most in need, EMS and palliative care integration should be pursued, particularly in areas of increased demand, such as peri-urban environments, and during times of greater need.

Section 2 Overview

Additional Considerations

The studies in this section provide novel quantitative data in SA on the intersection between EMS and palliative situations. The findings corroborate previous qualitative evidence in the country which suggested frequent EMS and palliative situation intersection. (16) It appears EMS and palliative care integration, as discussed in the international literature, (97,110) is applicable in the SA context as substantial intersection between EMS and palliative situations has now been demonstrated (33% of patients who received palliative care in the study made use of EMS averaging 41 EMS transports per month). Furthermore, a link to the shifting global trends in patient populations towards NCDs documented by the WHO (143) was likewise found with cancer 32% (n=159), renal 13% (n=65) and cardiovascular disease 12% (n=60) the most common diagnoses in palliative situations managed by EMS.

These studies also indicate potential reasons for EMS use in palliative situations. A clinical reason appeared to be for relief of distressing symptoms such as dyspnoea 36% (*n*=178) and pain 16% (*n*=80). Practical reasons appeared to revolve around the need for improved access to palliative care services. A lack of home palliative care services was present as in only 1% (n=4) of cases was a home palliative care service the primary caregiver. Family members were the primary caregivers in most instances 89% (*n*=440). A lack of personal transportation options also seems likely as cases were often in close proximity to palliative services (mean driving time of 5.16min and mean distance of 2.86km) and the majority of cases were from areas of decreased socio-economic status 78% (n=385). A lack of community awareness concerning palliative care and service availability may be another potential explanation. Thus, the EMS role in palliative care may include symptom management and improving access to palliative care.

The spatio-temporal analysis of EMS and palliative situations presented here was the first of its kind globally. Given the abilities of EMS to traverse geography and provide patients with access to healthcare 24/7, and the need for improved palliative care access globally, further international spatio-temporal analyses may prove beneficial to the efficient integration of EMS and palliative care systems.

Section 2 Summary

Key Messages:

- Substantial intersection exists between EMS and palliative situations in SA.
- EMS are used in palliative situations for distressing symptoms, such as dyspnoea, and practical needs, such as transport.
- Concerning palliative situations, EMS may have a role to play in symptom management and improving access to palliative care.
- Local contextual factors, such as those in peri-urban environments, may influence EMS use for palliative situations.
- Integrative approaches suggested in this study: Education, Communication and Information Sharing, Stakeholder Collaborations, Research.

Table 6 Evidence gaps addressed in Section 2

Evidence Gaps Include:	Addressed in this Section:
Map of current EMS and palliative care literature.	Scoping Literature Review (Chapter 3)
Extent of intersection between EMS and palliative situations.	Retrospective Chart Review – Clinical Analysis (Chapter 4)
Clinical reasons for EMS use in palliative situations.	Retrospective Chart Review– Clinical Analysis (Chapter 4)
Practical reasons for EMS use in palliative situations.	Retrospective Chart Review – Spatio-temporal Analysis (Chapter 5)
Palliative care provider perspectives on the use of EMS in palliative situations.	Palliative Care Provider Interviews (Chapter 6)
Patient and family member perspectives on the use of EMS in palliative situations.	Patient and Family Member Interviews (Chapter 7)
Patient and family member reasons for EMS use in palliative situations.	Patient and Family Member Interviews (Chapter 7)
Development and prioritisation of implementable approaches to EMS and palliative care integration.	Nominal Group Technique (Chapter 8)
Role of EMS in palliative situations.	Scoping Literature Review (Chapter 3), Retrospective Chart Review (Chapters 4 and 5), Palliative Care Provider Interviews (Chapter 6), Patient and Family Member Interviews (Chapter 7), Nominal Group Technique (Chapter 8)

Evidence gaps addressed in this section and their corresponding studies are highlighted in green.
Evidence gaps previously addressed and their corresponding studies are highlighted in turquoise.
EMS=Emergency Medical Services

Section 3

Role-Player Perspectives on Emergency Medical Services in Palliative Situations

Section Introduction

Section 3 provides qualitative data from interviews with primary stakeholders on the topic of EMS and palliative care. One study included palliative care providers and a separate study included patients and family members with palliative needs. SA EMS provider interviews on this topic were performed previously. (16) Perspectives of each of these stakeholder groups are compared in the below chapters of this section and triangulated with the quantitative findings from the retrospective chart review study in Section 2. These qualitative interview studies contribute to the understanding of primary stakeholder perspectives, the reasons for EMS use in palliative situations and the role EMS play in palliative situations.

The discussion schedules of these interview studies were informed by the scoping literature review and the findings of the retrospective chart review study. In turn, the findings from these interview studies informed the NGT presented in Section 4 of this thesis.

This section consists of the following sub-sections:

- Chapter 6: Gage CH, Gwyther L, Stassen W. South African palliative care provider perspectives on emergency medical services in palliative situations. Afr J Emerg Med. 2024;14(4):231-239.
- Chapter 7: Gage CH, Gwyther L, Stassen W. The Dynamic of Control: Perspectives of Patients and Family Members With Palliative Care Needs on Emergency Medical Services. ***Under Peer Review: Sage Journals.***
- Section 3 Overview

The chapters which make up this section include two published articles which are replicated verbatim but formatted and referenced appropriately for consistency throughout this thesis. This section concludes with an overview including additional considerations, key messages and how these contribute to thesis in its entirety.

Chapter 6: South African Palliative Care Provider Perspectives on Emergency Medical Services in Palliative Situations

Chapter Introduction

This chapter contains the first of two qualitative interview studies performed in this thesis. In this study, palliative care providers were interviewed. The purpose of this study was to incorporate the views of primary stakeholders on the research topic.

Declaration from author and co-authors

The following co-authors contributed to this publication: Gwyther L, Stassen W.

Contributions of the authors were as follows: All authors conceptualized the idea for the study. CHG performed data collection, analysis, and drafted the manuscript. WS and LG assisted in data analysis and acted as study supervisors. All authors approved the final submitted version.

The extent of contributions from each person are as follows:

CHG 70%; LG 10%; WS 20%

In accordance with the UCT Doctoral Degrees Board guideline titled, “GUIDELINES FOR THE INCLUSION OF PUBLICATIONS IN A DOCTORAL THESIS”, each author has signed below for approval to include this manuscript.

Signed by candidate	16 January 2025
Caleb Gage	Date
Signed by candidate	16 January 2025
Liz Gwyther	Date
Signed by candidate	16 January 2025
Willem Stassen	Date

South African Palliative Care Provider Perspectives on Emergency Medical Services in Palliative Situations

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Citation: Gage CH, Gwyther L, Stassen W. South African palliative care provider perspectives on emergency medical services in palliative situations. Afr J Emerg Med. 2024;14(4):231-239.

Abstract

Introduction: Due to the frequent intersection of Emergency Medical Services (EMS) with palliative situations and the increasing global need for palliative care, there has been increased recognition of the need for palliative care integration with EMS. However, EMS and palliative care systems remain segregated in the Low-to-Middle Income Country (LMIC) context of South Africa (SA). The aim of this study was to gather perspectives of palliative care providers in SA concerning EMS in palliative situations.

Methods: A qualitative design employing individual semi-structured interviews was implemented. Ten interviews with experienced doctors and nurses holding post-graduate palliative medicine qualifications were conducted. Verbatim transcriptions of interviews were subjected to content analysis with an inductive-dominant approach to develop codes and categories.

Results: Four categories were developed: 1) Disposition towards EMS, 2) Perceived EMS challenges, 3) Positive EMS impact across patients' palliative care journeys and 4) Methods of EMS and palliative care system integration. Participants maintained an overall positive view of EMS and palliative care integration, noting the beneficial impact of EMS and suggesting various methods of integration, while also highlighting challenges and concerns.

Conclusion: EMS and palliative care integration would be mutually beneficial to both systems while benefiting patient well-being and the broader healthcare system. Potentially low-cost, high-impact interventions suggested by participants, such as palliative care cards for patients and enhancing EMS and palliative care system communication, represent efficacious and judicious use of limited resources within the SA LMIC context. Pilot studies investigating these suggestions should be conducted.

Introduction

Palliative care is *'an approach that improves the quality of life of patients and their families facing the problems 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.'* (114) Palliative care is integrative in nature, incorporating a broad spectrum of healthcare disciplines, including emergency medicine, to provide holistic patient care. (114,144) Recently, there has been increased recognition of the need for palliative care integration in out-of-hospital emergency medical services (EMS). (41,53,97,110) This is due to the frequent intersection of EMS with palliative situations (31) and the increasing global need for palliative care. (104) For the purposes of this study, 'palliative situation' is defined as any event involving the care of a patient with palliative needs, including emergency, non-emergency, and end-of-life situations.

Progress has been made with EMS and palliative care integration in various high-income countries (HICs), such as Australia (41) and Canada. (91) Part of the approach in these contexts has been gaining the perspectives of EMS and palliative care providers, patients, and family members on EMS in palliative situations. (3,145) Despite raising some concerns, such as a lack of EMS provider palliative care training, these role-players have generally viewed EMS involvement in palliative situations positively. (145) However, palliative care provider perspectives are relatively scarce and further research, particularly in low-to-middle income countries (LMICs), has been recommended. (110)

Within the LMIC context of South Africa (SA), EMS and palliative care systems remain segregated. (130) There is little research on the topic in SA, and within LMICs more generally, despite a greater need for palliative care when compared with HICs due to disproportionately high burdens of disease and life-limiting complications thereof. (110) SA literature which does exist has demonstrated frequent intersection between EMS and palliative situations (130) and has gained EMS provider perspectives on palliative care. (16) However, palliative care provider perspectives concerning EMS are absent in the country. To assist in filling this knowledge gap, our study aimed to gather perspectives of palliative care providers in SA concerning EMS in palliative situations.

Methods

Design

A qualitative design employing individual semi-structured interviews was implemented. Husserlian descriptive phenomenology, which seeks to describe the lived experience of participants, provided the underlying theoretical framework. (146)

Setting

SA maintains two healthcare sectors: private and state. (121) State healthcare is provided by the government to all citizens while private healthcare is accessible exclusively to those with adequate financial means or healthcare insurance. EMS are, likewise, divided into these sectors. Out-of-hospital emergency care is provided using a paramedic-led rather than physician-led model. (16) Formal higher education (HE) training is required to register as an EMS provider, however, this requirement is recent, and many providers with vocational training remain registered and practicing. (116) HE courses range from one (assistant) to four years (practitioner) in duration.

Most SA palliative care is provided by non-governmental organizations (NGOs) which provide hospice services. (22) These NGOs are registered as charities and are reliant on donations and volunteers including doctors, nurses and social workers. As of 2018, 150 hospices and 8 hospital-based palliative care services exist in SA. (24) However, inequalities exist in the distribution of these facilities and many areas of the country lack access to palliative care.

Data Collection

The interview schedule was jointly developed by CG, LG and WS based on contextualisation of current literature and previous work by Gage *et al*. (16,110) The interview schedule (Appendix 5) contained six questions referencing career background, utility, barriers, concerns, and feasibility *vis-à-vis* EMS use for palliative situations in SA. Pre-determined prompts and probes were included for each question to enhance in-depth exploration of participant perspectives and limit the introduction of interviewer biases.

Interviews were performed virtually by CG using Microsoft Teams™, with cameras, audio-recording, and transcription enabled, at an agreed upon time. A pilot interview was performed prior to data collection by CG and LG. Data from this interview has been included in the final report as LG met inclusion criteria and content from this pilot aligned with the other interviews. Interviews were conducted one-on-one with no third parties present.

Palliative care providers were contacted *via* email circulation through palliative and hospice databases: The Association of Palliative Care Practitioners of South Africa (PALPRAC), Association of Palliative Care Centres (APCC), University of Cape Town (UCT) Division of Interdisciplinary Palliative Care and Medicine. PALPRAC is a non-profit organization made up of SA doctors trained in palliative medicine. (144) The APCC is a national association of hospices with members from all nine SA provinces. (147) The UCT Division of Interdisciplinary Palliative Care and Medicine is the section of the university dedicated to palliative care education. (148) A brief description of the study was presented and interested providers meeting inclusion criteria signed a consent form.

Inclusion criteria were palliative care providers with post-graduate palliative qualifications (e.g. Post-Graduate Diploma) with a minimum of two years palliative care experience in SA. Exclusion criteria were palliative care providers other than nurses and medical doctors.

Eight interviews, including the pilot, were held from April to October 2023 meeting recommendations for phenomenological studies. (149) After analysis, two further interviews were performed in March 2024 to confirm saturation. Four participants knew of the interviewer from previous collaborations and all participants were aware the study formed part of the interviewer's post-graduate studies. No participants refused or dropped out of the study. No repeat interviews were conducted.

Analysis

Content analysis was performed using the framework of Erlignsson and Brysiewicz with an inductive dominant approach. (150) Transcriptions were read repeatedly for familiarisation after which initial coding was performed. Meaning units were captured, condensed, coded and categorized using Nvivo version 14 (Figure 8). Categories were then reviewed, refined, named, defined and written in the final report. These steps were performed alongside data collection as field notes were recorded during interviews.

CG independently analysed the data. Researcher triangulation was then performed between all authors where codes and categories were discussed and finalised. Data saturation, as detailed by Saunders *et al*., (151) was confirmed after ten interviews as evidenced by a lack of additional data during the final two interviews.

	Example 1	Example 2
Category	Positive EMS Impact Across Patients' Palliative Care Journeys	Methods of EMS and Palliative System Integration
Code	Liaising with palliative care providers	Education of all role-players
Condensed Meaning Unit	EMS role in managing palliative emergency then connecting with homecare team	Would like EMS to be trained in palliative care and palliative emergencies
Meaning Unit	*"So if there was a situation that was more like a palliative emergency, I would see you guys as coming in, assessing the situation and noticing this is palliative emergency and then connecting with our home care team."*	*"So I would like EMS personnel to be trained in palliative care so that you know the things that are palliative care, emergencies like superior vena cava obstruction, which is actually absolutely, glaringly obvious to, to recognize if you have been trained in that in that particular area."*

EMS=Emergency Medical Services

Figure 8 Coding Tree

Reflexivity and Trustworthiness

This study formed part of my (CG) postgraduate studies in Emergency Medicine. During this study I was employed as a lecturer at an SA EMS college. My previous experience with qualitative interviewing was gathering EMS provider perspectives on palliative care. My personal bias is in favour of EMS and palliative care integration. However, several participants raised valid concerns which must be considered. The framework of Guba was applied to ensure data trustworthiness regarding credibility, transferability, dependability and confirmability. (152) Table 7 denotes the methods by which these criteria were pursued.

Table 7 Methods employed to ensure data trustworthiness

Credibility	Pilot interview, opportunity for participants to refuse participation, frequent debriefing sessions among research team, researcher triangulation, member checking (resulting in no changes), reflexive commentary.
Transferability	Thorough description of data collection methods including number and length of interviews and the data-collection time-period, results compared with available literature, use of the *Consolidated Criteria for Reporting Qualitative* (COREQ) research checklist. (153)
Dependability	Thorough descriptions of research design, implementation, and data collection, reflexive commentary.
Confirmability	Researcher triangulation, member checking, *verbatim* transcriptions of audio-recordings produced.

Ethical approval for the study was provided by the UCT Human Research Ethics Committee (HREC Reference Number: 220/2023).

Results

Ten participants were interviewed (Table 8). Interviews lasted between 34 and 57 minutes. Four categories, with subcategories, were developed (Table 9). Participants maintained an overall positive view of EMS and palliative care integration, noting the beneficial impact of EMS and suggesting various methods of integration, while also highlighting challenges and concerns.

Table 8 Interviewee and interviewer details

	Gender	**Qualifications**	**Post-Grad Palliative Experience**	**Environment**
Interviewee #1	Female	Medical Doctor - specialised in family medicine, PGDip Palliative Medicine, MSc Palliative Medicine, PhD Palliative Medicine	30 years	Urban
Interviewee #2	Female	Medical Doctor - specialised in family medicine, MPhil Palliative Medicine, PGDip Health Professions Education	19 years	Urban
Interviewee #3	Male	Medical Doctor, Palliative Care Short Course	9 years	Urban and Peri-Urban
Interviewee #4	Female	Medical Doctor, MPhil Palliative Medicine	27 years	Urban
Interviewee #5	Female	Professional Nurse, Short Course Palliative Care	9 years	Urban

Interviewee #6	Female	Medical Doctor, Psychiatrist, Master's in Early Childhood Intervention, PGDip Interdisciplinary Pain Management, PGDip Palliative Medicine	4 years	Peri-Urban and Rural
Interviewee #7	Female	Medical Doctor, PGDip HIV Management, MSc Palliative Medicine	8 years	Urban
Interviewee #8	Female	Professional Nurse, Bachelor of Social Science, PGDip Palliative Medicine	7 years	Urban
Interviewee #9	Female	Medical Doctor, PGDip Palliative Medicine, MPhil Palliative Medicine, MPhil Bioethics	9 years	Urban
Interviewee #10	Female	Intermediate Life Support[1], Medical Doctor - specialised in emergency medicine, PGDip Palliative Medicine	5 years	Urban and Peri-Urban
Interviewer (CG)	Male	Emergency Care Practitioner[2], MPhil Emergency Medicine, Palliative Care Short Course[3]	10 years (EMS experience)	Urban and Peri-Urban

PGDip=Postgraduate Diploma, MPhil=Master of Philosophy, MSc=Master of Sciences, PhD=Doctor of Philosophy, HIV=Human Immunodeficiency Virus

[1] Vocational paramedic training. Historically this training involved a three-tier system: basic, intermediate, advanced.

[2] In SA, an Emergency Care Practitioner is a paramedic with a 4-year Bachelor's Degree in Emergency Medical Care.

[3] 10-week course through UCT introducing basic palliative care management principles.

Table 9 Categories and subcategories developed from interviews

1) Disposition Towards EMS	**2) Perceived EMS Challenges**	**3) Positive EMS Impact Across Patients' Palliative Care Journeys**	**4) Methods of EMS and Palliative Care System Integration**
a) Calming effect b) Capabilities in palliative situations c) Unreliability in service delivery	a) Persisting EMS and palliative care cultures b) Decision-making in challenging circumstances c) Moral distress	a) Unique insight into determinants of patient health b) Providing initial containment c) Liaising with palliative care providers d) Safe patient transitioning e) Determining trajectory of care	a) Collaborative approaches b) Education of all role-players c) Potential, unintended consequences

EMS=Emergency Medical Services

Discussion

Participants were asked to share their perceptions regarding EMS in palliative situations regarding feasibility, utility and concerns within the SA context. Below, each category is discussed with supporting quotations extracted from interviews. Interviewees are identified by number. (e.g. Interview #1)

Disposition Towards EMS

Overall, participants expressed a positive disposition towards EMS in palliative situations, however, some concerns and negative views were raised. Their disposition was grounded in personal experience and discussed in terms of EMS a) calming effect, b) capabilities in palliative situations and c) unreliability in service delivery.

a) Calming effect

Participants noted the calming effect which EMS bring to palliative situations due to their expertise and professionalism, expressing appreciation and respect for the role they play.

"It may be a small [EMS] role…but I think it's really an important role bringing the patient to us in a comfortable, calm, professional way. I appreciate that." – Interview #4

"…it was a…really hectic case…and it was such a relief to just know that they [EMS] were there." – Interview #8

Previous qualitative work in HICs has likewise demonstrated a positive disposition of palliative care providers towards EMS and the reassurance which EMS bring. (3,145) Juhrmann *et al.*, noted that EMS held a revered public identity and were perceived as crisis resolvers. (145) An earlier Canadian study found that patients and families with palliative needs experienced peace of mind knowing EMS were available 24/7. (3) Moreover, participants highlighted the reassurance EMS bring to palliative care providers themselves, particularly in emergency situations. These perceptions align with those of SA EMS providers who likewise perceived palliative care positively. (16)

b) Capabilities in palliative situations

While integration was recommended, there were mixed perceptions concerning current EMS capabilities in palliative situations. Some participants expressed confidence in EMS while others expressed negative views.

"We've used EMS around here and yeah, I'm pretty confident in their skills and expertise, I wouldn't hesitate to call them." – Interview #5

"I think from the doctors' side of things, there's a lack of respect for paramedics." – Interview #9

Confidence in EMS was based primarily on their clinical abilities in emergency situations. Such expertise is valuable when managing patients with palliative needs as they are prone to abrupt deterioration and acute exacerbations of illness. (20,28,73) While EMS are trained in the management of some common palliative emergencies, such as seizures, they are untrained in others, for example, superior vena cava obstruction. Thus, several participants questioned EMS provider ability to manage these situations appropriately while others described negative views of EMS providers, perceiving a lack of capabilities and interest, particularly among basic EMS providers.

"A lot of our…lower tier EMS professionals, just don't have the ability. I mean most of the guys we see… will see a patient [in respiratory distress]…and not do anything about it…So like to try and train those guys up when they're not interested…" – Interview #7

As basic EMS providers in SA form the majority of the workforce, such perceptions evoke concern. The potential integration of EMS and palliative care in SA across specific EMS qualifications remains an area for study, however, it appears logical that such integration must incorporate basic providers to be of significant benefit. Lamba *et al*., (7) previously suggested only those EMS providers with a desire for palliative care would be suitable for integration. This may be a beneficial criterion for basic EMS providers in SA to be involved with palliative care.

Several participants further expressed negative views of EMS concerning unnecessary transport. While transport is an important EMS function, it is not always appropriate in palliative situations. Many patients wish to be treated without conveyance to a medical facility. (127,128)

EMS were described as *"glorified bus drivers"*, *"taxi"* and *"transport services"* with participants recounting invariable patient transportation regardless of context. Thus, one participant has suggested patients *"…don't phone an ambulance"* (Interview #8).

These perceptions appear aligned with a large study in the Western Cape province of SA which found that 98% (n=240 730) of patients responded to by EMS were transported to hospital despite 83% (n=199 062) of these not having received any EMS treatment. (154) Within LMICs EMS are frequently used solely for transportation purposes. (155) Should EMS and palliative care integration take place in SA, mechanisms for homecare without conveyance, for example a *"treat and release"* approach (41) that is underpinned by an appropriate legislative framework, require development.

c) Unreliability in service delivery

"When you call EMS, you are just trying them…to see if they will come or not." – Interview #3

"I would say out in [rural area]…people probably choose a taxi rather than going with ambulance, just cause the taxi is faster than waiting for an ambulance to arrive." – Interview #6

Participants distinguished between private and state EMS services within SA. Whereas private EMS were described as reliable, quick and available, state EMS were described as unreliable and problematic. Furthermore, according to participants, while private EMS were willing to transport patients to private hospices, state EMS were unwilling and did not prioritise end-of-life situations resulting in prolonged waiting times for an ambulance.

Due to financial constraints and a lack of transportation options, patients with palliative needs in rural areas are largely reliant on state EMS along with the vast majority of SA citizens who do not hold health insurance (83%). (122) Compounding the problem is the relative lack of available palliative services in these areas. Within HICs, EMS integration with palliative care has been recommended specifically in rural areas where 24/7 palliative care services are unavailable as EMS may fill this gap. (42) However, within LMICs, this may be of only theoretical benefit as EMS systems are frequently underdeveloped. (155) Despite SA maintaining one of the most developed EMS systems within Africa, (156) the unreliability of (state) EMS, remains a challenge. This unreliability may be due to geographic challenges, the significant number of rural areas, and a lack of rural infrastructure all of which restrict EMS access. In addition, as one participant noted, some areas may be unsafe for both EMS and

palliative care providers to enter. Attacks on EMS providers have been frequently reported in SA, resulting in certain areas requiring a police escort. (141,157) For meaningful EMS and palliative care integration in SA, EMS systems should be further capacitated, particularly in rural areas.

Perceived EMS Challenges

While expressing some concerns, participants also perceived challenges faced by EMS providers in palliative situations, potentially inhibiting their abilities to appropriately manage such situations. These challenges were expressed as a) persisting EMS and palliative care cultures, b) decision-making in challenging circumstances and c) moral distress.

a) Persisting EMS and palliative care cultures

"That's kind of the traditional…EMS [life-saving approach]*, but that's not necessarily appropriate in palliative care. It might not be within the patient's goals of care to bring them to hospital."* – Interview #7

EMS culture is interventionist in nature, through curative approaches in emergency settings, with the aim of saving life and limb. Supportive palliative approaches, such as allowing natural death, are relatively foreign to EMS culture. Thus, EMS feel uneasy in palliative situations, as SA EMS providers have detailed. (16) This apparent cultural conflict has been a frequently cited reason for EMS and palliative care segregation. (18,28,77) However, with correct training, EMS and palliative care cultures may be complementary. (20,28)

While EMS culture requires a change in palliative situations, participants identified that palliative culture too, may require a shift to allow EMS inclusion. For example, one participant noted palliative care providers often feel protective of their patients and may avoid including other providers. EMS may be particularly avoided as they may provide inappropriate care and transport. Another participant, however, noted that palliative care may benefit from the more structured approach used by EMS and may, therefore, benefit from training concerning EMS.

b) Decision-making in challenging circumstances

Decision-making for EMS in palliative situations was described as difficult due to competing wishes of those involved, minimal system and legal support, and a lack of on-scene information.

"I also think one of the biggest barriers [for EMS] *is the medico-legal things that are not unpacked yet and that decision making..."* – Interview #2

"So there is that very difficult information gap…because there's a mismatch between what the patient and family expect...So I think it is very, very challenging for EMS personnel." – Interview #1

Participants noted the unfair nature of expectation upon EMS providers to make challenging decisions under time pressure in isolation. They also detailed the consequences of poor decisions including overlooking patients with unidentified palliative needs and failing to diagnose emergencies in palliative situations which require active intervention. *"Missing"* these emergencies was identified as worse than unnecessary conveyance by EMS. One participant described such a situation in which an EMS provider decided against conveyance due to the palliative nature of the situation when, in fact, conveyance was necessary for emergency treatment. Such difficulties may partly explain why conveyance is the default EMS decision. Murphy-Jones and Timmons (30) remarked that conveyance provides a *"safety net"* for EMS providers, ostensibly providing medico-legal protection. SA EMS providers have likewise identified decision-making challenges in palliative situations for similar reasons, feeling constrained in their approach to palliative situations as a result. (16) To alleviate these challenges, one participant described the potential creation of a palliative care card.

"You've got a Road to Health for children. Should there be a palliative care card for people who have got a progressive illness…which immediately gives all the clinical information that the EMS personnel needs at that particular time?" – Interview #1

The Road to Health booklet, in widespread use across SA, keeps a record of children's growth, immunisations, and healthcare interventions from birth. (158) SA EMS providers refer to these booklets when managing paediatrics and are trained in their use. Implementing a similar palliative care booklet represents a potentially low-cost, high-impact intervention which may

be of use not only to EMS, but to the broader healthcare system. We highly recommend this intervention be explored.

c) Moral distress

"I think we are absolutely not using our resources correctly…if we don't teach our EMS healthcare professionals to provide palliative care. I think we are firstly creating moral distress in our healthcare professionals and therefore they won't stay in the profession long." – Interview #2

"The training of EMS is very algorithmic…[But] sometimes… palliative care, it's not algorithmic." – Interview #9

EMS providers globally, including in SA, have expressed their experiences of distress when disregarding their training in palliative situations and have likewise identified the need for palliative care education. (16,18,73) This suggests EMS providers realise an alternate approach is required in palliative situations, however, they are unaware of appropriate strategies. As stated by participants, the ability to effectively calm stressful palliative situations through symptom control, communication strategies, and care planning, relieves moral distress in healthcare workers, however, this cannot be achieved without education. Participants referred to this ability as *"containment"* of palliative situations. Furthermore, they noted healthcare providers themselves require containment to avoid moral distress and, if not adequately equipped, will *"crumble"* in palliative situations. Not only would palliative care integration assist EMS providers in palliative situations, but the containment strategies learned may benefit them more generally as they are often required to contain chaotic emergency situations.

Positive EMS Impact Across Patients' Palliative Care Journeys

Despite these challenges and concerns, participants identified the unique position of EMS as intermediaries and its potential positive impact across patients' palliative care journeys. As EMS arrive in palliative situations they gain a) unique insight into determinants of patient health, b) provide initial containment, c) liaise with palliative care providers, d) safely transition patients, and e) determine trajectory of care.

a) Unique insight into determinants of patient health

"…[EMS] *provide such a unique insight into people's lives…You see people at their worst. So its a great opportunity to network and collaborate."* – Interview #6

As first-responders, EMS providers frequently enter patient homes. This privileged position within healthcare provides access to valuable information, such as living conditions, socioeconomic status, educational needs, and barriers to care. (46) This unique insight into social and structural determinants of health allows EMS to contribute toward bespoke care plans based on observed circumstances and link patients with relevant services within the broader palliative care team. (46) To leverage this unique insight for palliative care provision may require a mindset shift for EMS providers. Information regarding determinants of health may frequently be overlooked, particularly in emergency situations where their focus is, appropriately, on intervening and transporting. Thus, a need exists for EMS to identify divergent contexts and shift priorities accordingly.

b) Providing initial containment

"…[EMS] *would be like a first-responder…If they could feedback to the home care doctor…could give morphine…and hand over to a homecare team instead of taking the patient to hospital, then that would be really helpful..."* – Interview #8

Initial containment functions would be valuable for palliative care providers as EMS may arrive at palliative situations sooner than home palliative services and relay necessary information. This EMS ability to rapidly respond to an incident and stabilize palliative emergencies before linking the patient with further care would improve patient wellbeing. To achieve participants' visions of initial containment, avoiding unnecessary conveyance, and homecare team handover, SA EMS providers must be capacitated to do so. This may involve the development of new policies allowing on-scene discharges by advanced EMS providers; a skill within their scope of practice, though not currently used.

c) Liaising with palliative care providers

Participants noted EMS providers may act as their *"eyes and ears"* in palliative situations not only by relaying information, but also implementing management strategies.

"[EMS] *need to be able to link with services. You've been called, there's a crisis, an initial assessment of the patient, an understanding that this is…a known palliative care patient…and linking…being able to communicate with the patient's treating providers."* – Interview #10

Dent et al. (74) demonstrated that palliative telephonic advice provided to EMS resulted in decreased rates of unnecessary transport and improved patient care. Cultivating communication between EMS and palliative care systems represents another potentially low-cost, high-impact intervention. Through increased homecare, the use of EMS as liaisons may decrease overall healthcare costs by reducing unnecessary hospital admissions. Though a cost-benefit analysis is yet to be performed in SA, this benefit has been frequently emphasized in the literature and should be studied as it is particularly relevant to LMIC settings. (42,91,110)

d) Safe patient transitioning

Furthermore, participants expounded upon the benefits of safe patient handling and transportation by EMS. EMS provider handling of patients with palliative needs was described as pleasant and professional.

"For a patient to get into a family's car, it's horrific. When you can't walk properly and you drag them out and you're pulling and pushing them and they're ill, they can't sit up…but somehow [with EMS] *it just seems more professional. It seems more controlled."* – Interview #4

While EMS transport may be beneficial, two participants questioned whether it necessitated EMS. One recommended dedicated palliative care transport services apart from EMS, while another objected to this, and another enquired whether patient handling and transport could be performed by non-EMS personnel. Within the resource-limited SA setting it has been argued that integrating current EMS and palliative care systems may be more cost-effective than establishing a new specialised unit. (130) Despite differing ideas, participants agreed that

safe patient transitioning is an important aspect of palliative situations which EMS are capable of managing.

e) Determining trajectory of care

According to participants, EMS decision-making determines patient trajectory and consequences of inappropriate decisions include artificial life-prolongation, increased healthcare costs, and negative patient and family experience. However, with appropriate training, participants perceived beneficial trajectories being set by EMS.

"[EMS] *intubating the patient at the end of life…now the patient lands up in ICU* [Intensive Care Unit]*. It's expensive. There's the trauma of it. The patient is not where they want to be when they die. The family is separated from their loved one at the end of their life. Apart from the pain and discomfort to the actual patient".* – Interview #7

Breyre et al. (63) found that implementation of an EMS and hospice collaboration, which involved training EMS providers in palliative care, decreased EMS transport rates in palliative situations from 80.3% to 19.6%, allowing more beneficial care trajectories. Given the substantial impact of EMS decision-making in palliative situations on patients, families, healthcare providers and economy, EMS integration with palliative care appears desirable. This may be particularly relevant in LMIC contexts which contain the vast majority of patients with palliative needs globally (112,113) and require efficient use of limited resources.

Methods of EMS and Palliative Care System Integration

All participants agreed integration was necessary and identified various integrative methods for implementation in SA. These methods were discussed in terms of a) collaborative approaches, b) education of all role-players and c) potential, unintended consequences.

a) Collaborative approaches

"So it's about creating awareness in government and policymakers about why palliative care is so important in South Africa…that's where I would start: creating awareness with the public and from the top". – Interview #6

"Research is a very strong integration tool… So I do think…a next step is to do a pilot study". – Interview #2

When considering EMS, participants recognized the need for palliative care provider input which is currently lacking. As one participant said, *"You give us input. How much input do we give?"* (Interview #4) To foster this input, areas for collaboration, such as regular, joint EMS and palliative care meetings, were suggested.

In 1990 the Commission on Health Research and Development stated that improving LMIC research capacity is *'one of the most powerful, cost-effective and sustainable means of advancing health and development.'* (102) Pilot studies within the LMIC context of SA may be of worldwide benefit and should be conducted. We recommend these studies analyse modes of EMS palliative care delivery such as community paramedic models, methods of enhanced EMS and palliative system communication, and the effect of these upon hospital conveyance rates, overall EMS caseload, patient and family member satisfaction. Secondary analyses may include safety and efficacy of *"treat and release"* approaches and expanded EMS scope of practice to include commonly used medications within palliative care.

b) Education of all role-players

Education for all role-players, including EMS and palliative care providers, patients, families, and general public, was identified by participants as the primary method of EMS and palliative care integration.

"More needs to be done to bring the two services closer to each other. So this can only be done by…giving more training to…EMS so that [they] can understand how palliative care services work and how these two services can collaborate." – Interview #3

"…I don't know what [EMS] study, but if I look at…what we were taught as doctors [about EMS], I was taught nothing." – Interview #6

One participant reasoned that palliative care training would *"make for a better paramedic all round."* (Interview #5). This is likely true as EMS and palliative care systems, despite differing functions, share several key goals including patient quality of life, symptom management, and

relief of suffering. Therefore, just as EMS and palliative care integration may improve palliative care provision, it may likewise improve emergency care provision.

Participants identified the following areas for EMS provider education: basic palliative care principles, communication practices, management of common palliative symptoms and emergencies, ethical issues, end-of-life care and situational recognition (i.e. curative vs support care). As no EMS palliative care curriculum in SA exists, these areas may inform curriculum development. Participants recommended a palliative care module for EMS at undergraduate level and an introductory short course for qualified EMS providers.

c) Potential, unintended consequences

Though EMS and palliative care integration may confer benefits, some participants warned of potential consequences such as EMS providers misinterpreting end-of-life and emergency situations.

"The EMS…may also find itself in a situation where you guys are overwhelmed, but also faced by…new situations…having to make very difficult decisions that you wouldn't normally make." – Interview #3

The concern regarding overwhelmed EMS has been raised previously. (106) An expanded palliative care role may strain EMS resources due to amplified caseload and incident times. Current evidence has failed to demonstrate this; though such evidence is limited to HICs. (42) Within LMICs, given their greater burdens of palliative needs, this concern may remain valid. However, EMS and palliative care integration may decrease overall caseload through provision of homecare. In SA, for example, many patients in palliative situations use EMS repeatedly throughout a given year for hospital conveyance (130) and many of these may be unnecessary should adequate homecare be available. Thus, through decreased repeat patient cases, overall EMS caseload may decrease in the long-term. Along with current SA EMS palliative caseload, this represents an area for further inquiry.

Concerns raised by participants over potential consequences require thoughtful consideration. While the integration of EMS and palliative care has been recommended internationally, the possibility of unintended consequences remains. It should be recognized that EMS and palliative care integration, while providing benefits, will likely result in novel challenges. This further justifies pilot studies before large-scale implementation.

"It's very feasible. We [also] don't really have a choice. Families phone ambulances, ambulances go to houses…It's already happening." – Interview #10

"Why haven't we done it yet?" – Interview #2

Despite these potential consequences, participants concluded the benefits of EMS and palliative care integration outweigh potential risks and integration is both feasible and necessary in SA. Integration would be mutually beneficial to both EMS and palliative care systems, while concurrently benefiting patient well-being and the broader healthcare system through provision of homecare and reduced rates of unnecessary hospital admission. This represents efficacious and judicious use of limited resources within the LMIC context of SA.

Limitations

This study must be interpreted considering its inherent limitations. The perspectives of participants may not represent those of other palliative care providers within SA or abroad, limiting transferability. Given the voluntary nature of participation, self-selection bias is likely present. However, participants were broadly distributed across SA and situated in diverse contexts which resulted in a range of perspectives. Furthermore, the transferability of perspectives contained here have been discussed in light of similar studies in various contexts.

Conclusion

The aim of this study was to gather perspectives of palliative care providers in SA concerning EMS in palliative situations. Four categories were developed from the interviews: 1) Disposition towards EMS, 2) Perceived EMS challenges, 3) Positive EMS impact across patients' palliative care journeys and 4) Methods of EMS and palliative care system integration. Participants demonstrated an overall positive disposition towards EMS while highlighting various concerns and challenges involving EMS use. Despite these challenges, participants described many benefits of EMS use in palliative situations and recommended integration through various methods such as creating awareness, education and collaborative efforts. Many suggested methods, such as palliative care cards for patients and enhancing EMS and palliative care system communication, represent potentially low-cost, high-impact interventions. Pilot studies investigating these suggestions should be conducted.

Chapter 7: The Dynamic of Control: Perspectives of Patients and Family Members With Palliative Care Needs on Emergency Medical Services

Chapter Introduction

This chapter contains the second of two qualitative interview studies performed in this thesis. In this study, patients and family members with palliative needs were interviewed. The purpose of this study was to incorporate the views of primary stakeholders on the research topic. In addition, this study contributes to improved understanding of the reasons EMS are used in palliative situations and the role EMS play.

Declaration from author and co-authors

The following co-authors contributed to this publication: Gwyther L, Stassen W.

Contributions of the authors were as follows: All authors conceptualized the idea for the study. CHG performed data collection, analysis, and drafted the manuscript. WS and LG assisted in data analysis and acted as study supervisors. All authors approved the final submitted version.

The extent of contributions from each person are as follows:

CHG 70%; LG 10%; WS 20%

In accordance with the UCT Doctoral Degrees Board guideline titled, “GUIDELINES FOR THE INCLUSION OF PUBLICATIONS IN A DOCTORAL THESIS”, each author has signed below for approval to include this manuscript.

Signed by candidate	16 January 2025
Caleb Gage	Date
Signed by candidate	16 January 2025
Liz Gwyther	Date
Signed by candidate	16 January 2025
Willem Stassen	Date

The Dynamic of Control: Perspectives of Patients and Family Members with Palliative Care Needs on Emergency Medical Services

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Abstract

Background: Person-centred care requires interdisciplinary collaboration. Within palliative medicine, collaboration is further necessary to meet the increasing global demand for palliative care. One area of developing collaboration involves Emergency Medical Services (EMS). However, there remains a dearth of research exploring patient and family member perspectives on EMS in palliative situations. The aim of this study was to gather perspectives of South African (SA) patients and family members with palliative needs concerning EMS use in their care.

Methods: A qualitative design using individual semi-structured interviews was employed. Ten interviews were conducted with patients and family members with palliative needs. Verbatim transcriptions of interviews were subjected to thematic analysis with an inductive-dominant approach to develop categories and themes.

Results: One overarching theme, The Dynamic of Control, and three categories were developed: 1) Loss of Control: Heavy Burdens of Living with Chronic and End-of-Life Illness, 2) Maintaining Control: Longings and Exigencies in Times of Suffering, 3) Transferring Control: Consequential EMS Influence on Palliative Situations. Participants described a loss of previous control they held over their lives and a subsequent longing to maintain what control remained. EMS care was viewed positively when this longing was satisfied and negatively when further control was seized.

Conclusions: Understanding the Dynamic of Control in palliative situations is fundamental to the EMS establishment of a person-centred approach in palliative situations. Practical developments which would allow this approach include alternative care pathways, on-scene information availability, and palliative care education for EMS providers. Including palliative care in EMS education may have benefits beyond improved palliative situation management as it encourages a cultural shift towards person-centred care.

Background

Person-centred care, a core component of high-quality healthcare, has been defined as *"an approach that consciously adopts the perspectives of individuals, families and communities, respects and responds to their needs, values, and preferences, and sees them as participants in their own healthcare rather than just beneficiaries."* (159) This aligns with palliative care which implements this approach in the context of life-threatening illness to improve both patient and family quality of life. (9) Person-centred care is particularly suited to palliative situations due to severity of illness, multiplicity of involved persons, and subsequent complex needs. (159)

Achieving a person-centred approach to care requires interdisciplinary collaboration, which enhances patient experience, and exploration of personal perspectives to understand specific needs. (6,159–161) Within palliative medicine, collaboration is further necessary to meet the increasing global demand for palliative care, (114) particularly in low-to-middle income countries (LMICs) which contain up to 80% of the demand. (112,113) One area of developing collaboration involves Emergency Medical Services (EMS). (110) EMS frequently intersect with palliative situations and, thus, an opportunity exists to enhance the supply of person-centred palliative care through collective efforts. (31,130) Despite this developing collaboration, there remains a dearth of research exploring patient and family member perspectives on EMS in palliative situations. (110) Current evidence demonstrates positive experiences of EMS by patients and family members; however, such studies are rare and limited to high-income countries (HICs). (3,95,145) Within South Africa (SA), an LMIC, studies have explored the perspectives of EMS (16) and palliative providers (162) on collaboration, but patient and family member perspectives on this topic remain unknown.

The World Health Organization (WHO) *Global Strategy on People-Centred and Integrated Health Services* has stated that context specific research is required to promote person-centred care as no single, best-practice model exists. (111) Thus, to fill this knowledge gap within the SA context, the aim of this study was to gather perspectives of SA patients and family members with palliative needs concerning EMS use in their care to the ultimate end of enhancing person-centred care in this domain. For the purposes of this study, 'palliative situation' refers to any event involving the care of a person with palliative needs.

Methods

Design

A qualitative design conducting semi-structured individual interviews was implemented. Husserlian descriptive phenomenology, in which the lived experience of participants is described, provided the theoretical framework. (146)

Setting

The SA healthcare system is divided into two sectors: private and state. (121) State healthcare is provided to all citizens by the government while private healthcare is restricted to those with medical insurance or other financial means. Likewise, EMS are divided into private and state sectors. Out-of-hospital emergency care is provided using a paramedic-led rather than physician-led approach. (16)

SA palliative care is largely delivered by non-governmental organizations (NGOs) which provide hospice services. (22) These NGOs are registered as charities and are reliant on donations and professional volunteers including social workers, nurses, and doctors. Although palliative care integration among medical disciplines and allied health services has improved in some areas, equitable access to palliative care for those in need remains the primary challenge to SA palliative care.

Data Collection

The interview schedule was jointly developed by CG, LG and WS based on contextualisation of current literature and previous work by Gage et al. (16,110,162) The interview schedule (Appendix 6) contained four questions referencing patient demographic information, reasons for EMS use, satisfaction, and confidence with EMS providers. To enhance in-depth exploration of participant perspectives, guide the interviewer, and limit the introduction of biases, pre-determined prompts and probes were included for each question.

Participants meeting inclusion and exclusion criteria were identified through palliative care providers within the Association of Palliative Care Centres (APCC), Association of Palliative Care Practitioners of South Africa (PALPRAC) and the University of Cape Town (UCT) Division of Interdisciplinary Palliative Care and Medicine who provided participants with a copy of the information and consent form. The APCC is a national association of hospices with members from all SA provinces. (147) PALPRAC is a non-profit organization made up of doctors trained in palliative medicine. (144) The UCT Division of Interdisciplinary Palliative Care and Medicine

is the section of the university devoted to palliative care education. (148) Interested patients and family members then contacted CG directly or provided permission to the palliative care provider to be contacted by CG. During the interviews, a summary of the participant information and consent form was presented and an opportunity for questions provided.

Inclusion criteria were adult (≥18 years old) patients with palliative needs residing in SA who experienced SA EMS care, and family members of patients with palliative needs residing in SA who experienced SA EMS care for the needs of their family. Exclusion criteria were patients and family members who experienced SA EMS care prior to developing palliative needs or who experienced EMS care outside SA. Palliative needs were equated with those receiving palliative care at the time of EMS contact.

Interviews were performed telephonically at an agreed upon time. Telephonic interviews were selected as they represented the safest, least intrusive, and most widely available mode of communication given participant health, vulnerability, and geographic distribution. (163) Interviews were performed by CG, who is experienced in qualitative interviewing, and recorded using an application on his cellular device. All recordings were manually transcribed *verbatim* by CG. A pilot interview was not performed as the authors felt it inappropriate given the vulnerability of the population group. Rather, the Authors met to thoroughly deliberate upon the discussion schedule and interview techniques prior to data collection.

Ten interviews were held from September 2023 to March 2024 meeting recommendations for phenomenological studies. (149) No participants knew the interviewer previously and all were aware the study formed part of the interviewer's post-graduate studies.

Analysis

Thematic analysis of transcribed data was performed using the framework of Braun and Clark with an inductive dominant approach. (164) This was performed in the following steps: 1) CG familiarised himself with the transcribed data through repeated readings, 2) Initial coding was performed, 3) Codes were sorted into categories, 4) Categories were reviewed, refined, named, and defined, 5) An overarching theme was identified, named and defined, 6) Data, and the analysis thereof, were written in the final report.

These steps began alongside data collection through field notes and were flexible as CG alternated between them for data refinement. Meaning units were captured, condensed, coded, and categorized using Nvivo (version 14, Lumivero, 2023) (Figure 9). Data analysis was independently performed by CG. Researcher triangulation was then performed between all authors where codes, categories and the overarching theme were discussed, refined, and

finalised. Data saturation, as detailed by Saunders et al., was reached after ten interviews as evidenced by repetitive comments and a lack of additional data after the tenth interview. (151)

	Example 1	Example 2
Theme	The Dynamic of Control	
Category	Loss of Control: Heavy Burdens of Living with Chronic and End-of-Life Illness	Maintaining Control: Longings and Exigencies in Times of Suffering
Sub-Category	Dealing with death, dying, and suffering	Readily accessible care
Code	Pain	24-hour care
Condensed Meaning Unit	Tumour pain became excruciating	Big, huge help EMS available 24/7
Meaning Unit	*"That tumour just grew and grew and grew. And it became excruciating, the pain."*	*"It's such a big help to know that they are on hand 24/7. It's huge. And that we're getting such good, good service from them."*

EMS=Emergency Medical Services

Figure 9 Coding tree

Reflexivity

This study formed part of my (CG) postgraduate studies. During this study I was employed as a programme co-ordinator at a state SA EMS college. I found the present interviews more challenging than in previous studies as significantly more probing was required to gather in-depth answers. Furthermore, probing itself was, at times, difficult due to the emotional nature of the topics being recounted. Despite this, the discussion schedule seemed to function well, and participants appreciated the discussions. While my bias is in favour of EMS and palliative care integration, some participants detailed negative experiences of EMS which must be carefully considered. Words cannot express my gratitude towards each participant for allowing me, a stranger, to delve into such personal moments. I trust this study will positively impact all others experiencing the heavy burdens of palliative needs.

Trustworthiness

To ensure trustworthiness of the data, the framework of Guba was used in seeking credibility, transferability, dependability, and confirmability. (152) The following denotes methods by which these criteria were pursued:

Credibility: Interview technique was practiced and thoroughly deliberated upon. Participants were able to refuse participation. Frequent communication and debriefing sessions were held between the interviewer and research team. Researcher triangulation was performed. Member checking, where each participant was sent a summary of the thematic analysis, was undertaken to check agreement. No subsequent changes were required as it was referred to as *"accurate"* and *"resonating deeply."* A reflexive commentary has been included.

Transferability: A thorough description of data collection methods has been given, including the number and length of interviews, and the total time-period of data collection. Results have been compared with available literature. This study has been written according to the *Consolidated Criteria for Reporting Qualitative* (COREQ) research checklist.

Dependability: Thorough descriptions of research design, implementation, and data-gathering as well as a reflexive commentary have been presented.

Confirmability: Preliminary hypotheses held by the research team which were not demonstrated in the data have been reflected upon. Researcher triangulation and member checking were performed. *Verbatim* transcriptions of audio recordings were produced.

Ethical approval was provided by the University of Cape Town's Human Research Ethics Committee (HREC Reference Number: 221/2023).

Results

Ten participants were interviewed (Table 10). Interviews lasted between 18 and 37 minutes. Three categories and one overarching theme were developed (Table 11). Participants described the heavy burdens of experiencing chronic and end-of-life illness. As a result of these heavy burdens, they discussed various longings and exigencies in their difficult situations. Finally, they reflected upon the effect of EMS, both positive and negative, in various emergency, non-emergency, and terminal situations. In each of these categories, the Dynamic of Control was prominent. Emergency situations referred to acute, life-threatening illness or injury, non-emergencies involved practical needs such as mobility assistance, and terminal situations described the final moments before death or those already deceased.

Table 10 Interviewer and participant details

	Age and Sex	**Qualifications[1]**	**Areas of Experience**	**Post-Graduate Experience**
Interviewer (CG)	33 years, Male	BTech Emergency Medical Care, MPhil Emergency Medicine, Palliative Care Short Course, Qualitative Research Short Course	EMS Operations (Road, HEMS[2], Fixed Wing), Primary Healthcare, EMS Education, Research	10 years
	Age and Sex	**Medical Conditions**	**Clinical Reason for EMS**	**Situation Type(s)**
Patient #1	76 years, Female	Spinal compression fracture (chronic pain), Diverticulosis, Squamous Carcinoma (with leg tumor)	Anaphylaxis (new medication)	Emergency
Patient #2	82 years, Male	Metastatic Prostate Cancer, Previous Myocardial Infarction	Myocardial Infarction, Urinary Catheter Change, Transport for Blood Infusions (bedridden)	Emergency, Non-Emergency
	Patient Age and Sex[3]	**Patient Medical Conditions**	**Clinical Reason for EMS**	**Situation Type(s)**
Family Member #1	60 years, Male (Father)	Aortic aneurysm, Previous Myocardial Infarction, Hypercholesterolaemia	Ruptured Aortic Aneurysm, Cardiac Arrest	Terminal
Family Member #2	2-14 years[4], Male (Son)	Early Infantile Epileptic Encephalopathy	Seizures, Interfacility transfers	Emergency, Non-Emergency
Family Member #3	62 years, Male (Husband)	Hypercholesterolaemia, Abdominal Aortic Aneurysm	Ruptured Abdominal Aortic Aneurysm	Terminal
Family Member #4	66 years, Male (Husband)	Leukaemia	Interfacility transfers	Non-Emergency
Family Member #5	73 years, Female (Sister)	Parkinson's Disease, Asthma	Dyspnoea (chest infection), Lack of Mobility	Emergency
Family Member #6	77 years, Male (Husband)	Metastatic Lung Cancer, Previous Stroke (left sided hemiparesis)	Haemorrhage (ruptured tumour)	Emergency
Family Member #7[5]	61 years, Female (Sister)	Renal Failure, Diabetes, Previous Stroke	Pain, Falls, Immobility	Emergency, Non-Emergency
	86 years, Female (Mother)	Metastatic Ovarian Cancer	Interfacility Transfer	Non-Emergency

Family Member #8	82 years, Male (Husband)	Metastatic Prostate Cancer, Previous Myocardial Infarction	Myocardial Infarction, Urinary Catheter Change, Transport for Blood Infusions (bedridden)	Emergency, Non-Emergency

[1] Bachelor of Technology (BTech) is a 4-year degree allowing for registration as an Emergency Care Practitioner (ECP). MPhil=Master of Philosophy. Both degrees include research methodology. Palliative Care short course: 10-week programme through introducing basic palliative care management principles. Qualitative Research short course: 2-week programme introducing the basic principles of qualitative research and interviewing.

[2] HEMS = Helicopter Emergency Medical Services

[3] Patient Age and Sex are the details of the loved ones family members were caring for, including their relationship.

[4] Family Member #2 made use of EMS on multiple occasions for their son between his ages of 2-14yrs.

[5] Family Member #7 cared for two loved ones with palliative needs for whom EMS were contacted.

Table 11 Theme, categories, and subcategories developed from interviews

Overarching Theme	**The Dynamic of Control**		
Categories and Sub-Categories	**1) Loss of Control: Heavy Burdens of Living with Chronic and End-of-Life Illness** a) Dealing with death, dying, and suffering b) Difficult decisions concerning care c) Necessitated lifestyle changes	**2) Maintaining Control: Longings and Exigencies in Times of Suffering** a) Desire to be treated as persons b) Readily accessible care	**3) Transferring Control: Consequential EMS Influence on Palliative Situations** a) Fulfilling the desires for compassion and reassurance b) High regard for EMS c) Amplified needs resulting from poor EMS care

EMS=Emergency Medical Services

Discussion

Participants were asked to share their experiences regarding reasons for EMS use, satisfaction, and confidence with EMS. Below, the theme and categories are discussed with supporting quotations extracted from interviews. Interviewees are identified as either patients or family members and by number (e.g. Patient/Family Member #1).

The Dynamic of Control

Participants described the heavy burdens of experiencing chronic and end-of-life illness, ensuing longings and exigencies, and the effect of EMS upon their situations. The overarching theme in these discussions was the Dynamic of Control. The chronic illnesses experienced by participants imposed various constraints upon them, resulting in a loss of much control they previously held over their lives. For example, difficult decisions and lifestyle changes, previously extraneous, became necessitated as life began to revolve around the illness.

"…we don't want him to suffer unnecessarily, and our neurologist has said to us we need to…plan for the worst and hope for the best. And if it goes the route of intubation and induced comas…we need to actually think about some kind of timeline that we're willing to have high levels of intervention." – Family Member #2

"I was a credit controller for the many years that I was working and then I stopped working as a result of my husband's illness which was really hard." – Family Member #4

This loss of control produced a yearning in participants to be treated in a person-centred manner and be deferred to by any involved in their care. Participants desired autonomy to maintain the remaining control they possessed. EMS were contacted for assistance when further control was lost (such as with patient deterioration) for assistance re-establishing control. EMS care was viewed positively when this was achieved and negatively when even further control was seized from participants.

"They [EMS] *understood, they never questioned me…they were so kind."* – Family Member #1

"I was getting so frustrated because I was worried about my husband haemorrhaging…[EMS are] *supposed to be coming in to save his life that's already about half an hour into after I phoned them. And this* [EMS provider couldn't drive]*. I was almost ready to jump in the ambulance and try and drive it* [myself]*."* – Family Member #6

Understanding why patients and family members with palliative needs contact EMS is fundamentally important to establishing a person-centred approach in EMS and palliative care collaborations. Commonly documented reasons for EMS interactions with palliative situations are unexpected patient deterioration, caregiver exhaustion, and distressing symptoms.

(3,10,31,107) Other reasons in the present study included practical needs such as mobility assistance, planned transport, and minor procedural interventions. Previous studies interviewing EMS and palliative providers in SA have also offered insight into the various needs of patients and family members such as autonomy, homecare, and 24/7 availability of care. (16,162) While these findings are valuable, demonstrating legitimate needs from provider perspectives, the voices of those experiencing these needs are lacking. From patient and family member perspectives, our findings suggest the Dynamic of Control explains an underlying reason for contacting EMS. The needs for autonomy, homecare, and 24/7 availability of care are practical expressions of this dynamic, while clinical situations provide the contexts in which control must be regained. Patients and family members deeply desire autonomy to avoid further control being removed. Homecare and 24/7 care availability provide comfort in the setting of their choice and knowledge that should control be lost it may be regained quickly during any time of day or night.

Previous studies have highlighted the suitability of EMS to meet these needs. (6,7,42,46,63) For example, a Canadian study demonstrated increased confidence among those in palliative situations simply through knowledge of EMS 24/7 availability. (3) We suggest a reason for this confidence was a sense of increased control over an unpredictable future.

The Dynamic of Control should also inform the tone of EMS interactions with patients and family members in palliative situations. Speaking of areas for EMS improvement, one participant said, *"*[Allow] *the family to…set the tone…*[Give] *the family time to kind of indicate where they are at in their frame of mind"* (Family Member #2). This requires a perspicacious approach from EMS providers as they must be receptive to the tone set by patients and family members while simultaneously deciding where to take and cede control. Typically, EMS providers are trained to take complete control of often chaotic emergency situations. In these situations, this is often appropriate. However, EMS providers appear to apply this approach universally, including in palliative situations, where it may be harmful. In the palliative care setting the tone should be one of deference to patients and families according to their needs, regaining control where necessary and transferring it back wherever possible, thereby viewing patients and family members as participants in their care, allowing them to guide the interaction. This person-centred approach, by EMS providers' own admission, runs contrary to their typical mindset and is an area for improvement. (16,18,73) Thus, EMS should be trained in the identification of and differing approach to palliative situations. Furthermore, any EMS and palliative care collaboration should aim at a deferential, person-centred tone to meet the unique needs of this population.

1) Loss of Control: Heavy Burdens of Living with Chronic and End-of-Life Illness

When questioned regarding their circumstances, participants detailed heavy burdens they live(d) with due to chronic and end-of-life illness. These burdens may be categorized as: a) Dealing with death, dying, and suffering, b) Difficult decisions concerning care, and c) Necessitated lifestyle changes.

a) Dealing with death, dying, and suffering

Many participants recounted strong, negative emotions when faced with personal suffering or when witnessing the suffering and, in some cases, the death of a loved one. Feelings of loneliness, weariness, desperation, and pain were prominent.

"It's not easy to do this at home because it's basically just you…and your partner. And you're watching them die…I had to call the ambulance, I was alone…there was nobody." – Family Member #6

"So then unfortunately she got a stroke…and she was in a coma for three weeks. That was quite painful…And then it's the pain of watching somebody slowly dying." – Family Member #7

Providing care for a dying loved one has been described as one of the most stressful human experiences. (165) It is not surprising, therefore, that caregiver exhaustion is a frequently cited reason for EMS assistance in palliative situations. (110) Caregiver pain is likewise involved as witnessing the suffering of a loved one is itself a form of pain. This relates to the palliative care concept of '*Total Pain*' which recognises the potential for pain to affect persons *in toto*. (166,167) In this holistic view, pain is not a purely physical phenomenon but also psychological, social, and spiritual. While some patients in this study experienced excruciating physical pain, many family members experienced other aspects of pain.

SA EMS providers are trained principally in physical pain management through pharmacological means. Furthermore, they are primarily focussed on patient management and have described difficulty in handling family members in palliative situations due to a lack of agreement concerning care. (16) Thus, EMS providers may see family members as interfering with their management, leading them to take complete situational control. This fails to recognise family member suffering and denies their autonomy. The concepts of *'Total Pain'*, inclusion of family members, and an understanding of the Dynamic of Control, therefore, are important for EMS providers to understand in palliative situations.

b) Difficult decisions concerning care

Participants shared various challenging decisions imposed upon them involving place of care, level of intervention, withholding and withdrawing of care. In some instances, these decisions resulted in conflict, feelings of regret and insecurity. For example, one participant decided against resuscitation during her father's cardiac arrest and was left asking, *"What did I do? What if he was ok?"* (Family Member #1).

"She was very upset about everything…didn't want treatment…But I could not have left her there, not being able to breathe, I couldn't do it." – Family Member #5

"They put her on the ventilator and…next time I will not allow someone to go on the ventilator…But the moment when they phoned me to say she's in a coma we need to do something you allow and say ok please look do whatever to save the person." – Family Member #7

Conflict between patients and family members in palliative situations is not uncommon. (6,7,10) Deliberating upon life and death choices may be overwhelming for both patients and family members adding to the burdens of these situations. As seen in this study, complete control over decision-making may be ceded to healthcare providers, displaying profound trust in them. This may conceivably be a relief to some; however, it may also contribute to a sense of helplessness for others. Identifying these differing situations requires insight from EMS providers to allow patients and family members to set the tone of interaction.

One suggested method of ameliorating these decision-making challenges has been advance care planning. (18,109,145) Advance care plans (ACPs) allow patients and family members to make crucial healthcare decisions for future eventualities prior to stressful moments of suffering. (168) Moreover, ACPs may prevent conflict concerning goals of care and contribute to a sense of control for those with palliative needs as decision-making remains in their purview. Despite their potential benefit, ACPs are not common in SA and where they are in place EMS providers often lack access to this information. (16) Additionally, SA EMS providers have expressed confusion over such plans as no legal guidance exists concerning their use in the out-of-hospital setting. (16) To enhance person-centred care in palliative situations involving EMS, guiding policies on ACPs should be developed and information concerning patient and family member wishes should be made available to EMS. One recommended mechanism for information availability, suggested by SA palliative providers, has been development of a palliative care booklet which patients would have in their homes. (162) We

recommend this booklet contain information regarding patient condition and treatment, care goals, desired place of care, existing ACPs, and contact details of involved healthcare providers.

c) Necessitated lifestyle changes

Other burdens of living with chronic and end-of-life illness involved necessitated lifestyle changes. Changes were required concerning work, retirement, finances, and priorities. Furthermore, because of various illnesses, participants noted the necessity of continual healthcare use.

"For my sister it [EMS calls] *was regularly…She was very frail and sickly and had, like I say, everything in her body was broken. She had like mini-strokes and also she got COVID* [coronavirus disease] *and everything. She regularly had to go to the hospital, so that was the reason we had to call the ambulance."* – Family Member #7

"I'm divorced and remarried. My first marriage didn't survive the trauma of [son's] *disability. So yeah, that was that was quite difficult…my dad has chosen to retire…and he pays half of* [son's] *fees…This places a further financial burden upon him as he has had to take this into account and tailor his retirement due to this factor."* – Family Member #2

While most participants described these changes negatively, one participant, despite being bedridden, described his situation as the *"happiest time of my life"* as he was otherwise *"blessed with good health"* and maintained a happy marriage (Patient #2). Another participant described her husband at the end-of-life and their decision to *"use the* [remaining] *time well"* by doing *"quite a bit of travel in those years"* (Family Member #4). These provide further examples of the need for EMS providers to understand the dynamics of a given palliative situation and allow the patients and family members to set the tone. However, EMS providers, internationally and in SA, have expressed difficulties in approaching palliative situations due to EMS cultural and system constraints. (16–18) Many have experienced moral distress when disregarding their typical emergency training in palliative situations and fear disciplinary action against them should they deviate from standard protocol. (16) Thus, it appears EMS providers may be unable to allow those with palliative needs to set the tone of interaction with the current lack of support structures. A recent study aiming to develop a 'palliative paramedicine framework' allocated various methods of support at micro-, meso-, and macro-levels. (109)

These included EMS provider training in palliative care capabilities (micro), developing guidelines for palliative care provision (meso), and including EMS in national palliative care policies (macro). (109) We recommend these measures in the SA setting, however, a preparatory cultural shift among SA EMS will likely be necessary. (16) While many recommendations for EMS and palliative care collaboration have been made, future study is required to prioritise these within the resource-restricted SA context.

2) Maintaining Control: Longings and Exigencies in Times of Suffering

The heavy burdens experienced by participants resulted in deeply intuited longings and exigencies which were related to their underlying desire to maintain control: a) Desire to be treated as human beings and b) Readily accessible care.

a) Desire to be treated as persons

Participants longed for a person-centred approach from healthcare providers. For example, describing a positive experience, one participant said, *"They're* [hospice staff] *very kind and they took an interest in me as a person which I found really endearing."* (Patient #1). The desire for this approach was also evidenced in participants' positive reflections upon receiving compassionate care, being listened to, and involved in decision-making.

"But the way they [EMS] *treated me…I can only speak of great patience from them…with real dignity and respect."* – Family Member #3

"They [EMS] *were very kind and caring…and made everyone feel very comfortable."* – Family Member #5

"They're [EMS] *well practised and confident…even down to saying which hospital would you like to go to?"* – Patient #2

Studies in Canada, (3) Australia, (145) and New Zealand (95) have likewise demonstrated the desires of patients and family members with palliative needs for person-centred care, noting the capabilities of EMS in this regard. These studies also demonstrated the desire of many with palliative needs to be cared for in their homes and avoid hospital conveyance. Within SA this, likewise, appears to be true. For example, a study in Soweto found home to be the preferred place of death in 67% (*n*=126) of patients with advanced cancer. (128)

To fulfil this desire, and so cede control to patients and family members through respect of autonomy, alternative care pathways for EMS require development. Facilitating patient desires in this manner represents a practical means by which a person-centred approach may be achieved. Typically, EMS involvement results in emergency department (ED) conveyance, particularly in LMICs which frequently use EMS solely for transportation. (155) This was demonstrated in a large Western Cape (province of SA) study which found that 98% (n=240 730) of patients managed by EMS were transported to a hospital despite 83% (n=199 062) of these not having received any EMS treatment. (154) In palliative situations this is often inappropriate as it imposes the EMS system upon those with palliative needs rather than adjusting the system to meet their desires. Lacking alternative care pathways have been identified previously as a barrier to EMS provision of palliative care. (11,169)

Participants in the present study reacted positively when alternative care pathways were used. For example, EMS provided homecare without conveyance (Family Member #8), transported a patient to hospice (Family Member #4), and transported a patient home from hospice (Patient #2). Though these pathways were used in some situations, they were limited to private sector EMS and are not normative, particularly in the state sector which appears unwilling to accommodate alternatives to ED conveyance. (162) Where alternative pathways have been studied, they have resulted in improved patient satisfaction with care and significantly decreased ED conveyance rates. (3,63) Such benefits are germane to the SA context and, therefore, suitable alternative care pathways should be developed in the country.

b) Readily accessible care

An important exigency identified by participants to maintain control in palliative situations was the availability of additional support as and when needed, particularly when their home treatment was insufficient. EMS fulfilled this requirement through 24/7 availability and rapid response times.

"Very, very reassuring to know that we have an excellent, locally based paramedic service here which gives great peace of mind for me to know that if our doctor is not available, we immediately have the paramedics on call, and they are here literally within five minutes." – Family Member #8

Access to healthcare comprises several dimensions: 1) Availability: the balance of supply and demand, 2) Accessibility: the location of services in relation to clients including transport needs, 3) Accommodation: the way services facilitate clients, 4) Affordability: the cost of services relative to clients' purchasing power, and 5) Acceptability: clients' attitudes toward services. (40) From the current study patients and family members have found EMS valuable regarding Accessibility (transport) and Accommodation (24/7 availability, homecare). However, despite EMS benefiting most participants in these ways, some described a lack of Accessibility, and another highlighted a potential Affordability barrier.

"They know that the patient is going on to die and now they can't find an ambulance, so I don't know how are we going to get more ambulances. Ask the government, I don't know. It's an issue, the waiting period." – Family Member #1

"I…looked at the cost of the [private] *ambulance service and I said to my wife, 'god that's high' and it goes up 10% every year… It's my best recommendation* [but] *people have just got to have the funds."* – Patient #2

The majority of the SA population is reliant on state EMS as 83% do not hold health insurance. (122) However, in palliative situations, state EMS have been described as unreliable, problematic, and failing to prioritise end-of-life situations. (162) State EMS unreliability may result from several factors including a lack of resources (such as ambulances), the significant number of SA rural areas, the populations of which are largely reliant on state EMS, and a lack of rural infrastructure restricting EMS access. The lack of rural infrastructure is, in fact, a challenge even for the relatively reliable private EMS sector as mentioned by Family Member #6 who lived in an area with rural characteristics. She described how a private EMS company were *"lost"* and when they arrived, *"couldn't even get the ambulance in"* due to poor road conditions. For meaningful impact of EMS and palliative care collaborations in SA, state EMS must be included and both sectors should be further capacitated in rural areas.

3) Transferring Control: Consequential EMS Influence on Palliative Situations

Given the heavy burdens, resultant deeply felt longings and exigencies of participants, EMS involvement was significantly consequential, whether positive or negative. EMS, in many instances, gained situational control and transferred this to participants, thereby a) Fulfilling the desires for compassion and reassurance, which resulted in b) High regard for EMS.

However, when EMS failed to transfer control, participants experienced c) Amplified needs resulting from poor EMS care.

a) Fulfilling the desires for compassion and reassurance

In most cases, EMS providers fulfilled participant desires for person-centred care through compassion and reassurance, which restored a sense of control over stressful circumstances. Participants described the dignity and empathy with which EMS providers treated them and the comfort, security, and confidence this provided. The fulfilling of these deeply experienced desires brought some participants to tears as they recounted *"extraordinary"* EMS care that, *"doesn't get better"* (Patient #1), demonstrating the significant impact EMS have in palliative situations.

"…those [EMS providers] *actually cried with me. They were absolutely amazing...Such empathy for people that they don't know. Just, I mean, it touches you very deeply."* – Family Member #4

"…they just make you feel that…you're in good hands…your stress level usually goes down upon their [EMS] *arrival and then when they are so calming and competent and efficient and kind it just takes your stress level down you know. Still a highly stressful situation, but they just make it easier, in a big way."* – Family Member #8

A further way in which EMS providers delivered person-centred care was through proactive assistance which went beyond their required duties. For example, several participants mentioned EMS providers patiently waiting at hospitals to assist in the admission process and provide updates on their loved one's condition. Other studies have also noted the compassionate and proactive care EMS providers deliver in palliative situations. (3,95) SA palliative providers have, likewise, expressed feelings of reassurance when EMS provide assistance. (162) Moreover, many EMS providers have found provision of this person-centred care fulfilling. (93,96)

Given the intense burdens and desires of those experiencing palliative situations, it is of important significance EMS providers have the ability to fulfil these desires. For EMS and palliative care collaborations to achieve person-centred care, this ability is pre-requisite. EMS providers may be uniquely beneficial in this manner due to their expertise in controlling stressful situations. However, not all EMS providers may be well-suited to fulfilling these

desires as many may be uninterested in palliative care. SA EMS providers have recommended only those with a desire for such care would be suitable. (16) Therefore, according to the recommendations of Lamba et al., a starting point for EMS and palliative care collaborations in SA would require identifying *"EMS-palliative care champions."* (7)

b) High regard for EMS

As a result of these fulfilled needs, most participants held EMS in high regard, expressing gratitude, praise, and satisfaction. Further demonstrating the consequential nature of EMS care in palliative situations, one participant expressed lasting memories from her experience.

"That actually brings tears to my eyes. I would like you to pass a message on to him that I speak so highly of him. I find it's extraordinary that I'm still here thanks to [EMS provider]*. This is very overwhelming for me to hear that you know* [him]*."* – Patient #1

"My experience I'll never forget it…I remember it as yesterday the way they cared about me." – Family Member #3

Jurhmann et al. found that EMS had a revered public identity due to their ability to fix crises which aligns with the views of participants in the present study. (145) SA palliative care providers, likewise, were found to hold EMS high regard. (162) Given this common positive view of EMS among patients, family members and palliative care providers, it appears reasonable that EMS and palliative care collaboration is pursued in SA.

While discussing the positive views of EMS providers in palliative situations, it became evident that some participants misunderstood EMS capabilities. For example, Patient #1, who required EMS for an anaphylactic reaction, said, *"They* [EMS] *wouldn't have known, but yeah it was life-threatening."* Other participants appeared unaware of EMS provider ability to administer medications.

"I know they [EMS] *can't administer anything,* [just] *make* [patients] *as comfortable as possible and just make the transportation then as quickly and pain-free as possible."* – Family Member #7

To optimise EMS and palliative care collaboration, public education has been previously recommended. (10,18,109) From our findings, this education should include the capabilities of EMS providers. Furthermore, an appropriate collaborative strategy between two unique systems requires the delineation of roles which should also be shared with the public. (170) According to the principles of person-centred care, the development of these roles should be performed in conjunction with patients and family members who are the intended beneficiaries. (159) As a result, these roles will likely be context-specific according to unique population needs, allowing these populations to set the tone. Therefore, even within SA, EMS and palliative care collaborative efforts may vary across regions.

c) Amplified needs resulting from poor EMS care

While EMS were held in high regard overall, some participants experienced poor care from EMS resulting in the deepening, rather than fulfilling, of their needs. These participants expressed frustration, disappointment, and increased stress when poor care was received.

"I was actually horrified. I thought [husband] was going to bleed to death. And [EMS are] *moaning about this and that…I was very disappointed."* – Family Member #6

"I think our biggest challenge is trying to explain to medical personnel…just how severe [the] *condition is…And that's difficult. And then of course tempers tend to flare a little bit because we feel frustrated, and they don't necessarily understand."* – Family Member #2

Poor EMS care was characterised by provider failure to gain situational control, thus precluding the re-establishment of patient and family member control. Furthermore, in these situations, EMS providers failed to allow those under their care to set the tone of interaction. This was demonstrated in the case of Family Member #2 who recalled EMS providers *"joking and bantering"* during her son's worrying episode of seizure activity. In the case of Family Member #6, EMS providers were unable (or unwilling) to access her home due to difficult terrain and presence of dogs on the property: *"They* [were] *too scared to do anything."* Because of these perceived EMS failures, these participants experienced a sense of incredulity at the treatment they received. Both instances were highly stressful and out of their control requiring trust in the EMS providers. Their expectation was for EMS to regain control and provide reassurance, however, they were left feeling *"ambivalent"* and *"shocked"* about these *"bizarre," "surreal"* circumstances. In these cases, it appears EMS providers worsened the experienced burdens

through setting an inappropriate tone and betraying trust. These situations may be avoided with an appropriate understanding of the Dynamic of Control and the heavy burdens which patients and family members carry.

Despite these negative experiences, which require thoughtful reflection for EMS, participants were generally understanding of EMS challenges, suggesting training in the areas of communication and various conditions requiring palliative care. It has been previously hypothesised that EMS education in palliative care would develop more well-rounded EMS providers, not only improving their care in palliative situations, but out-of-hospital situations in general. (162) We suggest this development would occur by stimulating the needed cultural shift within EMS towards a person-centred approach which palliative care espouses. (9) Person-centred approaches are valuable in all healthcare situations and have been associated with high-performing systems, improved quality and outcomes, increased provider job satisfaction, and financial strength. (171,172)

The current SA EMS approach may be described as system-centred, often imposing itself upon patients in a 'one-size-fits-all' manner. For example, EMS systems tend to implement ED conveyance regardless of context, case severity, mechanism of injury, or patient wishes. (154,162) In palliative situations, this approach frequently leads to conflict with patients and family members which worsens their situations. Furthermore, this system-centred approach denies the heavy burdens patients and family members suffer, fails to set a deferential tone and, therefore, seizes control in situations where it should be transferred. Other negative consequences include increased strain on already overfull EDs with limited resources and amplified healthcare system costs. (130) Thus, we strongly recommend palliative care education for EMS as a standard, not only for improvement in palliative situations, but as a catalyst for EMS cultural change, thereby benefiting patients, family members, EMS providers, and healthcare systems in their entirety.

Limitations

This study contains limitations regarding transferability. The sampling strategy resulted in a relatively homogenous participant demographic making use of, primarily, private EMS services. Self-selection bias cannot be excluded as participation was voluntary. However, participants were broadly distributed across SA, experiencing a range of palliative situations, resulting in various perspectives which were discussed in view of similar studies in differing contexts. While the transferability of specific participant emotions and needs may be limited, the general principles drawn (e.g. deferential tone of interaction) remain vital. Only two participants were patients while the remainder were family members. While there is a need for

further patient interviews, the perspectives of patients and family members in this study were well-aligned.

Conclusions

The aim of this study was to gather perspectives of SA patients and family members with palliative needs concerning EMS use in their care. One overarching theme, the Dynamic of Control, and three categories were developed: 1) Loss of Control: Heavy Burdens of Living with Chronic and End-of-Life Illness 2) Maintaining Control: Longings and Exigencies in Times of Suffering 3) Transferring Control: Consequential EMS Influence on Palliative Situations. Participants described a loss of previous control they held over their lives and a subsequent longing to maintain what control remained. EMS care was viewed positively when this longing was satisfied and negatively when further control was seized. Understanding this Dynamic of Control is fundamental to the EMS establishment of a person-centred, deferential tone in palliative situations. Practical developments which would enhance person-centred care in these situations include alternative care pathways, availability of on-scene information, and palliative care education for EMS providers. Including palliative care in EMS education may have far-reaching benefits beyond improved palliative situation management as it challenges the current system-centred approach and encourages a cultural shift towards person-centred care.

Section 3 Overview

Additional Considerations

With the addition of the studies presented in this section, there is improved understanding of primary stakeholder perspectives concerning EMS and palliative care. EMS providers, palliative care providers, and patients and family members with palliative care needs all view EMS and palliative care integration positively and have made suggestions for integrative approaches. (16,162) While previously EMS providers stated they have a role to play in palliative situations, it was unclear what this role was. (16) Palliative care providers specified what this role should be: the provision of initial containment. (162) Initial containment entails initial assessment and stabilisation of palliative situations followed by linking patients and family members with palliative care services. (162) Furthermore, EMS may be beneficially used by palliative care services to assist with patient transitioning and after-hours care. (162) This aligns well with patient and family member perspectives and needs as presented in this section.

The patient and family member interviews also provided invaluable insight into the reasons EMS are used in palliative situations. These included symptom management and improved access to healthcare as likewise found in the retrospective chart review study (Section 2). In addition to these practical needs, EMS are used as they are readily available and to regain control over palliative situations. These are functions which EMS are well-suited to, (46) and it appears patients and family members with palliative needs have recognized this and so make use of EMS to fulfil these needs.

A common desire within all the needs of patients and family members, was for person-centred care. These individuals wished to be treated ‘like people’. They desired to be heard, understood, reassured, and treated with compassion. In the majority of cases, EMS were able to fulfil this need.

With EMS and palliative care integration being supported in SA by all primary stakeholders, quantitative data, and international literature, it is clear this integration should be pursued. While in these previous studies various integration methods have been suggested (i.e. education), these require further specificity, prioritisation, and contextualisation in the SA setting for them to be implementable. The NGT study in Section 4 addresses these requirements.

Section 3 Summary

Key Messages:

- All primary stakeholders (EMS and palliative care providers, patients and family members with palliative care needs) support EMS and palliative care integration.
- A role of EMS in palliative situations is to provide initial containment.
- EMS are used in palliative situations as they are readily available to assist in regaining control of palliative situations.
- A person-centred approach to care is essential to fulfil the desires of patients and family members with palliative needs.
- The WHO IPCHS recommends context specific research be performed to develop integrated, person-centred approaches to healthcare such as the studies performed in SA in this thesis.
- Integrative approaches suggested in this study: Awareness, Community Engagement, Education, Communication and Information Sharing, Stakeholder Collaborations, Need for Future Research, Alternative Pathways and Approaches

Table 12 Evidence gaps addressed in Section 3

Evidence Gaps Include:	Addressed in this Section:
Map of current EMS and palliative care literature.	Scoping Literature Review (Chapter 3)
Extent of intersection between EMS and palliative situations.	Retrospective Chart Review– Clinical Analysis (Chapter 4)
Clinical reasons for EMS use in palliative situations.	Retrospective Chart Review – Clinical Analysis (Chapter 4)
Practical reasons for EMS use in palliative situations.	Retrospective Chart Review – Spatio-temporal Analysis (Chapter 5)
Palliative care provider perspectives on the use of EMS in palliative situations.	Palliative Care Provider Interviews (Chapter 6)
Patient and family member perspectives on the use of EMS in palliative situations.	Patient and Family Member Interviews (Chapter 7)
Patient and family member reasons for EMS use in palliative situations.	Patient and Family Member Interviews (Chapter 7)
Development and prioritisation of implementable approaches to EMS and palliative care integration.	Nominal Group Technique (Chapter 8)
Role of EMS in palliative situations.	Scoping Literature Review (Chapter 3), Retrospective Chart Review (Chapters 4 and 5), Palliative Care Provider Interviews (Chapter 6), Patient and Family Member Interviews (Chapter 7), Nominal Group Technique (Chapter 8)

Evidence gaps addressed in this section and their corresponding studies are highlighted in green.
Evidence gaps previously addressed and their corresponding studies are highlighted in turquoise.
EMS=Emergency Medical Services

Section 4: Expert Panel Recommendations for Emergency Medical Services and Palliative Care Integration

Section Introduction

Section 4 presents the results from an expert panel discussion which was held in the form of an NGT. The expert panel consisted of both EMS and palliative care experts. Findings from this study contribute to the development and prioritisation of implementable approaches to EMS and palliative care integration as well as the role of EMS in palliative situations. These implementable approaches are categorized and compared with healthcare system integration literature.

This study was informed by the findings of all previous studies contained in this thesis. In turn, findings from the NGT are used to inform the conceptual framework developed in Section 5.

This section consists of the following sub-sections:

- Gage CH, Gwyther L, Ambler J, Burke J, Holmes L, Evans K, Krause R, Lachenicht K, Lincoln D, Payne K, Ratshikana-Moloko M, Stander C, Stassen W. Facilitating the Integration of Emergency Medical Services and Palliative Care in South Africa: A Nominal Group Technique. ***Accepted for Publication in African Journal of Primary Healthcare and Family Medicine.***
- Section 4 Overview

The chapter which makes up this section includes an original article which is replicated verbatim but formatted appropriately for consistency throughout this thesis. This section concludes with an overview including additional considerations, key messages and how these contribute to the thesis in its entirety. In addition, as this section concludes the presentation of individual studies within this thesis, key findings concerning addressed research gaps are presented.

Chapter 8: Facilitating the Integration of Emergency Medical Services and Palliative Care in South Africa: A Nominal Group Technique

Chapter Introduction

This chapter contains the NGT study which employed an expert panel consisting of EMS and palliative care experts. The purpose of this study was to provide practical guidance for the implementation of EMS and palliative care integration in SA while considering findings from all previous studies.

Declaration from author and co-authors

The following co-authors contributed to this publication: Gwyther L, Ambler J, Burke J, Holmes L, Evans K, Krause R, Lachenicht K, Lincoln D, Payne K, Ratshikana-Moloko M, Stander C, Stassen W.

Contributions of the authors were as follows: CHG, LG and WS conceptualized the idea for the study and developed the methodology. CHG performed data collection, analysis, and drafted the manuscript. JA, JB, LH, KE, RK, KL, DL, KP, MR and CS assisted with data collection. WS and LG assisted in data collection and acted as study supervisors. All authors reviewed approved the final submitted version.

The extent of contributions from each person are as follows:

CHG 60%; JA 2%; JB 2%; LH 2%; KE 2%; RK 2%; KL 2%; DL 2%; KP 2%; MR 2%; CS 2%; LG 10%; WS 10%

Given the large number of co-authors, the principal investigator and the supervisor hereby sign for approval on behalf of the group, in accordance with the UCT Doctoral Degrees Board guideline titled, “GUIDELINES FOR THE INCLUSION OF PUBLICATIONS IN A DOCTORAL THESIS.”

Signed by candidate

Caleb Gage

16 January 2025
Date

Signed by candidate

Willem Stassen

16 January 2025
Date

Facilitating the Integration of Emergency Medical Services and Palliative Care in South Africa: A Nominal Group Technique

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Abstract

Introduction: The need for integrated healthcare has been increasingly recognised as health systems face mounting challenges associated with the proliferation of injuries and non-communicable diseases. A developing example of this integration is collaboration between Emergency Medical Services (EMS) and palliative care. However, despite recommendations for EMS and palliative care integration in South Africa (SA), these services remain segregated in the country. The aim of this study was to develop and prioritise approaches facilitating EMS and palliative care system integration within SA.

Methods: A nominal group technique, involving experts from both EMS and palliative care, was employed to answer the question "what do you think should be done to most effectively integrate EMS and palliative care services in South Africa?" Answers were sorted into categories, awarded scores by participants, and ranked according to their impact and feasibility within SA.

Results: The following categories of answers, listed in rank order from highest to lowest, were generated: Awareness, Education, Community Engagement, Communication and Information Sharing, Stakeholder Collaborations, Alternative Pathways and Approaches, Research, Funding, Policy Development, Governance. The top five individual answers ranked by participants were 1) Enable EMS to administer already prescribed medications, 2) EMS undergraduate training in palliative care, 3) Improve EMS recognition of signs of dying at the end-of-life, 4) Palliative care awareness for the EMS community, and 5) Palliative care awareness for in-hospital healthcare providers, particularly those in emergency medicine.

Conclusions: The categories developed in this study should be used to guide EMS and palliative care integration in SA. The top five individual answers generated are practical starting points for integration as they represent high-impact, low-cost interventions which are appropriate and readily implementable in the SA setting. Future research should aim at establishing the safety and efficacy of these interventions.

Introduction

The need for integrated healthcare has been increasingly recognised as health systems face mounting challenges due to ageing populations, globalization of unhealthy lifestyles, urbanization, and subsequent proliferation of injuries and non-communicable diseases (NCDs). (111) Fragmented modern health systems exacerbate these challenges through inefficient resource use leading to inflated healthcare costs, poor quality of care, and decreased patient satisfaction. (111) These challenges are of concern in low-to-middle income countries (LMICs) which contain disproportionately high disease burdens with concurrent resource limitations and cannot afford such inefficiency. (173) The World Health Organization (WHO) global strategy on Integrated People-Centred Health Services (IPCHS) states, *"The focus on hospital-based and self-contained 'silo' curative care models undermines the ability of health systems to provide universal, equitable, high-quality, and financially sustainable care."* (111) Integrated health systems, defined as *"the coordination of health services and the collaboration amongst provider organizations to establish an effective health system"*, (174) have been recommended to improve accessibility, affordability, and quality of care, particularly for those with complex healthcare needs. (175)

A developing example of health system integration which may achieve these benefits is collaboration between Emergency Medical Services (EMS) and palliative care. (110) Palliative care itself is aligned with health system integration as it applies a multi-disciplinary, holistic approach to those with complex, life-limiting illnesses. (9) Furthermore, the WHO has specifically recommended palliative care integration across multiple systems as part of its global response to NCDs to meet the subsequent increasing global demand for palliative care. (143) Several studies have demonstrated the effectiveness of EMS and palliative care integration in this regard as it enhances patient satisfaction, improves quality of life, avoids unnecessary hospital admissions and associated costs, and improves access to palliative care. (3,6,42,74)

Within the LMIC context of South Africa (SA), these benefits have been noted by EMS (16) and palliative care providers (162) as well as patients and family members with palliative care needs (Chapter 7). Furthermore, each of these stakeholder groups have recommended EMS and palliative care integration. (16,162) Despite these findings, EMS and palliative care systems remain 'siloed' within the country and no clear guidance exists for integration. Thus, there is a need to develop implementable approaches facilitating such integration. Given the resource constraints experienced in SA there is a further need to prioritise approaches with the greatest potential impact and feasibility. Therefore, the aim of this study was to develop and prioritise approaches facilitating EMS and palliative care system integration within SA.

Methods

Design

A nominal group technique (NGT), involving both EMS and palliative care experts, was employed. A Complex Adaptive System (CAS) theory of healthcare underpins the study. (176,177) CAS theory views healthcare as an open, self-organizing system consisting of multiple agents with complex interactions analogous to a living organism which constantly adapts to change. (176,177) Thus, rather than seeking permanent solutions to the problem of segregated EMS and palliative care, we sought to identify facilitators of integration which may be applied cross-contextually in SA.

Setting

The SA health system is divided into private and state sectors. The state sector, operated by the government, provides healthcare to all citizens while the private sector is restricted to those with medical insurance or other financial means. EMS are likewise divided into state and private sectors. EMS care is provided using a paramedic-led rather than physician-led approach. (16) Formal higher education (HE) training is required to register as an EMS provider, however, as this was a recent requirement, many providers with vocational training, remain registered and practicing. (124) HE training ranges from one (assistant) to four years (practitioner) in duration. Palliative care in SA is frequently delivered *via* non-governmental organizations which provide hospice services, though there has been significant growth in state sector palliative care provision. (22,23) Although palliative care integration has improved in many areas among medical and allied health disciplines, equitable access to palliative care remains a significant challenge. (178)

Sample and Sampling

EMS and palliative care experts meeting inclusion and exclusion criteria were purposefully sampled. ‘Palliative care experts’ were qualified medical nurses and doctors with a minimum of 5 years post-graduate experience and a post-graduate higher education qualification in a palliative care related field (i.e. Post-Graduate Diploma in Palliative Care). ‘EMS experts’ were advanced life support (ALS) providers with higher education qualifications (National Diploma, Bachelor of Technology, Bachelor of Health Sciences in Emergency Medical Care), a minimum of 5 years post-graduate EMS experience and a post-graduate higher education qualification in an EMS or palliative care related field (i.e. Post-Graduate Diploma in Palliative Care or

Emergency Medicine). EMS and palliative care experts without experience and qualifications in SA were not included. Participants were individually invited to the study *via* email. A brief description of the study along with a proposed meeting time was presented and willing participants signed a consent form.

Procedure

One virtual nominal group meeting was performed using Microsoft Teams (Microsoft Corporation, USA) with audio-recording and transcription functions enabled. A single meeting was held as there is limited and ambiguous information regarding data analysis across multiple meetings in a single study. (179) A virtual platform was used as participants were broadly distributed across SA. CG and WS facilitated a pilot meeting with LG as the palliative care expert and an additional EMS expert to ensure procedural quality. After this pilot the procedural schedule (Appendix 7) was finalised. Unique findings from the pilot were presented in the formal meeting for discussion and were ultimately included in the final list of approaches.

Prior to the meeting, pre-reading was sent to participants *via* email introducing the study topic, aim, and question along with an explanation of the study process. CG facilitated the meeting with WS and LG assisting. As described by McMillan *et al.* (179) the study was conducted in four consecutive phases. Time allocations for each phase were flexible based on participants' needs and discussions:

1) Silent Idea Generation: As pre-reading had been sent, participants were given 5 minutes to silently and individually record as many answers as possible to the question, "what do you think should be done to most effectively integrate EMS and palliative care services in South Africa?" During this time the research team remained silent.

2) Round Robin Discussion: Participants individually presented a single answer at a time in a round robin fashion until all ideas were exhausted. Answers were not discussed, but simply recorded by CG for all participants to see. Answers were placed into pre-defined categories (Appendix 8) based on previous SA research, (16,162) (Chapter 7) the pilot meeting, and health system integration literature. (170) This phase was allocated 30 minutes.

3) Clarification: In this phase, 1 hour was allocated for discussion and clarification concerning each answer. Participants were given the opportunity to ask questions about the submitted answers and clarify their meaning. Based on the discussions, similar answers were combined, some were excluded, and new answers were recorded. After each answer was discussed, a final list of answers was produced.

4) Ranking: Participants were asked to individually rank each answer according to its impact and feasibility in the SA setting. This was done *via* email with a link to a Microsoft Forms (Microsoft Corporation, USA) survey (Appendix 9). Impact and feasibility were divided into low, moderate, and high which were awarded scores of 1, 2, and 3 respectively. Thus, for example, an idea could be ranked as having high impact (3), but low feasibility (1). Scores were then totalled across all participants and ideas arranged from highest to lowest score producing a prioritised list. Average impact and feasibility scores were also calculated to place ideas in final categories of low, moderate, or high. For example, if an idea averaged a score of 2.6 for impact, this was rounded to 3 and the idea placed in the high impact category. For the purposes of this study, impact referred to the effectiveness of an approach in integrating EMS and palliative care, thereby improving patient care, and feasibility referred to how easily implementable an approach would be in the SA context. Thus, a high impact approach would be very effective, and a highly feasible approach would be easily implementable.

Analysis

Data analysis was, likewise, performed according to the recommendations of McMillan et al: (179)

1) Descriptive Analysis of Raw Data: Answers and their priorities were descriptively analysed in terms of number of participant scoring.

2) Categorical Analysis of Raw Data: The answers generated by participants were coded into categories by CG. Researcher triangulation was then performed between the authorship where codes and categories were discussed, refined, and finalised. Member checking of these categories was performed thereafter to ensure the intended meaning of the participants was retained.

3) Analysis of Secondary Coded Data: Categories were ranked by averaging the total scores of answers within each category.

4) Qualitative Analysis: The transcript of the meeting was deductively analysed according to the developed categories to provide further context such as reasons for answers.

Summary descriptive statistics (means, standard deviations) were used to calculate individual answer and category scores using SPSS Statistics for Windows version 28.0 (IBM Corp., USA).

Ethical Approval

Ethical approval was provided by the University of Cape Town's Human Research Ethics Committee (HREC Reference Number: 453/2024).

Results

Nine experts participated in the meeting (Table 13) which lasted 2 hours 27 minutes. Seven participants knew CG from previous collaborations, and all were aware the study formed part of his post-graduate studies. No participants dropped out of the study or refused participation. All participants completed each phase of the procedure. In total, 52 answers were generated and ranked (Table 14). Answers fell into the following categories (Table 15): Awareness, Education, Community Engagement, Communication and Information Sharing, Stakeholder Collaborations, Alternative Pathways and Approaches, Research, Funding, Policy Development, Governance. Based on average impact and feasibility scores, ideas were plotted on a prioritisation matrix (Figure 10).

Table 13 Expert Panel Member and Research Team Details

	Area of Expertise	Years of Experience	Qualifications	SA Province
Participant #1	Palliative Care	10	BCur, PG Dip Palliative Medicine, MPhil Palliative Medicine.	Western Cape
Participant #2	Palliative Care	25	MBChB, MRCGP, PG Dip Palliative Medicine, DCH	KwaZulu-Natal
Participant #3	Palliative Care	20	MBChB, MMed Family Medicine, MPhil Palliative Medicine, PhD Palliative Medicine	Western Cape
Participant #4	EMS	10	BTEMC, MPhil Emergency Medicine	Gauteng
Participant #5	EMS	13	BTEMC, PG Dip Health Science Education, PG Dip Medical Simulation, MSc Health Science Education	Gauteng
Participant #6	EMS	11	BTEMC, MPhil Emergency Medicine	Gauteng
Participant #7	Palliative Care	14	MBChB, DTM&H, MPhil Palliative Medicine	Gauteng
Participant #8	Palliative Care	35	MBChB, MPhil Palliative Medicine	Gauteng
Participant #9	Palliative Care and Emergency Medicine	16	MBChB, MMed Emergency Medicine, PG Dip Palliative Medicine	Western Cape
Pilot Study Participant	EMS and Palliative Care	14	BTEMC, PG Dip Higher Adult Education, PG Dip Palliative	Western Cape

			Medicine, MPhil Palliative Medicine	
WS	EMS	14	BTEMC, PG Dip Applied Ethics, MPhil Emergency Medicine, PhD Emergency Medicine	Western Cape
LG	Palliative Care	31	MBChB, MMed Family Medicine, PG Dip Palliative Medicine, MSc Palliative Medicine, PhD Palliative Medicine	Western Cape
CG	EMS	11	BTEMC, MPhil Emergency Medicine, Palliative Care Short Course[1]	Gauteng

Bcur=Bachelor of Nursing Science, PG Dip=Post-Graduate Diploma, MPhil=Master of Philosophy, MBChB=Bachelor of Medicine and Bachelor of Surgery, MRCGP=Membership of the Royal College of General Practitioners, DCH=Diploma in Child Health, MMed=Master of Medicine, PhD=Doctor of Philosophy, BTEMC=Bachelor of Technology in Emergency Medical Care, MSc=Master of Science, DTM&H=Diploma in Tropical Medicine and Hygiene.

[1] 10-week course introducing basic palliative care principles and management.

Table 14 Generated Answers in Rank Order

Ideas	Category	Total Impact Score (mean, SD)	Total Feasibility Score (mean, SD)	Total Score
Palliative care awareness for the EMS community.	Awareness	26 (2.89, 0.33)	24 (2.67, 0.71)	50
Palliative care awareness for in-hospital healthcare providers, particularly those in emergency medicine.	Awareness	26 (2.89, 0.33)	23 (2.56, 0.53)	49
EMS undergraduate training in palliative care.	Education	24 (2.67, 0.50)	25 (2.78, 0.44)	49
Enable EMS to administer already prescribed medications.	Alternative Pathways and Approaches	24 (2.67, 0.71)	24 (2.67, 0.50)	48
Improve EMS recognition of signs of dying at the end-of-life.	Education	24 (2.67, 0.50)	23 (2.56, 0.73)	47
Improve EMS understanding of palliative care – including legal and ethical implications, DNRs, ACPs, qualification levels.	Education	25 (2.78, 0.44)	22 (2.44, 0.88)	47
Develop policies for EMS medication administration in palliative situations.	Policy Development	25 (2.78, 0.44)	21 (2.33, 0.50)	46
Post-graduate palliative care training for EMS educators.	Education	25 (2.78, 0.44)	21 (2.33, 0.87)	46
Ongoing education in palliative care for EMS such as Continual Professional Development (CPD) training.	Education	24 (2.67, 0.71)	22 (2.44, 0.73)	46

Develop palliative care teams at hospital level to identify patients with palliative needs.	Alternative Pathways and Approaches	26 (2.89, 0.33)	20 (2.22, 0.97)	46
Develop EMS palliative care networking teams.	Stakeholder Collaborations	24 (2.67, 0.50)	21 (2.33, 0.87)	45
Provide palliative care advice for EMS at the point of care.	Communication and Information Sharing	24 (2.67, 0.50)	21 (2.33, 0.71)	45
EMS training in subcutaneous medication administration.	Education	22 (2.44, 0.73)	23 (2.56, 0.73)	45
Train EMS in patient and family member communication.	Education	23 (2.56, 0.53)	22 (2.44, 0.53)	45
EMS palliative care curriculum development.	Education	24 (2.67, 0.50)	21 (2.33, 0.87)	45
Develop guidelines and standard operating procedures for EMS at the point of care – including who to contact for advice.	Policy Development	25 (2.78, 0.44)	20 (2.22, 0.83)	45
Provide support for EMS to fulfil advance care plans by including information (instructions, contact details) specific to EMS in the plans.	Communication and Information Sharing	24 (2.67, 0.71)	21 (2.33, 0.71)	45
Collaboration between EMS and palliative care societies.	Stakeholder Collaborations	22 (2.44, 0.73)	23 (2.56, 0.53)	45
24/7 availability of palliative care contacts for patients and family members.	Community Engagement	26 (2.89, 0.33)	19 (2.11, 0.60)	45
Develop a model for EMS and palliative care integration at various healthcare system levels and within various EMS environments.	Research	26 (2.89, 0.33)	18 (2.00, 0.71)	44
Develop mechanisms for EMS to handover patient care in palliative situations to family members.	Alternative Pathways and Approaches	23 (2.56, 0.53)	21 (2.33, 0.87)	44
Develop EMS support tools to assist in the identification of patients with previously unrecognized palliative needs.	Alternative Pathways and Approaches	24 (2.67, 0.71)	20 (2.22, 0.83)	44
Adjust private sector EMS funding models relating to medical insurance.	Funding	24 (2.67, 0.50)	19 (2.11, 0.60)	43
Define processes for EMS linking palliative situations with outpatient services, community healthcare, and community oriented primary care.	Alternative Pathways and Approaches	25 (2.78, 0.44)	18 (2.00, 0.87)	43
Develop palliative care committees inclusive of EMS, hospice and in-hospital management at all levels of care.	Stakeholder Collaborations	23 (2.56, 0.53)	20 (2.22, 0.83)	43
Post-graduate palliative care training for EMS providers.	Education	23 (2.56, 0.53)	20 (2.22, 0.83)	43

Enable early EMS recognition of palliative cases.	Education	24 (2.67, 0.71)	19 (2.11, 0.78)	43
Engage community concerning specific palliative care needs.	Community Engagement	21 (2.33, 0.71)	21 (2.33, 0.50)	42
Establish EMS palliative care case reviews and debriefing sessions for quality improvement.	Governance	24 (2.67, 0.50)	18 (2.00, 0.71)	42
Include EMS in inter-disciplinary palliative care education.	Education	22 (2.44, 0.73)	19 (2.11, 0.60)	41
Establish cross-disciplinary communication and information-sharing with EMS, palliative care, in-hospital providers.	Communication and Information Sharing	23 (2.56, 0.53)	18 (2.00, 0.50)	41
EMS and palliative care networking with locally available resources.	Stakeholder Collaborations	23 (2.56, 0.53)	18 (2.00, 0.50)	41
Allocate budget for palliative care within EMS – education, policy and guideline development, service provision.	Funding	25 (2.78, 0.44)	15 (1.67, 0.50)	40
Perform ongoing EMS and palliative care research concerning efficacy of integration.	Research	20 (2.22, 0.83)	20 (2.22, 0.67)	40
Provide palliative care awareness and education for the public.	Community Engagement	22 (2.40, 0.73)	18 (2.00, 1.00)	40
Develop care packages for EMS in palliative situations based upon scope of practice.	Alternative Pathways and Approaches	21 (2.33, 0.71)	19 (2.11, 0.78)	40
Include EMS within advance care plans.	Communication and Information Sharing	24 (2.67, 0.71)	16 (1.78, 0.83)	40
Include EMS in palliative care policies to link services and prioritise palliative care cases.	Policy Development	21 (2.33, 0.71)	18 (2.00, 0.71)	39
Perform EMS and palliative care integration cost-benefit analyses.	Research	20 (2.22, 0.67)	18 (2.00, 0.71)	38
Define alternative care pathways for EMS in palliative situations.	Alternative Pathways and Approaches	22 (2.44, 0.53)	16 (1.78, 0.83)	38
Make advance care plans available for EMS at the point of care.	Communication and Information Sharing	23 (2.56, 0.73)	15 (1.67, 0.71)	38
Allocate finances for EMS in palliative care in the public sector.	Funding	24 (2.67, 0.50)	13 (1.40, 0.58)	37
Create specialist out-of-hospital palliative care teams inclusive of EMS and/or non-EMS staff.	Alternative Pathways and Approaches	21 (2.33, 0.87)	16 (1.78, 0.83)	37

Develop an EMS community care approach.	Alternative Pathways and Approaches	20 (2.22, 0.67)	17 (1.89, 0.78)	37
Have EMS providers spend time in palliative care practices.	Stakeholder Collaborations	21 (2.33, 0.87)	16 (1.78, 0.67)	37
Recognize palliative care trained EMS providers.	Governance	21 (2.33, 0.71)	15 (1.67, 0.71)	36
Provide legal and ethical support for EMS in palliative situations.	Governance	20 (2.22, 0.83)	16 (1.78, 0.97)	36
Improve EMS scope of practice for EMS at the Health Professions Council of South Africa (HPCSA).	Governance	23 (2.56, 0.53)	12 (1.33, 0.50)	35
EMS and palliative care decision-maker collaboration at a national level.	Stakeholder Collaborations	22 (2.44, 0.73)	12 (1.33, 0.50)	34
Develop telehealth systems for patients, family members, and EMS.	Alternative Pathways and Approaches	18 (2.00, 0.50)	13 (1.44, 0.73)	31
Register advanced EMS providers in palliative care at HPCSA.	Governance	20 (2.22, 0.67)	11 (1.22, 0.44)	31
Develop policies for EMS to independently prescribe medications.	Policy Development	16 (1.78, 0.83)	13 (1.44, 0.73)	29

Answers are ranked from highest to lowest priority based on total score which is the sum of total impact and feasibility scores. As there were 9 participants with a highest rating score of 3 (high) for each answer, the highest possible impact and feasibility scores were 27, while the highest possible total score for an idea was, therefore, 54. Mean impact and feasibility scores refer to the average of individual scores awarded by participants.

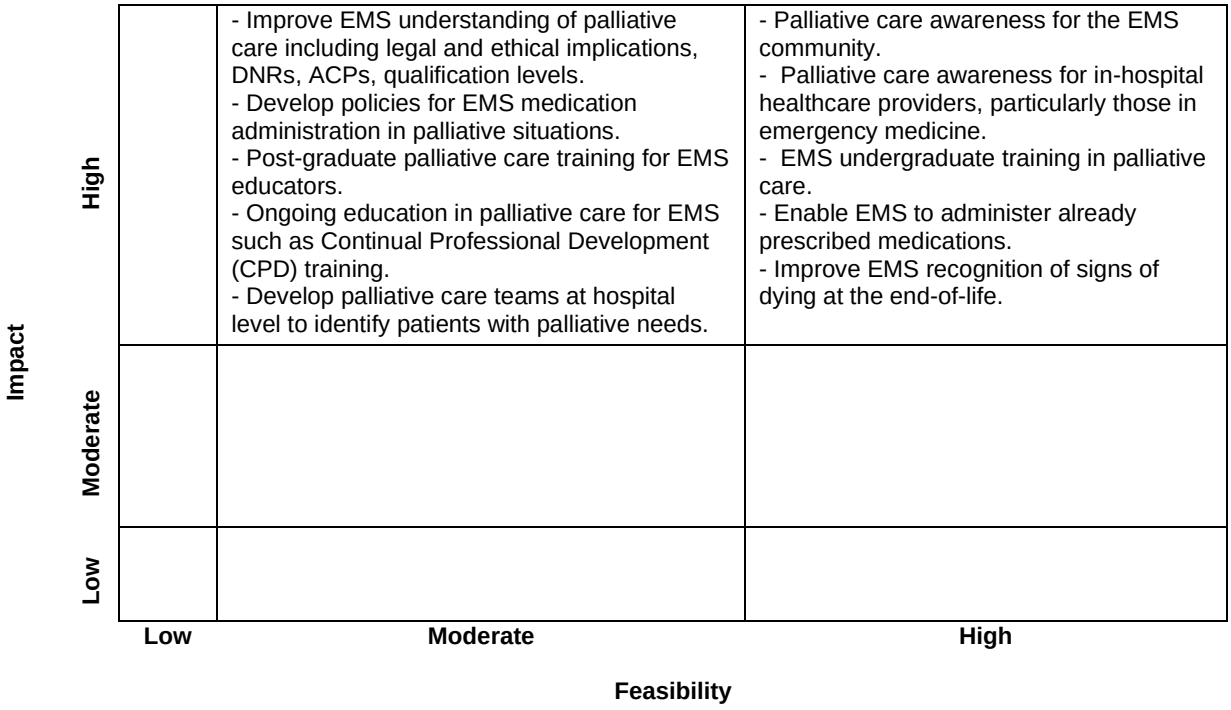
SD=Standard Deviation, DNR=Do Not Resuscitate, ACP=Advance Care Plan, EMS=Emergency Medical Services

Table 15 Categories in Rank Order

	Number of Ideas	Mean Total Impact Score (SD)	Mean Total Feasibility Score (SD)	Mean Total Score (SD)
Awareness	2	26.00 (0.00)	23.50 (0.71)	49.50 (0.71)
Education	11	23.64 (1.03)	21.55 (1.81)	45.18 (2.23)
Community Engagement	3	23.00 (2.65)	19.33 (1.53)	42.33 (2.52)
Communication and Information Sharing	5	23.60 (0.55)	18.20 (2.77)	41.80 (3.11)
Stakeholder Collaborations	6	22.50 (1.05)	18.33 (3.93)	40.83 (4.49)
Alternative Pathways and Approaches	10	22.40 (2.46)	18.40 (3.10)	40.80 (5.14)
Research	3	22.00 (3.46)	18.67 (1.15)	40.67 (3.06)
Funding	3	24.33 (0.58)	15.67 (3.06)	40.00 (3.00)
Policy Development	4	21.75 (4.27)	18.00 (3.56)	39.75 (7.80)
Governance	5	21.60 (1.82)	14.40 (2.88)	36.00 (3.94)

Categories are ranked from highest to lowest priority based on mean total score.

SD=Standard Deviation



This figure includes the top ten ranked ideas. A complete figure may be found in Appendix 10.

DNR=Do Not Resuscitate, ACP=Advance Care Plan, EMS=Emergency Medical Services

Figure 10 Prioritisation Matrix

Awareness

Participants suggested palliative care awareness for both EMS and in-hospital healthcare providers. These approaches were awarded the highest impact scores, and perceived as highly feasible. Thus, the awareness category was ranked as the highest overall priority in this study as participants noted the lack of palliative care knowledge even among medical providers.

"We need to define palliative care a bit better in the pre-hospital setting...If we [EMS] *think palliative care, we just think about the stage four cancer getting morphine. That's essentially EMS's knowledge of palliative care."* – Participant #6

Education

Ranked second overall, educational approaches to integration formed the largest category of discussion. Participants recommended palliative care training for EMS at all levels (under-graduate, post-graduate, and ongoing professional development), and emphasized the need for curriculum development. As part of this curriculum, specific items, such as subcutaneous medication administration, were highlighted. The highest ranked educational approaches, prioritised as high impact, high feasibility, were EMS undergraduate training in palliative care. and to improve EMS recognition of signs of dying at the end-of-life.

"The training and the education of the [EMS] *providers is so important…at an undergraduate level. I think it must start there."* – Participant #8

"So [EMS] *education around recognizing the signs of dying, and…using the subcutaneous route instead of intravenous access."* – Participant #1

Community Engagement

Engaging with local communities was recommended by participants to identify specific palliative care needs. Palliative care awareness and education within local communities was likewise recommended as misconceptions regarding palliative care were perceived as prevalent. Overall, the ideas within this category were ranked as having moderate impact and moderate feasibility. The highest ranked approach was 24/7 availability of palliative care contacts for patients and family members.

"…with the awareness and community, I think a lot of patients and family sees it [palliative care] *as you giving up. Let them understand it's not you're giving up… it's just a different type of care…"*– Participant #4

"So they must have a way for the patient to communicate with [the palliative care team]*…if they don't, they are going to phone EMS because there's no one else to phone…in hours and then after hours."* – Participant #9

Communication and Information Sharing

Several ideas developed by participants involved enhancing communication and information sharing between EMS and palliative care systems. Significant emphasis was placed on inclusion of EMS within advance care planning as a support tool for EMS providers at the point of care. All approaches within this category were ranked as high impact, moderate feasibility. The highest ranked approaches were to provide palliative care advice for EMS at the point of care, and to provide support for EMS to fulfil advance care plans by including information specific to EMS in the plans.

"It's developing the culture of conversation within the EMS spaces and…not just within the EMS space…because palliative care is gonna happen across multiple different spaces and that would require loads of communication…" – Participant #5

"The advanced care planning documents and recognition of those documents when they do exist is really important…We've had quite a few cases where there are documents in place…and then when they EMS arrive…the patient still ends up going to hospital." – Participant #1

Stakeholder Collaborations

Various collaborations between EMS and palliative care stakeholders were recommended to promote integration. Stakeholders included EMS, palliative care, hospice, and in-hospital healthcare providers, managers, national decision-makers, and societies. These collaborations were recommended at all levels, from individual providers to national stakeholders. The top ranked approaches within this category were collaboration between EMS and palliative care societies and to develop EMS palliative care networking teams. Each of these fell into the high impact, moderate feasibility section of the prioritisation matrix.

"So what I would like to see is perhaps at a district level the development of palliative care committees…Representatives from district hospitals, from the EMS, from pharmacy, from hospice services from…the hospital management." – Participant #2

"…so when you talk about stakeholder engagement…we need all levels of care to be involved here." – Participant #7

Alternative Pathways and Approaches

This category was the second largest and referred to differing approaches to patient care within EMS and palliative care systems than the current norm. For example, one approach was to develop mechanisms for EMS handover of patient care in palliative situations to family members. Currently EMS providers are obligated to handover care to a medical provider and no appropriate mechanism exists for treatment without conveyance. (162) The highest ranked approach in this category, which was ranked as high impact, high feasibility, was to enable EMS to administer already prescribed medications.

"I like to call it, not an on-scene discharge… but handover of care to family and the home-based care team who might not be on premises, but you are still handing over care to them." – Participant #9

Research

The need for ongoing research was emphasised by participants as important to monitor the efficacy of integration. The need for cost-benefit analyses was specifically highlighted. The top ranked approach within this category was to develop a model for EMS and palliative care integration at various healthcare system levels and within various EMS environments. This was ranked as a high impact, moderate feasibility approach.

"I think [research is] *important for us as work starts with the integration…to be able to start documenting lessons that we are learning because we are going to have to probably have a model that might work in* [some] *areas and not work in others, so there's going to be a lot of contextualization."* – Participant #7

Funding

Participants recommended allocating funds for education, policy and guideline development, and service provision in both state and private sectors to assist integrative efforts. The top ranked approach in this category was to adjust private sector EMS funding models relating to medical insurance as currently in SA, for example, medical insurance companies do not reimburse EMS in instances of patient non-conveyance. While each idea in this category ranked highly in terms of impact, feasibility scores were relatively low, particularly for the allocation of funds in the state sector.

"Let's be very specific about where the budget allocations need to be. It needs to be for education, for service provision, for policy development." – Participant #3

Policy Development

The need for policies, guidelines, and standard operating procedures for EMS providers in palliative situations was discussed by participants with a focus on medication administration and EMS linking patients with other services (i.e. hospice). It was also noted that existing palliative care policies do not mention EMS. The highest ranked approach for policy development was to develop policies for EMS medication administration in palliative situations. While this category was ranked low overall, this was primarily due to the low overall score of developing policies for EMS to independently prescribe medications.

"…guidelines would be very key…we've got a lot of policies, I don't even think our palliative care policies have actually recognized the need for us to…link together with EMS." – Participant #7

Governance

This category largely consisted of macro-level approaches involving specialist EMS provider registration with the Health Professions Council of South Africa (HPCSA), legal frameworks, and increasing EMS scope of practice for palliative situations. Due to moderate and low feasibility scores of ideas within this category, governance was ranked last overall. The highest ranked approach within this category with a high impact, moderate feasibility score, was to establish EMS palliative care case reviews and debriefing sessions for quality improvement.

"…those EMS providers that have had advanced training in palliative care need to be recognized by the boards or their councils." – Participant #3

Discussion

Health system integration literature has identified several components within integration frameworks and models: Adequate Funding, Co-Location, Communication, Community Engagement, Context, Culture, Governance, Defining Roles and Shared Goals, Stakeholder Management, Technological Connectivity, Awareness, and Education. (170) Though some differing categories were developed in the present study, participant answers aligned well with this literature. Categories not directly developed in our study were Co-Location, Culture, Defining Roles and Shared Goals, and Technological Connectivity. However, elements of these were present within specific approaches suggested by participants. For example, establishing cross-disciplinary communication and information-sharing would require technological connectivity and co-location to varying degrees. Furthermore, educational interventions have been previously recommended to impact EMS and palliative care cultures (Chapter 7). (180) Additional categories noted in our study, Research, Policy Development, and Alternative Pathways and Approaches, likewise contain similar elements as they would involve defining roles and shared goals. Thus, given their alignment with international health system integration frameworks and specificity to the SA setting, the categories developed here represent an appropriate starting point for EMS and palliative care integration in SA.

The approaches developed in our study may be achieved at macro- (national systems and policies), meso- (regional/district/organizational), and micro- (individual provider) levels. (109,175) For example, Stakeholder Collaborations may be achieved across all levels. This was demonstrated in a similar study aimed at implementing *'palliative paramedicine'* in Australia. (109) Within this Delphi study, thirty-two components for EMS and palliative care integration, divided into macro-, meso-, and micro-level interventions reached consensus. (109) Though several specific interventions differ between this and the present study, all categories of approaches are aligned apart from Funding which was not specifically mentioned, though it is implied, in the Australian study. (109)

Considering the LMIC context of SA with its inherent resource limitations, there is a specific need to focus on high impact, low-cost approaches to integration which are contextually feasible. The expert panel in this study identified several such approaches which we highly recommend for immediate implementation: 1) Enable EMS to administer already prescribed medications, 2) EMS undergraduate training in palliative care, 3) Improve EMS recognition of signs of dying at the end-of-life, 4) Palliative care awareness for the EMS community, 5)

Palliative care awareness for in-hospital healthcare providers, particularly those in emergency medicine.

Currently, EMS providers do not typically administer medications which have already been prescribed to patients, particularly if these medications fall outside of their scope of practice. (181) An example provided by one participant was that of a patient with palliative needs who has oral morphine at home but has not self-administered to relieve their symptoms due to a misunderstanding of when the medication should be used. EMS are then contacted for assistance due to the patient's distress – a common reason for EMS and palliative situation intersection. (10,31) In this case, EMS should be empowered to assist the patient in the self-administration of the oral morphine without subsequent conveyance to a medical facility should the symptoms be relieved. This approach may allow some patients to be safely treated in the setting of their choice, which is frequently home, (41,128) and prevent unnecessary costs to both the patient and healthcare system through avoidance of unnecessary conveyance (Chapter 5).

Educational approaches facilitating EMS and palliative care integration are the most frequently emphasized in the literature (5,75,79,110) and were, likewise, the most frequently highlighted approaches in the present study. EMS undergraduate training in basic palliative care has been recommended both internationally (180) and in SA. (162) In Australia, for example, Juhrmann et al. (180) recommended this as an approach to facilitate cultural change within the EMS from a curative approach to care to one which recognises patients with supportive needs in different contexts. A study interviewing SA patients and family members in palliative situations reasoned this EMS cultural change is necessary to provide the person-centred care required in palliative situations (Chapter 7). Furthermore, this study argued a cultural change to a person-centred approach would be beneficial in emergency care scenarios, not only palliative situations. However, cultural change will not arise from simply receiving palliative care training. Rather, palliative care principles should be embedded in the approach to care for all patients. For example, incorporating the palliative care principle of improving quality of life in a holistic manner to the EMS mindset would be beneficial in both palliative and emergency situations. We concur with Juhrmann et al. (180) that undergraduate EMS training in palliative care should not detract from the EMS emergency response function, but rather enhance it. Such training should not be aimed at producing 'paramedic palliative care providers', but rather producing a cultural shift to person-centred care which would enhance both emergency and palliative care provision.

Spreading awareness of palliative care among EMS and other healthcare providers, represents a simple, low-cost approach to integrating EMS and palliative care systems. One

area in which EMS providers require assistance is identifying palliative situations. (108,130) Due to their training, EMS providers tend to view all cases to which they are called from an emergency perspective and, by their own admission, are often not aware of alternative approaches. (16) Thus, by simply spreading awareness of an alternative (palliative) approach, EMS recognition of palliative situations may be improved. This may be done through CPD training, dissemination of EMS and palliative care research, inclusion of EMS in palliative care conferences, meetings, strategic planning sessions and *vice versa*. We recommend each of these opportunities for awareness be explored and further innovations be developed.

Whilst we recommend these highly impactful and feasible approaches, it should be recognized that even within SA, varying contexts exists between provinces and regions as some areas contain greater EMS and palliative care resources than others. (147,182,183) Thus, the feasibility of these approaches will likely vary dependent on area. This may explain much of the variance in feasibility scores awarded by participants in this study as they function in diverse contexts with differing resource availability and community requirements (see approaches with SD > 0.75). As a result, there is a need for flexibility in the application of these approaches within SA. From our findings, we suggest there is no 'one-size-fits-all' approach to EMS and palliative care integration in SA, but rather unique priorities may develop in various contexts. This is potentially counter-intuitive to the current EMS system which tends to apply a 'one-size-fits-all' approach, applying curative care principles regardless of situation type (Chapter 7). However, while unique priorities may develop, the categories of approaches presented here remain a reasonable starting point. Interestingly, no approaches were ranked as having low impact. Thus, each approach developed here may be beneficial and should be considered cross-contextually.

While discussing the integration of EMS and palliative care, participants highlighted the need for true collaboration and cautioned against palliative care services simply "*passing on their work"* to EMS. SA EMS providers have likewise cautioned against performing palliative care in isolation as it is not their primary role. (16) While integration between the services is necessary, the need to establish clear roles and boundaries is an important consideration (184) and has been highlighted in health system integration literature. (185,186) Future research is necessary to identify these roles and boundaries in various SA settings. Along with SA EMS and palliative care providers, (16,162) we suggest the EMS role in palliative situations is to identify palliative care needs, provide initial containment, and link patients with palliative care providers. (46) Additionally, EMS and palliative care integration should not be viewed as a *panacea*, but rather as part of an approach to improve palliative care provision in the country. (184) Thus, as suggested by participants, ongoing research into EMS and palliative care integration must be performed to monitor its safety, efficacy, and unintended consequences.

Our findings align with the WHO IPCHS strategy which recommends empowering and engaging people, strengthening governance and accountability, reorienting the model of care, and co-ordinating services. (111) These recommendations have been made while taking country development status and community needs into account and are aimed at creating an enabling environment for health system integration. (111) This further aligns with CAS theory which views health system integration as emerging through self-organization rather than central control. (187) Thus, rather than enforcing integration, broad guiding principles to foster a positive environment for integration are recommended. (177,188) According to a CAS approach, 'top-down' controls stifle creativity and negatively affect a health system's ability to adapt. (177,188) This approach is pertinent in the SA setting. The need for health system adaptation to the increasing prevalence of NCDs and the growing need for palliative care is apparent. Furthermore, given the diverse contexts present within SA, a central control approach to EMS and palliative care would be futile, whereas applying the findings of the present study as guiding principles would encourage integration cross-contextually.

Limitations

This study contains limitations involving generalisability as a purposive sampling strategy was employed, resulting in a small group of participants largely from two provinces within SA. However, these participants work in diverse contexts within their provinces in both private and state sectors, including higher education, management, and patient-facing roles. While experts from other provinces were unable to take part due to scheduling constraints, the high proportion of participants from the Gauteng and Western Cape provinces are reflective of the greater EMS and palliative care resources in these areas. (182,183) Study findings, including these contextual differences, have been discussed considering previous local and international research. Researcher bias may be present as the meeting facilitator may have unintentionally influenced the group discussion through subconscious demonstration of personal opinions. However, researcher triangulation and member checking were performed to limit this bias. Finally, this study placed time constraints on participants and, thus, the findings of this study may not be comprehensive. However, these findings align well with health system integration literature, represent the considerations of highly experienced SA providers, and therefore, remain applicable.

Conclusion

Through use of a nominal group, consisting of experts from both EMS and palliative care, this study aimed to develop and prioritise approaches facilitating EMS and palliative care system integration within SA, thereby providing guidance for implementation in the country. We recommend the following highest ranked approaches as a practical starting point for EMS and palliative care integration in the country: 1) Enable EMS to administer already prescribed medications, 2) EMS undergraduate training in palliative care, 3) Improve EMS recognition of signs of dying at the end-of-life, 4) Palliative care awareness for the EMS community, 5) Palliative care awareness for in-hospital healthcare providers, particularly those in emergency medicine. These approaches represent high impact, low-cost interventions which are appropriate in the LMIC setting of SA. Future research should aim at establishing the safety and efficacy of these interventions.

Section 4 Overview

Additional Considerations

The findings presented in this section provide a roadmap for the integration of EMS and palliative care in SA with a prioritised list of implementable approaches. Although these approaches have been developed in the SA setting, they compare well with the body of literature concerning health system integration frameworks. As a result, these approaches may have applications outside of SA, particularly in other LMICs with similar resource constraints. Future international research on this topic may benefit from considering the findings within this thesis. This is in line with the 1990 Commission on Health Research for Development, mentioned in Chapter 3, which notes that LMIC research may strengthen healthcare even in HICs. (102)

While elements of the NGT findings presented here may be internationally applicable to varying degrees, local context remains an important variable even within SA. As reflected upon in Chapter 2, the original approach to the NGT was to develop solutions to the problem of segregated EMS and palliative care. However, based on contextual differences between regions within SA, noted in the palliative care provider interviews (162) and the NGT, a need for flexibility exists when considering the approach to EMS and palliative care integration. Thus, a CAS view of healthcare systems was adopted for the NGT resulting in a changed approach which allowed for flexibility. Rather than developing generalised 'solutions' which are likely to fail in a CAS model, the new approach took local context into account and focussed on fostering a positive environment for integration. This is discussed in greater detail in Chapter 9.

The NGT contributes to the conceptual framework presented in the next section through the categorisation of approaches for EMS and palliative care integration. These categories, which encompass integration approaches from all previous studies in this thesis, are all included in the conceptual framework presented in the next chapter.

Section 4 Summary

Key Messages:

- The role of EMS in palliative situations is not to perform palliative care in isolation, but rather to be part of the broader palliative care team.
- Approaches to EMS and palliative care integration, as developed in the NGT, provide guidance for this integration in the country with the highest ranked approaches representing a logical starting point.
- Local contextual factors, such as available resources and community needs, are important to consider when integrating EMS and palliative care services.
- Healthcare system integration literature emphasises the importance of shared goals between integrated services within a local context.
- Flexibility in the approach to integration is required based on local contextual factors.
- The WHO IPCHS provides strategic directions for a person-centred approach to integrated care which are applicable to EMS and palliative care integration and align with the findings from this thesis.
- Given the diverse contexts present within SA and according to the CAS theory discussed in this section, a central control approach to enforce EMS and palliative care integration would be futile, whereas applying NGT findings as guiding principles would encourage integration cross-contextually.
- Integrative approaches suggested in this study: Awareness, Community Engagement, Education, Funding, Governance, Policy Development, Communication and Information Sharing, Stakeholder Collaborations, Need for Future Research, Alternative Pathways and Approaches.

Table 16 Evidence gaps addressed in Section 4

Evidence Gaps Include:	Addressed in this Section:
Map of current EMS and palliative care literature.	Scoping Literature Review (Chapter 3)
Extent of intersection between EMS and palliative situations.	Retrospective Chart Review– Clinical Analysis (Chapter 4)
Clinical reasons for EMS use in palliative situations.	Retrospective Chart Review – Clinical Analysis (Chapter 4)
Practical reasons for EMS use in palliative situations.	Retrospective Chart Review – Spatio-temporal Analysis (Chapter 5)
Palliative care provider perspectives on the use of EMS in palliative situations.	Palliative Care Provider Interviews (Chapter 6)
Patient and family member perspectives on the use of EMS in palliative situations.	Patient and Family Member Interviews (Chapter 7)
Patient and family member reasons for EMS use in palliative situations.	Patient and Family Member Interviews (Chapter 7)

Development and prioritisation of implementable approaches to EMS and palliative care integration.	Nominal Group Technique (Chapter 8)
Role of EMS in palliative situations.	Scoping Literature Review (Chapter 3), Retrospective Chart Review (Chapters 4 and 5), Palliative Care Provider Interviews (Chapter 6), Patient and Family Member Interviews (Chapter 7), Nominal Group Technique (Chapter 8)

Evidence gaps addressed in this section and their corresponding studies are highlighted in green.
Evidence gaps previously addressed and their corresponding studies are highlighted in turquoise.
EMS=Emergency Medical Services

Table 17 Summary of key findings concerning evidence gaps

Evidence Gaps Addressed	Key Findings
Map of current EMS and palliative care literature.	- Lack of LMIC literature. - EMS and palliative care integration recommended cross-contextually. - Further research required includes: EMS and palliative care intersection, reasons for EMS use in palliative situations, stakeholder perspectives on EMS (particularly patients and family members), approach and prioritisation of EMS and palliative care integration, role of EMS in palliative situations.
Extent of intersection between EMS and palliative situations.	- Apparently substantial intersection with an average of 41 cases/month with the inclusion of just two studied hospitals.
Clinical reasons for EMS use in palliative situations.	- Management of distressing symptoms. - Dyspnoea and pain the most common symptoms. - Cancer and Renal disease (NCDs) the most common diagnoses.
Practical reasons for EMS use in palliative situations.	- Improved access to palliative care services. - Transportation and mobility assistance. - Homecare provision.
Palliative care provider perspectives on the use of EMS in palliative situations.	- Overall positive due to EMS capabilities and calming effect, however, concerns regarding unreliability persist. - EMS and palliative care integration should be pursued.
Patient and family member perspectives on the use of EMS in palliative situations.	- Overall positive as EMS providers were generally kind and compassionate. - EMS care was viewed positively when situational control was regained and transferred to patients and family members and negatively when further control was seized.
Patient and family member reasons for EMS use in palliative situations.	- Overarching desire: person-centred care which EMS were able to demonstrate in many instances. - Readily available 24/7 resource. - EMS ability to regain situational control. - Symptom management. - Palliative emergencies. - Mobility assistance both within the home and in terms of conveyance.

	- Homecare (i.e. minor procedures without conveyance). - Caregiver distress.
Development and prioritisation of implementable approaches to EMS and palliative care integration.	- Implementable approaches in rank order from highest to lowest: Awareness, Education, Community Engagement, Communication and Information Sharing, Stakeholder Collaborations, Alternative Pathways and Approaches, Research, Funding, Policy Development, Governance. - These approaches align with the WHO IPCHS strategic directions: empowering and engaging people, strengthening governance and accountability, reorienting the model of care, and co-ordinating services. (111)
Role of EMS in palliative situations.	- To identify palliative care needs, provide initial containment (i.e. symptom management), and link patients with palliative care providers thereby improving access to palliative care.

EMS=Emergency Medical Services, LMIC=Low-to-Middle Income Country, NCD=Non-Communicable Disease, WHO=World Health Organisation, IPCHS=Integrated People-Centred Health Services

Section 5: A Conceptual Framework for Emergency Medical Services and Palliative Care Integration

Section Introduction

Section 5 presents the conceptual framework for EMS and palliative care integration in SA which is based on the findings from all previous studies conducted in this thesis. The development of this novel framework, and its individual components, is outlined and linked to the findings from the previous studies.

This section consists of the following sub-sections:

- Chapter 9: A Conceptual Framework for the Integration of Palliative Care and Emergency Medical Services in South Africa
- Section 5 Overview

This section concludes with an overview including key messages and how these contribute to the thesis in its entirety.

Chapter 9: A Conceptual Framework for the Integration of Palliative Care and Emergency Medical Services in South Africa

Chapter Introduction

This chapter presents a novel conceptual framework for EMS and palliative care integration (CFEPI) in SA developed from the research findings of Sections 1-4. Based on these findings and considerations thereof, the CFEPI presented in this chapter is composed of CAS Theory, the WHO IPCHS strategic directions, *local context, person-centred care*, and the following categories of integrative approaches: *awareness, community engagement, education, funding, governance, policy development, communication and information sharing, stakeholder collaborations, research, alternative pathways and approaches*. Figure 11 depicts the CFEPI. The methodology through which this framework was developed is discussed including the derivation of each framework element from the research. Each element is then individually defined and described in detail. This is followed by an examination of the rationales behind each element and their applicability to the CFEPI. Finally, the priorities of EMS and pallative care integration methods are identified based on feasibility, and practical guidance for CFEPI implementation provided.

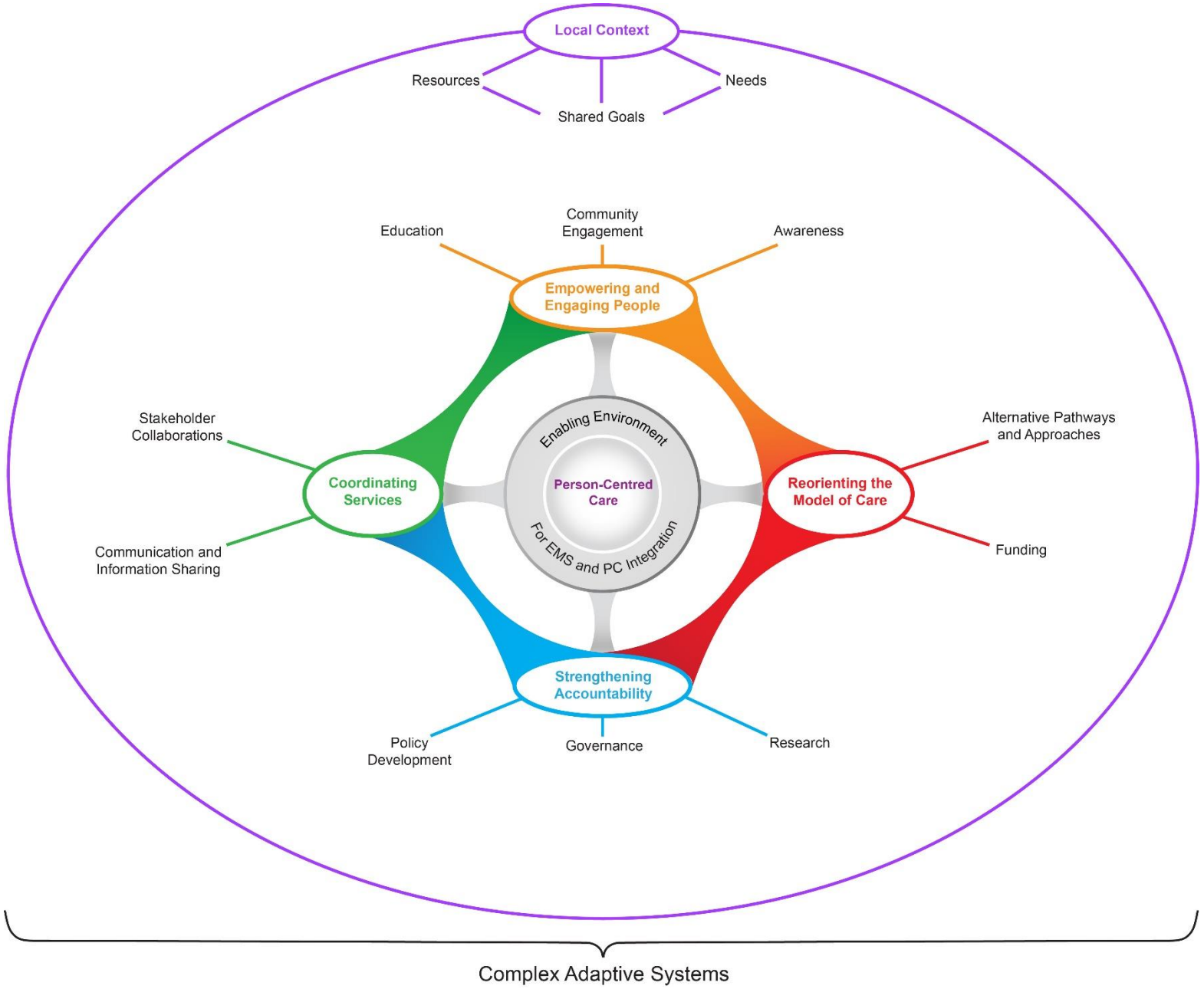


Figure 11 A Conceptual Framework for EMS and Palliative Care (PC) Integration (CFEPI) in South Africa

Methodology of CFEPI Construction

Derivation of Key Framework Elements

From the scoping literature review (Chapter 3), various recommendations for EMS and palliative care integration were noted: *education, stakeholder collaborations, policy development, alternative pathways and approaches*, and *research*. (110) In addition, the importance of research and integratve efforts within differing *local contexts* was highlighted as available resources and community needs may differ. (110) The importance of *local context* was again noted in the retrospective chart review study (Chapters 4 and 5) which produced quantitative data within the context of SA needs and resources. (130) Furthermore, this study re-enforced the integrative recommendations noted in the scoping review. (110,130) For example, as EMS providers encounter the common symptoms of dyspnoea and pain, they require *education* concerning the management of these symptoms in palliative situations as it may differ from their typical emergency management. (130) An additional integrative recommendation suggested in the retrospective chart review study was *communication and information sharing* as this may benefit EMS providers in identifying palliative situations. (130)

From the persepctives of palliative care providers (Chapter 6) and patients and family members with palliative needs (Chapter 7), the above categories of integrative approaches were again suggested with the addition of two further categories: *awareness* and *community engagement.* (162) The importance of *local context* was again identified as both palliative care providers, patients and family members resided in areas with varying resource constraints and needs. (162) In addition, the need for *person-centred care* became evident from these interview studies. (162) This need was discussed in view of the *WHO IPCHS* (111) in Chapters 7 and 8 which is an approach for both integrated and person-centred care which this thesis aimed to achieve. (162)

The expert panel in the NGT study (Chapter 8) developed two further categories for EMS and palliative care integration: *funding* and *governance*. Specific recommendations falling into these categories, as well as the categories from the previous studies, were likewise developed. For example, under *governance*, a specific recommendation was to *"establish EMS palliative care case reviews and debriefing sessions for quality improvement."* The NGT study was underpinned by a *CAS theory* (176) of healthcare systems.

CFEPI Construction

To fulfil the aim of this thesis, the CFEPI was developed in the following phases: 1) Review of relevant literature, 2) Inductive identification and categorisation of integrative approaches, 3) Deductive mapping of integrative categories into an existing framework and theory, 4) Synthesis of key elements and development of framework structure, and 5) Iterative refinement. These phases are consistent with those commonly used and recommended in conceptual framework development. (170,189–191)

The review of relevant literature was performed through the scoping literature review of Chapter 3. Each study in this review identified approaches for the integration of EMS and palliative care. (110) Further integrative approaches were identified in the subsequent studies of this thesis (Chapters 4-8). These approaches were organised into broader categories and these categories were finalised in the NGT study (Chapter 8). For example, approaches such as improving EMS understanding of signs of dying at the EoL and providing EMS training in subcutaneous medication administration were organised under the category of education. The identified categories of integrative approaches were then mapped into an applicable existing framework (WHO IPCHS) and underlying theory of healthcare systems (CAS theory). Having identified the key elements of the CFEPI, including the existing framework and theory, these elements were then synthesised to develop the structure of the CFEPI as visualised in Figure 11. Through a process of iterative refinement, making use of researcher triangulation among the research team, the CFEPI was finalised. The rationale behind selection of the WHO IPCHS and CAS theory as well as the synthesis of CFEPI key elements is described in detail below beginning with person-centred care which was identified as the essential purpose of the CFEPI.

Person-Centred Care

Description

Within the CFEPI, as in Chapter 7, person-centred care is defined as *"an approach that consciously adopts the perspectives of individuals, families and communities, respects and responds to their needs, values, and preferences, and sees them as participants in their own healthcare rather than just beneficiaries."* (159) Although the term 'patient-centred care' is frequently used to convey a similar concept, the term 'person-centred' has been employed here as it better captures a holistic view of personhood rather than potentially viewing a person as simply a patient. (192) The term 'people-centred care' likewise captures this holistic view. (159) Person-centred care is a critical component of high-quality healthcare. (159,193) The

WHO suggests person-centred care is a core-competency for healthcare providers and is fundamental to achieving its Universal Health Coverage (UHC) goals. (194,195)

Rationale and Applicability to the CFEPI

Person-centred care is the ultimate goal of EMS and palliative care integration as it is a necessary approach for those with complex healthcare needs. (159) Therefore, this component is the 'bullseye' in the middle of the CFEPI resulting from creation of an enabling environment for EMS and palliative care integration. The focus on person-centred care in this CFEPI stems from the very purpose of palliative care, (9) the problems with EMS and palliative care segregation (Chapters 1 and 3), (11,20,28) the patient and family member interview study (Chapter 7), and the author's personal beliefs (Chapter 2).

Palliative care seeks to provide holistic, person-centred care in the context of life-threatening illness to improve both patient and family quality of life. (9) As discussed in Chapter 7, person-centred care is particularly suited to palliative situations due to severity of illness, multiplicity of involved persons, and subsequent complex needs. (159) It is clear from Chapter 7 that patients and family members with palliative needs deeply desire to be treated as persons. However, where EMS and palliative care remain segregated, EMS often fail to provide this care in palliative situations through disregard of patient autonomy and performance of aggressive, futile interventions often due to a lack of alternative care pathways. (16) To correct this, EMS and palliative care integration must have a focus on person-centred care. This, in turn, will allow for the creation of what may be described as 'person-centred care pathways.' As true palliative care and person-centred care are inseparable, this focus is natural. This focus further aligns with the author's personal beliefs concerning healthcare (i.e. all healthcare should fundamentally be person-centred) as reflected upon in Chapter 2.

The definition of person-centred care presented here encompasses the idea of 'users as co-producers' of healthcare. In other words, those who use healthcare services should be involved in the designing, delivering, and monitoring of these services. Such an approach would greatly assist in fulfilling the palliative need for situational control as described in Chapter 7 as the "Dynamic of Control." The 'users as co-producers' approach is employed in the WHO IPCHS under the strategic direction of "Empowering and Engaging People" which the "Dynamic of Control" supports. (111)

World Health Organization Global Strategy for Integrated People-Centred Health Services

Description

The WHO IPCHS was developed in response to the challenges experienced by health systems faced with the changing patient landscape referenced throughout this thesis. (194) As the WHO states, *"Populations are living longer and the burden of costly long-term chronic conditions and preventable illnesses that require multiple complex interventions over many years continues to grow."* (194) According to the WHO, a people-centred, integrated healthcare system approach is required to meet these challenges, otherwise healthcare will become unsustainable. (194)

The five strategic directions recommended by the WHO IPCHS to achieve integrated, people-centred healthcare are: 1) Empowering and Engaging People, 2) Strengthening Governance and Accountability, 3) Reorienting the Model of Care, 4) Coordinating Services, 5) Creating and Enabling Environment. (111) These strategic directions are interdependent and, therefore, should be simultaneously pursued. (111) However, to what extent and in which ways each of these strategic directions are pursued is dependent on local context as likewise indicated in the CFEPI. (111)

Rationale and Applicability to the CFEPI

The aim of this thesis was to develop an integrative framework for EMS and palliative care in SA (Chapter 1) which has been achieved in the CFEPI development. During the research performed in this thesis, it became evident a person-centred approach to care was needed for patients and family members with palliative needs (see Chapters 6 and 7). (162) As the WHO IPCHS is both an integrative and person-centred approach, it forms the skeleton of the conceptual framework, providing strategic direction for EMS and palliative care integration. (111) The strategic directions contained in the WHO IPCHS align well with the integrative approaches recommended in this thesis. Furthermore, the IPCHS is well aligned with CAS theory as described below. (111,176)

Empowering and Engaging People refers primarily to providing healthcare users and communities with the tools and skills to make effective decisions concerning their health and collaborate with the health sector to contribute to health policy. (111) As with CAS theory, person-centred care, and findings concerning the "Dynamic of Control" (Chapter 7), this involves the concept of users as co-producers. (111,159,176) Within the CFEPI this category has been expanded to include all primary stakeholders involved in EMS and palliative care

integration: EMS and palliative care providers, patients and family members with palliative needs. Based on the findings in this thesis, each of these stakeholders requires empowerment and engagement for effective integration (Chapter 7). (16,162) For example, education, which is part of Empowering and Engaging People in the IPCHS, (111) has been recommended for each of these stakeholder groups (Chapter 7). (16,162)

Strengthening Governance and Accountability refers to improving transparency in decision-making and developing systems which allow for healthcare providers and managers to be held accountable. (111) This may be done at all levels of a healthcare system: macro, meso, micro. An example within the CFEPI is *policy development* which would develop guidelines allowing for improved accountability. Within the CFEPI, this strategic direction has been simply named "Strengthening Accountability" to avoid duplication as one of the integrative categories developed in the NGT (Chapter 8) was *governance.*

Reorienting the Model of Care refers to a shift from in-patient to out-patient care including the need for holistic and integrated care maximising scarce resources. (111) This is particularly useful in the LMIC context of SA. An example of how this may be achieved is through EMS use to provide care in patient homes. EMS may link patients to a palliative care service without subsequent conveyance to a medical facility as discussed in Sections 2 and 3. (130,162)

Coordinating Services refers to promoting activities which encourage integration amongst various healthcare and allied sectors to overcome healthcare system fragmentation. (111) For the purposes of the CFEPI presented here this involves EMS and palliative care services which may be integrated through various collaborations.

Creating an Enabling Environment may be achieved through pursuit of the previous four strategic directions. However, creation of this environment is a strategic direction itself, and, where this environment is developed it may likewise enhance the other strategic directions. (111) For example, where incentives promoting EMS and palliative care integration are created within a local context, the pursuit of Reorienting the Model of Care may be enhanced.

The WHO IPCHS is both an integrative and person-centred framework (111,194) designed to meet the same challenges faced by EMS and palliative care services in terms of a changing patient landscape. Furthermore, the IPCHS aligns with CAS Theory, (111,176) and its strategic directions may be achieved by the approaches for EMS and palliative care integration developed in this thesis. Thus, the IPCHS represents an appropriate strategy on which to base the CFEPI created in this thesis.

Categories of Integrative Approaches

Description

Throughout this thesis various recommendations for integrating EMS and palliative care have been made. The categories of integrative approaches included in the CFEPI encompass these recommendations. For example, the category *education* contains a specific recommendation for *"EMS undergraduate training in palliative care."* (Chapter 8) These approaches are used to pursue the strategic directions derived from the WHO IPCHS. (111)

Rationale and Applicability to the CFEPI

Although finalised in the NGT study (Chapter 8), the categories of integrative approaches presented here developed throughout the thesis as demonstrated in Table 18.

Table 18 Category development throughout the thesis

Integrative Approach Category	Study (Chapter)
Awareness	- Palliative Care Provider Interviews (Chapter 6) - Patient and Family Member Interviews (Chapter 7) - NGT (Chapter 8)
Community Engagement	- Palliative Care Provider Interviews (Chapter 6) - Patient and Family Member Interviews (Chapter 7) - NGT (Chapter 8)
Education	- Scoping Literature Review (Chapter 3) - Retrospective Chart Review (Chapters 4 and 5) - Palliative Care Provider Interviews (Chapter 6) - Patient and Family Member Interviews (Chapter 7) - NGT (Chapter 8)
Funding	- NGT (Chapter 8)
Governance	- NGT (Chapter 8)
Policy Development	- Scoping Literature Review (Chapter 3) - NGT (Chapter 8)
Communication and Information Sharing	- Retrospective Chart Review (Chapters 4 and 5) - Palliative Care Provider Interviews (Chapter 6) - Patient and Family Member Interviews (Chapter 7) - NGT (Chapter 8)
Stakeholder Collaborations	- Scoping Literature Review (Chapter 3) - Retrospective Chart Review (Chapters 4 and 5) - Palliative Care Provider Interviews (Chapter 6) - Patient and Family Member Interviews (Chapter 7) - NGT (Chapter 8)
Research	- Scoping Literature Review (Chapter 3) - Retrospective Chart Review (Chapters 4 and 5) - Palliative Care Provider Interviews (Chapter 6) - Patient and Family Member Interviews (Chapter 7) - NGT (Chapter 8)
Alternative Pathways and Approaches	- Scoping Literature Review (Chapter 3) - Palliative Care Provider Interviews (Chapter 6) - Patient and Family Member Interviews (Chapter 7) - NGT (Chapter 8)

NGT=Nominal Group Technique

These recommendations may likewise be categorised according to level of integration as demonstrated in Table 19. This table also indicates the feasibility of each recommendation based on scores given by the expert panel in the NGT study (Chapter 8) to assist in the implementation of the CFEPI.

Table 19 Implementation guide based on feasibility of approaches

		Macro	Meso	Micro
Empowering and Engaging People	**Awareness**			- Palliative care awareness for the EMS community. - Palliative care awareness for in-hospital healthcare providers, particularly those in emergency medicine.
	Education		- EMS undergraduate training in palliative care. - Post-graduate palliative care training for EMS educators. - Ongoing education in palliative care for EMS such as Continual Professional Development (CPD) training. - EMS palliative care curriculum development. - Post-graduate palliative care training for EMS providers. - Include EMS in inter-disciplinary palliative care education.	- Improve EMS recognition of signs of dying at the end-of-life. - Improve EMS understanding of palliative care – including legal and ethical implications, DNRs, ACPs, qualification levels. - EMS training in subcutaneous medication administration. - Train EMS in patient and family member communication. - Enable early EMS recognition of palliative cases.
	Community Engagement		- 24/7 availability of palliative care contacts for patients and family members.	- Engage community concerning specific palliative care needs. - Provide palliative care awareness and education for the public.
Coordinating Services	**Communication and Information Sharing**		- Provide palliative care advice for EMS at the point of care. - Provide support for EMS to fulfil advance care plans by including information (instructions, contact details) specific to EMS in the plans. - Establish cross-disciplinary communication and information-sharing with EMS, palliative care, in-hospital providers. - Include EMS within advance care plans. - Make advance care plans available for EMS at the point of care.	
	Stakeholder Collaborations	- EMS and palliative care decision-maker collaboration at a national level.	- Develop EMS palliative care networking teams. - Develop palliative care committees inclusive of EMS, hospice and in-hospital management at all levels of care.	- Collaboration between EMS and palliative care societies. - EMS and palliative care networking with locally available resources. - Have EMS providers spend time in palliative care practices.
Reorienting the Model of Care	**Alternative Pathways and Approaches**	- Enable EMS to administer already prescribed medications. - Develop mechanisms for EMS to handover patient care in palliative situations to family members. - Develop an EMS community care approach.	- Develop palliative care teams at hospital level to identify patients with palliative needs. - Develop EMS support tools to assist in the identification of patients with previously unrecognized palliative needs. - Define processes for EMS linking palliative situations with outpatient services, community healthcare, and community oriented primary care.	

			- Develop care packages for EMS in palliative situations based upon scope of practice. - Define alternative care pathways for EMS in palliative situations. - Create specialist out-of-hospital palliative care teams inclusive of EMS and/or non-EMS staff. - Develop telehealth systems for patients, family members, and EMS.	
	Funding	- Allocate finances for EMS in palliative care in the public sector.	- Adjust private sector EMS funding models relating to medical insurance. - Allocate budget for palliative care within EMS – education, policy and guideline development, service provision.	
Strengthening Accountability	**Governance**	- Recognize palliative care trained EMS providers. - Provide legal and ethical support for EMS in palliative situations. - Improve EMS scope of practice for EMS at the Health Professions Council of South Africa (HPCSA). - Register advanced EMS providers in palliative care at HPCSA.	- Establish EMS palliative care case reviews and debriefing sessions for quality improvement.	
	Policy Development	- Develop policies for EMS medication administration in palliative situations. - Include EMS in palliative care policies to link services and prioritise palliative care cases. - Develop policies for EMS to independently prescribe medications.	- Develop guidelines and standard operating procedures for EMS at the point of care – including who to contact for advice.	
	Research	- Develop a model for EMS and palliative care integration at various healthcare system levels and within various EMS environments. - Perform ongoing EMS and palliative care research concerning efficacy of integration.	- Perform EMS and palliative care integration cost-benefit analyses.	

Key: High Feasibility Moderate Feasibility Low Feasibility

Notes: High feasibility approaches are those which may be easier to achieve and less resource intensive. Lower feasibility approaches indicate a greater degree of difficulty. Feasibility rankings are based on average scores from the expert panel in Chapter 8, however, readers are encouraged to prioritise items based on their own local contexts. EMS=Emergency Medical Services, DNR=Do Not Resuscitate, ACP=Advance Care Plan

Local Context

Description

Local context refers to the area in which EMS and palliative care integration is desired. From the findings of this thesis, important contextual factors to be considered when integrating these services are needs, resources and shared goals. Needs refer to local community requirements as well as healthcare system requirements which may vary among regions. For example, needs may differ in urban, peri-urban, and rural locales (Chapter 5). Resources refer to available EMS and palliative care services, finances, infrastructure, human resources, and any other resources which may be required to integrate EMS and palliative care within a local context. Shared goals refer to common outcomes and a common vision for EMS and palliative care integration among EMS and palliative care providers and the community they serve. These goals are informed by community needs and available resources and will vary cross-contextually.

Rationale and Applicability to the CFEPI

The importance of EMS and palliative care integration being performed within a local context has been emphasised in each study within this thesis specifically concerning needs and resources. (110,130,162) Chapter 3 discussed differing contexts amongst countries, namely LMICs and HICs. (110) Similarly, the WHO IPCHS takes country status into account when discussing its strategic directions. (111) Chapters 4 and 5 demonstrated, quantitatively, palliative care needs within particular SA contexts. (130) Chapters 6 and 7 indicated the importance of considering local contextual needs as palliative care providers, patients and family members maintained varying needs and available resources. (162) Finally, in Chapter 8, the expert panel recognised the diverse contexts present within various parts of SA. Thus, within the present CFEPI, “Local Context” encircles the integrative approaches and strategic directions as EMS and palliative care cannot integrate apart from local contextual factors.

In addition to resources and needs within a local context, the CFEPI includes “Shared Goals”. This was included as a consideration from CAS Theory (176) and healthcare system integration literature. (170) A CAS approach to integration requires a purpose as integration is not a goal in itself. (176) Healthcare system integration literature highlights that integration requires shared goals among stakeholders to succeed. (170) Additionally, the considerations of local context contained within the CFEPI align with the comprehensive conceptual framework of context developed by Squires et al. which highlights the importance of needs and resources and their influence upon interventions within a healthcare system. (191)

Complex Adaptive Systems Theory

Description

Derived from complexity science, (176) CAS theory views healthcare systems as open, self-organizing systems consisting of multiple agents with complex interactions analogous to living organisms which constantly adapt to change. (176,196,197) As a result, healthcare systems change, heal, renew, and adjust naturally, often in novel, unpredictable and non-linear ways. (176,196) This theory diverges from the historical view of healthcare systems as machines composed of siloed parts which function together to form a whole. (176) In the machine view, parts are ordered, cause and effect relationships are predictable and healthcare systems may be managed through a top-down approach to achieve specific goals. (176) A CAS view, on the other hand, suggests healthcare systems are too complex for such predictability as they contain myriad interacting variables. (176,177,198) It is, therefore, impossible to design optimal systems *a priori* and control these systems from the top down. (177) Rather than managing healthcare systems through central control, CAS theory approaches these systems through basic guiding principles based on observed behavioural patterns. (177,199) As stated by Edgren and Barnard, *"The value of the CAS approach is that it seeks to manage the whole as a set of interacting parts instead of the efficient management of separate entities."* (176) Table 20 summarises CAS characteristics.

Table 20 CAS Characteristics (198)

1) Contextual	Multiple context dependent roles and identities exist within the system.
2) Open	Systems are nested within other systems with often ill-defined and overlapping boundaries, allowing potentially far-reaching interactions and consequences.
3) Relational	A network of diverse components exists within the system. Some may be redundant. Hierarchies may be present.
4) Dynamic	There exist periods of increased and decreased change with non-linear interactions amongst components. Multiple potential trajectories are possible.
5) Adaptive	Systems are self-organizing and continually evolving based on various contextual factors.
6) Emergent	System behaviours emerge from complex cause and effect interactions: similar conditions can result in differing outcomes, small inputs may produce large effects, any interventions will result in unintended consequences.

Rationale and Applicability to the CFEPI

It is this CAS theory which underpins the CFEPI developed in this thesis as it is the perspective from which healthcare systems are viewed. This theory likewise underpinned the NGT study

as described in Chapter 8. CAS theory is integral to the CFEPI as it is applicable to the real-world problems under discussion, is beneficial in healthcare system integration, (170) and links with the WHO IPCHS global strategy. (111)

The value of CAS theory may be seen in the real-world. For example, as the WHO has noted shifting epidemiological trends in the global population toward NCDs, healthcare systems have been forced to adapt to the changing patient landscape. (143) Perhaps the most noticeable feature of this adaptation has been the healthcare system trend towards integrated healthcare to meet the many and complex needs of those suffering from NCDs. (143,162,177) The WHO has recognized the complexity of these needs in its recommendation for improved palliative care access for those with NCDs. (143) To improve palliative care access, integration with other services has been recommended. (114) This adaptation towards integrated care is logical as complex needs cannot be effectively met through simple healthcare machines with siloed systems. Complex needs require integrated care.

Such adaptation is an essential element of CAS theory (176) and may be seen in the example of EMS and palliative care. As discussed in Section 1, both EMS and palliative care services have also been forced to adapt to the changing patient landscape. (110) A specific example of this was found in the palliative care provider interviews (Chapter 6) where one participant noted the working relationship they developed with a local EMS company to manage patients with palliative needs at home. (162) This EMS and palliative care integration occurred to meet local community needs with available local resources despite a lack of formal EMS and palliative care integration in SA. (162) Thus, adaptation within both EMS and palliative care services is already naturally occurring as these services self-organise to meet changing patient needs as predicted in CAS theory.

Through use of a CAS approach, further EMS and palliative care integration may be encouraged and existing integration may be enhanced. CAS theory has been recognised in healthcare systems literature as a useful approach for integrating systems. (170,176) This literature likewise recognises the complexity of healthcare systems. (170,185,186,200) Rather than enforcing integration between systems, which negatively affects their ability to adapt, a CAS approach seeks to create an environment which promotes connectivity between services. (176,177) Thus, as noted in Chapter 8, EMS and palliative care integration was discussed in terms of fostering this positive environment rather than producing definitive solutions. Based on this discussion, the conceptual framework presented here contains a circle in the centre of the figure which reads, *"*Enabling Environment for EMS and PC Integration*".* This is the goal of the integrative approaches and strategic directions contained in the CFEPI which will result in enhanced person-centred care for those with palliative needs.

This idea of creating an enabling environment for integration is also the approach taken by the WHO in its IPCHS strategy as discussed above. (111) To promote an enabling environment for healthcare system integration according to CAS theory, several seemingly simple approaches may be applied: creating awareness of needs, sharing knowledge and information, team building, continuous learning, fostering trust. (176) These approaches are captured within the conceptual framework under the headings “Awareness”, “Communication and Information Sharing”, “Stakeholder Collaborations” and “Education.” These categories fall into the broader IPCHS strategies of “Coordinating Services” and “Empowering and Engaging People.” (111) Given the complex nature of healthcare systems, these approaches may result in complex outcomes. (198,199) Furthermore, both the CAS approach to integration and the IPCHS take local contextual needs into account and acknowledge healthcare system users as co-producers. (111,176) Integration is not an end *per se* but is rather in response to a tangible need. (176) This, along with the CAS principle of self-organization, implies integrative efforts should be flexible rather than static. (177) The level and type of integration may evolve over time with changing needs. Thus, CAS theory and the IPCHS inform the “Local Context” section of the framework including the “Needs” and “Resources,” as well as the “Person-Centred Care” core of the CFEPI.

From this discussion of CAS theory, the reflections in Chapter 2 and the NGT in Chapter 8, approaching EMS and palliative care integration through a CAS lens in SA appears both appropriate and beneficial. Patients and family members with palliative needs require complex, person-centred care which a CAS approach embraces. (162,176) As demonstrated throughout this thesis, the delivery of such complex care is inextricably linked to local contextual factors such as varying community needs and available resources. The CAS approach embraces these factors and allows for flexibility in integration based on these exigencies, promoting an enabling environment for integration as opposed to a ‘one-size-fits-all’, solution-based, top-down approach which would stifle integrative efforts. (176,177)

Practical Implementation

To practically implement the CFEPI this thesis recommends the following steps: 1) Perform a Needs Assessment, 2) Assess Available Resources, 3) Establish a Team, 4) Develop Shared Goals, 5) Develop an Integrative Approach, 6) Continual Monitoring and Adaptation. An initial evaluation of local contextual factors must be performed including a needs and available resources assessment. The needs assessment should evaluate the purpose(s) for EMS and palliative care integration and include community and healthcare system requirements within a given context. This may require an evidence review relevant to the local context as well as

community engagement. The purpose of community engagement is to *"empower communities, community leaders and community organisations to play a role in improving the equity and impact of the government, development, and humanitarian initiatives that affect them."* (201) Community engagement concerning EMS and palliative care integration within specific local contexts will empower communities to take ownership of integrative efforts. This will enhance the effectiveness of these efforts as they are tailored to relevant community needs. Just as EMS may fulfil the palliative need for situational control by transferring control to patients and family members in the care setting (see the "Dynamic of Control" in Chapter 7), so too will ownership of the integration process through community engagement fulfil this need in the very implementation of EMS and palliative care integration. To effectively engage communities regarding this integration, community awareness and education concerning EMS and palliative care will be required (Chapter 8). (16,162,201) Thus, through performing the initial step of a needs assessment, including community engagement, the implementation of the CFEPI through the strategic direction of "Empowering and Engaging People" will already be initiated.

Available resources with which to meet these needs should be assessed next including EMS and palliative care services in the area, finances, infrastructure, human resources, and any other resource which may be relevant to the identified needs. As part of this step, EMS and palliative care 'champions' may be identified to drive the integrative efforts. (7) The team developed to drive these integrative efforts should then discuss the goals of integration. Ideally, these shared goals are developed with input from, at a minimum, each group of primary stakeholders: EMS and palliative care providers, patients and family members with palliative needs. Other relevant stakeholders may be identified through use of the "7Ps Framework" developed by Concannon et al.: Patients and the Public, Providers, Purchasers, Payers, Policy Makers, Product Makers, Principal Investigators. (190) For example, other relevant stakeholders may include medical insurance companies (Payers) and HPCSA representatives (Policy Makers). Once the shared goals for integration are established, the strategic directions and integrative approaches within the CFEPI along with the practical implementation guide may be used to develop an approach to integration. The chosen approach should then be continually monitored for safety and efficacy and adapted as necessary. These steps are similar to, and adapted from, previous work by Lamba et al. (7) who suggested four steps for EMS and palliative care integration: 1) identify EMS 'champions', 2) review protocols and literature, 3) perform a needs assessment and 4) create an action plan. The CFEPI recognises the need for these steps and aims to provide strategic direction for the action plan. Table 21 provides an overview of the recommended steps. While it is not strictly necessary to perform the initial steps in the suggested order, it is recommended each of these steps are performed.

Table 21 Steps to Implement the Conceptual Framework for EMS and Palliative Care Integration

Step 1: Perform a Needs Assessment	- Establish the reason for EMS and palliative care integration. - Review relevant evidence. - Engage the local community.
Step 2: Assess Available Resources	- EMS and palliative care resources. - Human resources. - Infrastructure and finances. - Other.
Step 3: Establish a Team	- Made up of EMS and palliative care 'champions.'
Step 4: Develop Shared Goals	- Should have input from at least the primary stakeholders of EMS and palliative care providers, patients and family members with palliative needs.
Step 5: Develop an Integrative Approach	- Make use of the conceptual framework and implementation guide for integration.
Step 6: Continual Monitoring and Adaptation	- Safety and efficacy. - Adapt as required.

EMS=Emergency Medical Services

The above steps, the CFEPI and the implementation guide are designed to be used at any level, by any individual, group of individuals or organization(s) in the state or private sector, where EMS integration with palliative care has been recognised as a need. For example, an individual EMS provider who has recognised this need may begin to initiate Steps 1-3. This individual provider may perform integrative efforts with the less resource intensive approaches suggested in this guide such as creating palliative care awareness in their local EMS community. An organization such as an EMS company which has recognised this need, may choose to begin with various meso-level recommendations such as establishing cross-disciplinary communication and information-sharing with a local palliative care service. Furthermore, these tools may be used to assess which recommendations have already been implemented and what further recommendations could be applied. While this guide provides an evidence-based starting point for EMS and palliative care integration, users should adapt priorities based on their local contexts.

Conclusion

The primary aim of EMS and palliative care integration is to provide person-centred care for those with palliative needs. (41,162) Within the developed CFEPI, this is achieved through creation of an enabling environment for EMS and palliative care integration. This environment may be pursued *via* the strategic directions outlined in the WHO IPCHS. (111) These strategic

directions may be practically implemented through the categories of integrative approaches developed throughout this thesis. Each of these approaches and strategic directions must be informed by local contextual factors including specific needs, available resources and shared goals between primary stakeholders. This CFEPI is underpinned by a perspective of healthcare systems, including EMS and palliative care, as complex and adaptive in nature, self-organizing to meet arising needs. (176,196) Thus, CAS theory influences the approach to EMS and palliative care integration in this conceptual framework by suggesting integration should not be enforced, but rather encouraged where needed by creating a positive environment for integration. (176,177) The CFEPI may be practically employed at any level (macro-, meso-, micro-) and by any individual or organization in either the private or state sector recognising a need for EMS and palliative care integration. The practical implementation guide has divided specific recommendations into these various levels and indicated their feasibility based on scores given by the expert panel in the NGT study (Chapter 8) to assist in the deployment of this conceptual framework.

Section 5 Overview

Section 5 Summary

Key Messages:

- The CFEPI described in this chapter is underpinned by CAS theory and is aimed at patient-centred care, making use of the WHO IPCHS strategic directions while taking local contextual factors into account to achieve this aim.
- A guide for practical implementation of the conceptual framework has been produced.
- The CFEPI and implementation guide are designed for use at any level, by any individual, group of individuals or organization(s) where EMS integration with palliative care has been recognised as a need.
- Table 22 summarises the conceptual framework elements.

Table 22 Summary of Conceptual Framework Elements

Framework Element	Description
Person-Centred Care	- *"An approach that consciously adopts the perspectives of individuals, families and communities, respects and responds to their needs, values, and preferences, and sees them as participants in their own healthcare rather than just beneficiaries."* (159) - The primary purpose of EMS and palliative care integration.
Strategic Directions	- Gained from the WHO IPCHS (111) - Empowering and Engaging People: providing healthcare users, EMS and palliative care providers with the tools and skills to make effective decisions concerning health policy, EMS and palliative care integration. - Reorienting the Model of Care: shifting from in-patient to out-patient care including the need for holistic and integrated care maximising scarce resources. - Strengthening Accountability: improving transparency in decision-making and developing systems which allow for healthcare providers and managers to be held accountable. - Coordinating Services: activities which encourage integration amongst various healthcare and allied sectors to overcome healthcare system fragmentation. - Enabling Environment for EMS and Palliative Care Integration: achieved through pursuit of the previous four strategic directions though it is also a strategic direction itself.
Integrative Approaches	- Developed throughout the studies in this thesis. - Categories: Awareness, Community Engagement, Education, Funding, Governance, Policy Development, Communication and Information Sharing, Stakeholder Collaborations, Research, Alternative Pathways and Approaches (Chapter 8). - Used to achieve strategic directions.
Local Context	- The area in which EMS and palliative care integration is desired. - Contextual factors: needs, resources and shared goals. - Needs: local community requirements, healthcare system requirements.

	- Resources: available EMS and palliative care services, finances, infrastructure, human resources, other relevant resources. - Shared goals: common outcomes for EMS and palliative care integration.
CAS Theory	- Views healthcare systems as open, self-organizing systems consisting of multiple agents with complex interactions analogous to living organisms which constantly adapt to change. (176,177,196) - Underpins the conceptual framework.

EMS=Emergency Medical Services, WHO=World Health Organisation, IPCHS=Integrated People-Centred Health Services, CAS=Complex Adaptive Systems

Section 6: Discussion and Conclusions

Section Introduction

Section 6 discusses the thesis in its entirety. Conclusions are drawn based upon study findings and considerations presented throughout the thesis and areas for future research are presented.

This section consists of the following sub-sections:

- Chapter 10: Discussion
- Chapter 11: Conclusions

Chapter 10: Discussion

Chapter Introduction

This chapter discusses the thesis in its entirety suggesting implications for practice, identifying areas for future research and noting limitations. The aim of this thesis was to develop a framework for the integration of palliative care and EMS systems in SA. This was achieved through the following objectives, each of which represented a separate study culminating in the CFEPI:

1. To review existing literature concerning the intersection of palliative care and EMS (Scoping Literature Review – Chapter 3).

2. To examine EMS use for palliative situations in SA (Retrospective Chart Review Study – Chapters 4 and 5).

3. To gather the perspectives of palliative care providers on EMS use in palliative care in SA (Qualitative Individual Interview Study – Chapter 6).

4. To gather perspectives of SA patients and family members with palliative needs concerning EMS use in their care (Qualitative Individual Interview Study – Chapter 7).

5. To develop and prioritise approaches facilitating EMS and palliative care system integration within SA (NGT Study – Chapter 8).

Several of these studies represent novel and important contributions to the EMS and palliative care literature internationally. The scoping literature review is the broadest to be conducted on the topic. (110) The spatio-temporal analysis within the retrospective chart review study as well as the NGT are the first of their kind globally concerning EMS and palliative care. The perspectives of palliative care providers, patients and family members are under-researched (110) and, therefore, these studies strengthen this portion of the literature. Finally, each of these studies are unique within LMICs, contributing the first body of literature on this topic in these contexts.

Each of the aforementioned studies, apart from the retrospective chart review study, are also unique in the SA setting. An additional retrospective chart review was recently performed by Linley et al. (202) in which findings were similar to those found in this thesis. For example, Linley et al. (202) found frequent intersection between EMS and palliative situations involving NCDs with dyspnoea (43%, n=81) and pain (35%, n=66) the most frequent symptoms for which EMS were called. Thus, the findings of Linley, et al. corroborate results from this thesis (130) and likewise represent an important contribution to the literature. Furthermore, the study by

Linley et al. (202) gathered novel SA data not included in this thesis such as EMS provider interventions (i.e. oxygen administration, IV line placement) in various palliative situations. However, while findings from each of these retrospective studies are aligned, it should be noted these studies were both performed within Cape Town, SA and, therefore, further such research is required in other areas of the country. (130,202)

The research procedures employed in this thesis may be beneficial for use as a framework in other countries where EMS and palliative care integration remains unstudied as it incorporates current knowledge, examines quantitative evidence, gathers stakeholder perspectives, and draws upon healthcare provider expertise. Each of these elements are essential to an evidence-based approach to medicine. (44) A similar approach was successfully used to investigate EMS and palliative care in Australia though certain methodologies differed (for example a Delphi study was used in the Australian investigation and a NGT in the present thesis). (203) Furthermore, unique aspects of the present thesis include the spatio-temporal analysis (Chapter 5) and the development of a conceptual framework (Chapter 9). The results of these studies have addressed important local knowledge gaps such as the extent of the problem concerning EMS and palliative care segregation in SA. (130) This, in turn, has allowed for the appropriate prioritisation of EMS and palliative care integrative approaches within the SA context (Chapter 8). In SA it appears EMS and palliative care integration itself should be highly prioritised within the healthcare system.

Implications for Practice

High Priority of EMS and Palliative Care Integration in SA

Chapter 3 noted that while EMS and palliative care integration has been recommended, the priority of such integration globally or within specific countries is unclear. (110) Healthcare systems are inherently complex with many interacting parts and finite resources. The distribution of these finite resources requires appropriate prioritisation to maximise efficiency and efficacy. Chapter 3 argued that while this requires study within various contexts, EMS and palliative care integration may be of high priority for the following reasons: 1) potential to be a low-cost, high-impact intervention, 2) aligned with WHO priorities, 3) would improve palliative care provision and access, 4) may result in cost and resource savings which would free resources for other healthcare system needs, 5) would bring together siloed systems (EMS, palliative, in-hospital), and 6) would improve patient experience across the healthcare spectrum. (110)

Findings from the studies in this thesis support these arguments in the SA setting. Chapters 4 and 5 demonstrated significant intersection between EMS and palliative situations, implying that integrated efforts may have substantial benefit, for example through decreased rates of unnecessary medical facility conveyance. (130) Chapters 6 and 7 revealed that EMS and palliative care integration is already spontaneously occurring in some settings and patients with palliative needs find EMS care beneficial. (162) This spontaneously occurring intersection and integration due to patient needs requires support as it benefits both patients and the healthcare system. Chapter 8 noted that several integrative efforts are highly feasible, requiring minimal resources, for example spreading awareness of EMS and palliative care integration. In addition, these studies highlighted that palliative care has already been highly prioritised in SA through support of a WHA resolution, development of a National Policy Framework and Strategy for Palliative Care and inclusion of palliative care as an essential service in the NHI. (116,117) Thus, highly prioritising EMS and palliative care integration in SA would represent a logical extension of the already existing priority of palliative care provision.

With the recent signing of the NHI bill into SA law and plans for its gradual implementation over the coming decade, (204) it is crucial EMS and palliative care begin integrative efforts during this time to achieve highlighted benefits. In other countries with similar national health funding models, such as the UK (205) and Australia, (206) it has been found that medical facilities are often strained, operating at or above full capacity. (207) A consequence for EMS is what has been termed ‘ambulance ramping.’ (207–209) This occurs when patients are unable to be transferred from an ambulance into a hospital, often due to a lack of available hospital beds, leaving the ambulance to wait ‘on the ramp’ until resources are available. (207–209) Waiting times of up to 23 hours have been reported in parts of the UK. (207) Such ramping would be particularly harmful for those with complex palliative needs who may have wanted to stay home at the outset rather than experience further discomfort in an ambulance. This places significant strain on EMS resources. Part of the suggested approach to this problem has been to integrate healthcare services and enhance home palliative care provision thereby avoiding unnecessary medical facility conveyance and resultant ambulance ramping. (207,210) A community paramedic approach, which includes palliative care, may assist through reduction of unnecessary conveyance. (211)

As a result of the quadruple disease burden, SA hospitals, particularly in the state sector, are already strained. (32) Based on the examples of other countries this situation may worsen with the introduction of NHI. The SA healthcare system has the opportunity to anticipate emerging trends through proactive EMS and palliative care integration, thereby sparing healthcare system resources and avoiding harm to vulnerable patient populations.

A further consideration for highly prioritising EMS and palliative care integration is its alignment with the WHO Sustainable Development Goal (SDG) 3.8: *"Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all."* (212) The WHO UHC goal covers the full spectrum of healthcare including both emergency (213) and palliative care (214) as essential elements. Progress towards UHC is measured by two indicators: coverage of essential health services (SDG 3.8.1) and containment of catastrophic health spending (SDG 3.8.2). (214) As discussed throughout this thesis, EMS and palliative care integration will improve palliative care access (coverage) and may result in decreased health expenditure both for individuals and the healthcare system. Through NHI, SA has attempted to shift towards UHC in the country. (204) Including EMS and palliative care integration within the NHI approach will further enhance progress towards UHC in a manner beneficial to both patients and family members with palliative needs and the SA healthcare system. This would free system resources for other critical uses such as primary healthcare.

Rethinking EMS

In recommending EMS and palliative care integration, this thesis contributes to a broader discussion challenging the identity of EMS within healthcare systems. (215–217) Historically, EMS derived from military conflicts dating back to ancient Greek and Roman eras where there was a need to remove injured soldiers from the battlefield. (218,219) Evidence of EMS style treatment protocols have been found as early as 1500 B.C. (220) During the Napoleonic wars horse-drawn carriages, called *'ambulance volantes'* (flying ambulances), were used to transport injured soldiers to hospitals. (218) Interestingly, this battlefield influence may still be seen today in the para-military style training which some EMS providers receive. (221,222) Over time, the utility of hospital transport services was identified for civilian use. (219) After advancements in battlefield medicine during the World Wars, EMS scope of practice began to expand. (218) Modern EMS development may be traced back to the 1960s and 1970s where EMS systems began to formalise. (218)

From this brief historical sketch, it is clear EMS were developed to transport patients in emergency situations to hospitals. This function has been preserved from antiquity to the modern day where EMS systems continue to form part of public safety departments with a focus on resuscitation and transportation. (215) This historic EMS function is likewise clear in the terminology used to describe the EMS area of work: the 'pre-hospital' setting, which assumes that EMS do not function apart from hospital conveyance. Now in the early 21st century EMS are becoming more involved in non-emergencies and community-based care

without hospital conveyance. (215–217) Calls to rethink the term ‘pre-hospital’ have thus been made (223) and this thesis has intentionally made use of the term ‘out-of-hospital’ in its place. It may, likewise, be reasonable to rethink the term ‘EMS’. While emergency situation management remains the core function of EMS systems conceptually, this is not the case in practice. Several studies, including a large SA study, (154) have found that emergency situations account for only around 8-20% of EMS caseload. (224–226) This prompts the question, are EMS currently fit for purpose?

Despite this shift in EMS use, the EMS system remains structured primarily for emergency situation management resulting in much discussion over potentially inappropriate use of the EMS by the public. (227) Furthermore, this misalignment results in EMS systems which are unprepared for and have *“little to offer”* (215) in the vast majority of situations they manage. This has led to what in Chapter 7 was described as a system-centred EMS approach to care which is harmful in palliative situations. There are two general directions which may be taken given this current mismatch between EMS structure and use. EMS may maintain their current structure and focus on emergency situations and hospital transport or embrace a change in function and adapt accordingly.

Should EMS maintain the current emergency-focussed structure, systems preventing non-emergency responses from EMS will likely require development and alternative methods for non-emergency conveyance and homecare employed. EMS would remain siloed in this approach with the healthcare system failing to take advantage of unique and beneficial features of EMS systems. (215) In addition, maintaining the current EMS structure appears unsustainable as it would require the public to refrain from contacting EMS apart from emergency situations. This is unrealistic as recent history concerning EMS use has demonstrated. (154,225) It also may result in the unintended consequence of creating confusion for patients concerning when EMS should be utilised. Patients may be reluctant to contact EMS even for genuine emergencies as they fear ‘inappropriate’ service use. This would contradict a person-centred approach to care as it would force patients to adapt to the EMS system rather than the system to patient needs. For EMS systems to be person-centred they must adapt to the changing patient landscape rather than remain stagnant. As argued in Chapters 6 and 7, EMS education in palliative care principles may promote this cultural shift and improve EMS care provided in both emergency and non-emergency situations. (162) Such adaptation is not novel in the history of EMS systems as they have already adapted from purely battlefield to civilian use. (218) Now it appears EMS must adapt beyond purely emergencies to non-emergencies. It may be time to rethink the EMS identity from purely emergency services to ‘out-of-hospital healthcare services.’

Tavares et al. have made a similar argument concerning Canadian EMS systems. (215) They argue that the patient landscape has shifted in Canada as the public have broadened their use of EMS systems. (215) As a result, the current emergency-focussed EMS systems are misaligned with public needs and must adapt toward person-centred and integrated care. (215) To this end the authors developed an alternative EMS model of care called *"Improving Patient Access to Care in the Community (IMPACC)."* (215) This approach expands upon the existing emergency care function of EMS to provide appropriate support for non-emergent patients commonly encountered by EMS through use of EMS as an integrated resource within a multidisciplinary primary healthcare team. (215) Similar novel approaches should be investigated in the SA setting to better align EMS with the changing patient landscape present in the country. (130,154,202) Implementing such approaches which reconceptualise the identity of EMS will require gradual change over time, however, to truly align with patient needs it appears change is required. EMS integration with other services, such as palliative care, may be a step in this direction as it promotes a cultural change within EMS (162) and invites EMS to begin considering a broader role within healthcare.

Unintended Consequences

Whether the identity of EMS shifts or EMS simply integrate with other services such as palliative care, unintended consequences will arise. SA EMS providers have cautioned against EMS performing palliative care in isolation, suggesting they should rather become part of multi-disciplinary teams. (16) Palliative care providers in SA concurred with this suggestion and warned against palliative care services simply shifting their responsibilities onto EMS providers. (162) Such potentialities may result should EMS and palliative care systems integrate. From a CAS perspective unintended consequences are inevitable. (176) As individual EMS providers or organisations gain experience and capabilities in palliative situations, a temptation may arise to manage these situations alone, particularly in areas with underdeveloped palliative care services. Working in isolation and without support is familiar for EMS providers and they may default to this approach. However, this approach is unlikely to meet the complex needs of palliative situations and may, in fact, worsen them. Outsourcing palliative care responsibilities to EMS is, equally, inadvisable as it would force EMS to manage palliative situations in isolation. Furthermore, such task-shifting may overburden EMS systems. (162) As discussed in Chapter 8, EMS and palliative care integration should not detract from the EMS emergency response function, but rather enhance it. Thus, it is crucial for EMS and palliative care integrative efforts to clearly define roles and responsibilities in palliative scenarios as suggested in the conceptual framework (Chapter 9).

Eastwood et al. (184) have highlighted the importance of clearly defined roles within complex systems as these are directly linked to improved patient satisfaction and outcomes. They have noted that as a result of vague roles, *"Too often, role duplication and not role substitution is what has occurred, and without careful planning and consideration, paramedicine may not be distinguishing itself from other professions, and instead simply duplicating their field of practice."* (184) This duplication would be harmful in LMICs such as SA with already limited resources and is what both EMS and palliative care providers wish to avoid. (16,162) In truly integrated systems, role duplication must be avoided to improve patient satisfaction and well-being along the continuum of care. (184) This is particularly relevant for patients and families with complex palliative needs as they interact with many healthcare and related services. (159)

To avoid task-shifting from palliative care services to EMS, and resultant role duplication, it is important to identify why such task-shifting may occur. For example, in some instances it may be due to an imbalance in palliative care supply and demand emphasising the importance of identifying available local needs and resources (Chapter 9). It is also important to ask the question, "Who is task-shifting?" Eastwood et al. (184) have suggested that perhaps EMS systems themselves are taking on further tasks as they seek to professionalise and *"occupy more of the healthcare landscape."* Thus, the purpose of EMS expanding into areas of practice outside emergency management may not necessarily be for efficient resource use within an integrated system, but rather in response to pressure for growth within a broader healthcare system. (184)

While some evidence of the pressure for EMS growth exists, for example EMS within the UK National Health Service (NHS), (184,228) a further consideration concerning task-shifting in EMS and palliative care may be relevant. From an alternative perspective it may be that patients and family members with palliative needs are themselves 'task-shifting' onto EMS as the patient landscape has changed over time with the increase of NCDs and palliative care requirements. (143) As a result, EMS are more frequently called to palliative situations and patients and family members with palliative needs have recognised the utility of EMS to meet their needs (Chapter 7). From this perspective, the involvement of EMS in palliative care is less a question of EMS growth and more about the adaptation of healthcare systems and services to meet changing patient needs. From the evidence presented in this thesis, a tangible need for EMS and palliative care integration exists for the benefit of patient well-being rather than simply for EMS system growth. Should patients and family members themselves be the stakeholders 'task-shifting', a person-centred approach to care with due consideration for the 'Dynamic of Control' (Chapter 7) suggests these shifts are legitimate and EMS should adapt accordingly. (159) EMS adaptation and growth should be clearly focussed on patient needs rather than centred purely on system development as an end in itself.

Another unintended consequence to EMS and palliative care integration may be 'cost-shifting'. One method of integrating EMS and palliative care in SA which has been recommended for investigation is a community paramedic model (Chapters 5 and 6) as used in Australia for example. (162,229) While this approach has been successfully employed in several countries, it may increase costs for EMS. (211) A systematic review by Wilkinson-Stokes *et al.* (211) found that while community paramedic models decrease overall healthcare system costs, primarily through reduced ED conveyance, EMS system costs increased. This was due to increased on-scene times, community paramedic salaries, and initial training and system development costs. (211) Thus, in this study, EMS systems appeared to carry the cost of system development and operations while other sectors within the healthcare system gained the benefits. (211) Another barrier to the community paramedic approach has been the lack of EMS reimbursement for non-conveyance. (230) This has similarly been identified in SA (Chapter 8). While it may be argued that EMS too benefit from a community paramedic approach and may integrate with palliative care using alternative methods, this potential unintended consequence remains an important consideration. As stated by Wilkinson-Stokes *et al., "Redistribution of benefits may be necessary to incentivise EMS to invest in these programmes for a whole-of-system economic gain."* (211) This would likely include EMS reimbursement for non-conveyance which this thesis recommends in SA (Chapter 8). The current approach incentivises transport resulting in unnecessarily increased healthcare system costs.

Given the inevitable unintended consequences of EMS and palliative care integration such as those considered here, the findings of this thesis must be considered with equipoise. While EMS and palliative care integration is recommended, this represents a novel approach within SA healthcare and should be approached with due caution. Recommendations from this thesis require testing and refinement over time and should not be viewed as definitive. Though the conceptual framework for EMS and palliative care integration presented here itself requires further study, it attempts to take the discussed cautions into account by emphasising the importance of local contextual factors and enhancing EMS and palliative care system adaption which is already taking place in response to changing patient needs.

Ethical Imperative

As knowledge continues to develop concerning patient and family member palliative needs in relation to EMS systems, so too does an ethical imperative to use this knowledge for the benefit of those with palliative needs. As EMS providers and organisations become aware of the person-centred approach required in palliative situations and the harm the current system-

centred approach may cause, it is incumbent on them to enact change. In view of the foundational principles in medical ethics, (231) the current system-centred EMS approach to palliative situations may frequently be unethical. For example, where medical facility conveyance is imposed upon patients with palliative needs or advance directives concerning treatment ignored due to EMS system requirements, the principles of autonomy, beneficence and non-maleficence are explicitly contradicted. (16,231) Furthermore, the principle of justice may be contravened in these examples as healthcare system resources (in the ED for example) are inappropriately used for many patients with palliative needs who do not want or require these resources. (231) Through integration with palliative care, EMS ethical practice may improve in each of these domains as EMS are empowered to respect patients' wishes, act in their best interests, appropriately uphold *primum non nocere*, and distribute healthcare resources appropriately.

Overcoming Barriers to Integration

To enact this ethical imperative, several barriers to EMS and palliative care integration must be overcome. Common barriers to this integration, as highlighted in Chapter 1, are EMS disposition, complexities of the out-of-hospital environment, constrained EMS systems, lack of education, medico-legal challenges and conflicts among stakeholders. (4,10,16,31) The CFEPI developed in this thesis (Chapter 9) addresses each of these barriers. *Education* and *awareness* for EMS and palliative care providers as well as patients and family members has been recommended under the strategic direction of "Empowering and Engaging People." This would address the barriers of a lack of education and assist in addressing EMS provider disposition. As discussed in Chapters 6 and 7, EMS providers require a cultural change toward person-centred care and education is part of achieving this change. (162) To address EMS system constraints, for example mandated medical facility conveyance, *alternative pathways and approaches* as well as alternative *funding* models have been recommended under the strategic direction of "Reorienting the Model of Care." Along with *governance* and *policy development* under the strategic direction of "Strengthening Accountability", these alternative approaches may also address various medico-legal concerns. Through *stakeholder collaborations* and *communication and information sharing*, under the strategic direction of "Coordinating Services", various conflicts and out-of-hospital challenges may be addressed.

Application Outside of South Africa

Although the CFEPI was developed based on SA research and for the SA LMIC context, it may be beneficial internationally in both LMICs and HICs. The barriers to EMS and palliative care integration are similar cross-contextually (110) and, therefore, the CFEPI is relevant where these barriers are present. Furthermore, the CFEPI draws on elements from the international literature, (110) the WHO (111) and current healthcare system integration frameworks. (170) The WHO IPCHS, as well as existing healthcare system integration frameworks, have been designed for cross-contextual use and, therefore, emphasise the importance of considering local context as does the CFEPI. (111,170) Furthermore, as noted in Chapter 3, LMIC research such as that in this thesis, may be beneficial within HICs. (110) Thus, the CFEPI, though designed in SA, may be beneficial particularly in other LMICs with similar resource constraints, but also HICs where similar barriers and recommendations for healthcare system integration exist. (110)

Future Research

Overview

Each study within this thesis made recommendations for further research. Several of these research gaps were filled within this thesis as documented in Table 16 (Section 4 Overview). Other areas for research still require investigation: quantifying annual caseload of SA EMS and palliative situations, (130) cost-effectiveness studies, pilot studies, educational interventions including curriculum development, (162) perspectives of other stakeholders (for example medical insurance companies), (110) and community paramedic models for SA. (130)

Further to these areas, when considering findings from this thesis as a whole, additional research should be conducted to establish consensus on the EMS role in palliative situations and assess the safety and efficacy of the CFEPI presented here. Although a recommended role for EMS has been developed in this thesis (Chapter 6), (162) consensus both nationally and internationally remains unreached. However, it is likely consensus may not be reached, as this role is context-dependent and may vary widely in different areas. This thesis recommends the EMS role in palliative situations be tailored to local contextual factors.

To fulfil research recommendations within SA the following research agenda is proposed:

1) Pilot Studies
2) Cost-Effectiveness Studies
3) Curriculum Development
4) Ongoing Monitoring, Evaluation and Learning

Pilot Studies

As a body of literature concerning EMS and palliative care integration has now been developed in SA, implementation studies are the logical next step. This was likewise recommended by the palliative care providers in Chapter 6. (162) These studies should analyse modes of EMS palliative care delivery such as community paramedic models, use of the conceptual framework for integration, the effect of integration upon hospital conveyance rates, cost-effectiveness of integration, overall EMS caseload, and patient and family member satisfaction. (110,130,162) Other analyses may include the safety and efficacy of *"treat and release"* approaches and expanded EMS scope of practice to include commonly used medications and procedures within palliative care. (162) Pilot studies will assist in identifying unintended consequences prior to any large-scale implementation.

Cost-Effectiveness Studies

While cost-effectiveness studies may form a component of pilot studies, they represent a crucial area for research on their own merit. Throughout the studies of this thesis, cost-effectiveness studies have been recommended. The supposed positive cost-effectiveness of EMS and palliative care integration has been frequently highlighted as a benefit of integration (42,91,110) and used to argue for the high prioritisation of integration particularly within LMICs. (110) While recent economic evaluations have demonstrated the positive cost-effectiveness of EMS and palliative care integration and community paramedicine, this remains unresearched in SA and other LMICs. (211,232) SA cost-effectiveness studies should be prioritised as findings would significantly influence the extent and direction of EMS and palliative care integration within the country.

Curriculum Development

The most frequently suggested approach to EMS and palliative care integration within the literature has been EMS education in palliative care. (41,97,110) Thus, education is a key

component within the conceptual framework. However, within SA, no curriculum for such education has been developed. As discussed in Chapters 6 and 7, EMS education in palliative care principles may encourage a cultural shift within EMS systems towards person-centred care which would enhance their management of not only palliative situations, but emergency situations as well. (162) Given its potentially significant impact and primacy within the literature, palliative care curriculum development for EMS is a priority.

Ongoing Monitoring, Evaluation and Learning

As discussed in Chapters 6, 8 and 9, where EMS and palliative care integrate, the safety and efficacy of such integration must be monitored. (162) This may be done through development of a Monitoring, Evaluation and Learning (MEL) plan. (233) These plans, or similar, will be necessary to track progress in achieving the shared goals of integration and adapt the integrative approach where necessary. This in turn will allow for improved integration efficacy and continual learning. Through encouragement of adaptation, these plans align with CAS theory and will assist in the application of the conceptual framework. (176) Based on local contexts and changing needs, EMS and palliative care integration must be flexible (Chapters 8 and 9). Therefore, EMS and palliative care integration may be continually evolving and should be seen as an ongoing process. Viewing integration in a binary manner (achieved or not achieved) would stifle this adaptive process. A MEL plan, however, would enhance this process and should be used.

Dissemination of Results

Findings from this thesis must be disseminated to effectively translate this research into practice. (234) In light of the CFEPI, dissemination of research findings contributes towards the needs for Awareness and Research which fall into the strategic directions of “Empowering and Engaging People” and “Strengthening Accountability.” Thus, disseminating the results of this thesis is a positive step towards an enabling environment for EMS and palliative care integration in SA. Curtis et al. (235) have recommended the following methods for dissemination: sharing results with stakeholders, conference presentations, journal publications, social media use, legacy media use (for example newspapers) and through professional organisations. Table 23 outlines how these recommendations have been and will be pursued.

Table 23 Methods of Dissemination for this Thesis

Recommended Method (235)	**Dissemination Activity**
Sharing Results With Stakeholders	- Results from the retrospective chart review study (Section 2) have been shared with the participating hospitals. - Results from each qualitative interview study (Section 3) have been shared with study participants. - Results from the NGT study (Section 4) have been shared with and reviewed by the expert panel. - This thesis will be uploaded into the UCT repository. (236)
Conference Presentations	- Findings from Sections 1-3 have been presented at the Emergency Care Society of South Africa (ECSSA) 2024 conference. (237) - Future EMS and palliative care conferences will be pursued.
Journal Publications	- The scoping literature review study (Chapter 3) has been published (110) along with a protocol for the review. (53) - The clinical analysis of the retrospective chart review (Chapter 4) has been published. (130) - The spatio-temporal analysis of the retrospective chart review (Chapter 5) has been accepted for publication. - The palliative care provider interview study (Chapter 6) has been published. (162) - The patient and family member interview study (Chapter 7) is currently undergoing peer-review. - The NGT study (Chapter 8) has been submitted for publication. - A collaborative discussion paper on EMS and palliative care with authors from Australia was published in 2023 incorporating findings from this thesis. (46) - Publication(s) for Chapters 9 and 10 will be pursued. - All publications are open access in emergency medicine, palliative care and generalist journals. A range of local and international journals have been used.
Social Media	- Publications have been shared *via* various social media platforms. - Future publications will be shared *via* social media platforms when available.
Legacy Media	- Various platforms for media releases will be pursued (for example through professional newsletters).
Professional Organisations	- Publications have been shared with ECSSA (EMS organisation), (237) APCC (147) and PALPRAC (144) (palliative care organisations). - Findings will be shared with the UCT Division of Interdisciplinary Palliative Care and Medicine. (148) - Future publications will be shared with the same organisations. - The author has formed part of the international European Association for Palliative Care (EAPC) task force on palliative care and EMS in which thesis findings will be shared and incorporated. (238)
Other	- Lectures have been presented on EMS and palliative care to EMS provider students as a result of this thesis at two higher education institutions. - Multiple webinar presentations concerning the results of this thesis have been conducted.

	- As a result of thesis findings, the author provided input to a local palliative care practice in Johannesburg, SA which was seeking to incorporate EMS.

EMS=Emergency Medical Services, NGT=Nominal Group Technique, UCT=University of Cape Town, APCC=Association of Palliative Care Providers, PALPRAC=The Association of Palliative Care Practitioners of South Africa, SA=South Africa

As a result of research from this thesis, positive impact is already being made in SA concerning EMS and palliative care policy. The HPCSA recently published new clinical decision support tools for EMS providers to guide their practice in various scenarios including chest pain, seizures and airway management for example. (239) These tools are based on the latest EMS clinical practice guidelines released by the HPCSA. (181) One of these tools, in which the author was a lead developer, is entitled “Caring for the Adult at the End of Life.” (239) This tool is the first of its kind in SA to provide guidance for EMS in EoL situations and incorporates findings from this thesis, for example, encouraging shared decision-making and the avoidance of unnecessary interventions. (239) This corresponds with the need for policy development under the strategic direction of “Strengthening Accountability” within the conceptual framework (Chapter 9). Thus, findings from this thesis are already beginning to influence practice.

Limitations

Each study within this thesis contains its own limitations which are discussed in the relevant chapters. The external validity of thesis findings, particularly the CFEPI, is limited as the research was conducted within and for the SA context. Future research is required not only concerning conceptual framework implementation in SA, but in other LMICs as well as HICs. However, as argued in this chapter, the CFEPI may have applications in various contexts given its foundations of international literature and practice.

Selection bias is likely present within thesis findings and interpretations, particularly towards the author’s cultural background as participants held, like the author, a primarily Western view of modern medicine expressed in English. Conceptions (and misconceptions) of palliative care, and medicine in general, differ among various cultures. (240) Further research is required to explore the concept of EMS and palliative care integration among differing cultures as expressed in their corresponding languages. While this is a limitation, the conceptual framework attempts to mitigate this through its respect of the ‘Dynamic of Control’ (Chapter 7) and emphasis on local context and community engagement with healthcare users as co-producers.

Chapter 11: Conclusions

This thesis identified and filled knowledge gaps concerning EMS and palliative care integration in the SA setting through review of contemporary literature, retrospective analysis of palliative situations involving EMS, gathering of primary stakeholder views, and expert panel development of integrative methods.

In Section 1, a scoping literature review revealed a relatively small body of literature concerning EMS and palliative care, highlighting the current limited evidence base and need for further research. (110) Though small, the body of literature found that EMS have a role to play in out-of-hospital palliative care though the specifics of this role were unclear. This literature review identified the following evidence gaps: extent of intersection between EMS and palliative situations, reasons for EMS use in palliative situations, patient, family member and palliative care provider perspectives on the use of EMS in palliative situations, development, and prioritisation of implementable approaches to integration, role of EMS in palliative situations. Furthermore, the need for EMS and palliative care research in LMICs was highlighted as these contexts have varying needs and available resources.

While previously assumed, substantial intersection between EMS and palliative situations in SA was demonstrated in the retrospective chart review of Section 2 highlighting the significance of this topic within the country. (130) EMS were used in palliative situations for distressing symptoms, such as dyspnoea, and practical needs such as transport at all times of the day, week, month and year, particularly in peri-urban areas which suffer from decreased healthcare access. Thus, in palliative situations, EMS may have a role to play in symptom management and improving access to palliative care.

Section 3 provided insight into primary stakeholder perspectives concerning EMS use in palliative situations through qualitative interview studies. Patients and family members with palliative needs as well as palliative care providers offered support for EMS and palliative care integration. (162) According to palliative care providers, a role of EMS in palliative situations is to provide initial containment of these situations and link patients and family members with palliative care services. Novel insights into patient and family member experiences as expressed in the “Dynamic of Control” demonstrated the need for a person-centred approach to care. Patients and family members used EMS in palliative situations as they were readily available to assist in regaining control of palliative situations.

In Section 4, EMS and palliative care experts developed and prioritised approaches to EMS and palliative care integration in SA through an NGT study based on findings from Sections 1-3. These strategies, in order of priority from highest to lowest, were *awareness, education,*

community engagement, communication and information sharing, stakeholder collaborations, alternative pathways and approaches, research, funding, policy development, and *governance*.

Based on the evidence from the studies in Sections 1-4, Section 5 presented a conceptual framework for EMS and palliative care integration in SA (CFEPI) and guidance for its practical use. The core components of this framework are *CAS theory, WHO IPCHS strategic directions, local context, person-centred care*, and the categories of integrative approaches from the NGT. The implementation of this framework will assist in the efficient use of limited healthcare resources in SA while simultaneously improving access to and quality of palliative care for those in need through creation of an enabling environment for EMS and palliative care integration which enhances person-centred care.

Through implementation of the CFEPI strategic directions, the common barriers to EMS and palliative care integration may be overcome. “Empowering and Engaging People” would address the lack of EMS provider education and EMS provider disposition. “Reorienting the Model of Care” would address EMS system constraints. “Strengthening Accountability” would mitigate EMS medico-legal concerns. “Coordinating Services” would ameliorate conflicts and out-of-hospital challenges such as limited information.

Though the framework presented here was developed for the SA context, it contains elements from the international literature as well as WHO (111) and health system integration frameworks. (170) Thus, this framework may have applications outside of SA, particularly in other LMICs with similar resource constraints. Future research should monitor the safety and efficacy of framework implementation, investigate the economic impact of EMS and palliative care integration through cost-effectiveness studies, develop curriculum for EMS education in palliative care, and involve pilot studies.

Upon initial observation, EMS and palliative care approaches appear to be opposed. However, as demonstrated in this thesis, when these services are integrated, their respective approaches are complementary, providing benefits to patients, family members, EMS systems, palliative care systems and the broader healthcare system. With the advent of NHI in SA, and the ethical imperative to provide these benefits, it is essential EMS and palliative care services integrate within SA and adapt to changes in the patient landscape as EMS become involved in more intricate forms of care beyond emergency medicine.

END

Caleb Hanson Gage, January 2025

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APPENDICES

Appendix 1: Approval for the Inclusion of Published Research

Dear Mr Caleb Gage

We hereby confirm that the Doctoral Degrees Board has **approved** your request to include the specified publications in your PhD thesis.

In your thesis (after your declaration that it is your own work) please include the following separate signed statement listing the publications that you were given permission to include:

"I confirm that I have been granted permission by the University of Cape Town's Doctoral Degrees Board to include the following publication(s) in my PhD thesis, and where co-authorships are involved, my co-authors have agreed that I may include the publication(s): "

This declaration serves to notify examiners that the Doctoral Degrees Board has granted you permission to include publications in your thesis.

Kind Regards

UNIVERSITY OF CAPE TOWN
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Appendix 2: Ethics Approvals

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

G50 Old Main Building
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Telephone [021] 406 6492
Email: sumayah.arieffien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

14 September 2021

HREC REF: 588/2021

Dr W Stassen
Emergency Medicine
F51, OMB
Email: willem.stassen@uct.ac.za
Student: caleb.gage@gmail.com

Dear Dr Stassen

PROJECT TITLE: STUDY 1: A SCOPING REVIEW CONCERNING THE RELATIONSHIP BETWEEN PALLIATIVE CARE AND EMS-DOCTORATE CANDIDATE-MR CALEB GAGE

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

The HREC note that this is a scoping review of published, freely accessible literature.

HREC approval Is not required.

This is in accordance with Section 1.1.8 of the Department of Health's Ethics in Health Research: Principles, Processes and Structures (South African Department of Health, 2015), which states: "*Research that relies exclusively on publicly available information or accessible through legislation or regulation usually need not undergo formal ethics review. This does not mean that ethical considerations are irrelevant to the research.*"

The HREC recommend that researchers refer to the PRISMA website, for the PRISMA statement and checklist, to facilitate the reporting of systematic reviews and meta-analyses. For more information, please refer to http://www.prisma-statement.org/.

Further, fundamental ethical principles for health-related research should be considered in the objectives and methods of the systematic review. See, for example, the Declaration of Helsinki (Fortaleza, Brazil, 2013) and the Department of Health's Ethics in Health Research: Principles, Processes and Structures (South African Department of Health, 2015)

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

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

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14 September 2021

HREC REF: 589/2021

Dr W Stassen
Division of Emergency Medicine
F-51 CMB
Email: willem.stassen@uct.ac.za
Student: caleb.gage@gmail.com

Dear Dr Stassen

PROJECT TITLE: STUDY 2: A RETROSPECTIVE COHORT STUDY TO EXAMINE EMERGENCY MEDICAL SERVICE USE FOR PALLIATIVE SITUATIONS IN SOUTH AFRICA-DOCTORATE CANDIDATE-MR CALEB GAGE

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

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

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020: 06 July 2020 & 01 July 2021.

Approval is granted for one year until the 30 September 2022.

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/fhs/research/humanethics/forms)

The HREC acknowledge that the student: - Mr Caleb Gage will also be involved in this study.

Please quote the HREC REF 589/2021 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.

HREC/REF 589/2021rev

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

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 Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

UNIVERSITY OF CAPE TOWN

HUMAN RESEARCH ETHICS COMMITTEE
0 6 SEP 2022
HEALTH SCIENCES FACULTY

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS017: Annual Progress Report / Renewal

Record Reviews/Audits/Collection of Biological Specimens/Repositories/Databases/Registries

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30-9-23
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee	Signed by candidate	Date Signed	7/9/2022

Note: Please note that incomplete submissions will not be reviewed.
Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

Please clarify your plan for research-related activities during COVID-19 lockdown

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	06/09/2022		
HREC REF Number	589/2021	Current Ethics Approval was granted until	30/09/2022
Protocol title	A retrospective cohort study to examine emergency medical service use for palliative situations in South Africa		
Principal Investigator	Caleb Hanson Gage		
Department / Office Internal Mail Address	Division of Emergency Medicine ggxcal001@myuct.ac.za		
1.1 Does this protocol receive US Federal funding?		☐ Yes	✓ No

2. Protocol status (tick ✓)

✓	Research-related activities are ongoing
☐	Data collection is complete, data analysis only

Please indicate (in the block below) the titles and HREC reference numbers of any projects currently making use of the Database/registry/repository.

HREC Ref 589/2021 A retrospective cohort study to examine emergency medical service use for palliative situations in South Africa

3. Protocol summary

Total number of records or specimens collected, reviewed or stored since the original approval		0
Total number of records or specimens collected, reviewed or stored since last progress report		0
Have any research-related outputs (e.g. publications, abstracts, conference presentations) resulted from this research? If yes, please list and attach with this report.	☐ Yes	✓ No

4. Signature

Signature of PI	Signed by candidate	Date	06/09/2022

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

Room 45 E-52-E-Floor- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
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Website: www.health.uct.ac.za/home/human-research-ethics

04 April 2023

HREC REF: 220/2023

Dr W Stassen
Division of Emergency Medicine
F-51 OMB
Email: willem.stassen@uct.ac.za
Student: caleb.gage@gmail.com

Dear Dr Stassen

PROJECT TITLE: STUDY 3: A QUALITATIVE INTERVIEW STUDY OF THE PERSPECTIVES OF PALLIATIVE CARE PROVIDERS ON EMS USE IN PALLIATIVE CARE IN SA (DOCTORAL CANDIDATE-MR. CALEB GAGE)

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

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 April 2024.

Please submit a progress form, using the standardised Annual Report Form (FHS016) 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/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Mr Caleb Gage will also be involved in this study.

Please quote the HREC REF 220/2023 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.

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007

HREC/ref 220.2023

UNIVERSITY OF CAPE TOWN
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04 April 2023

HREC REF: 221/2023

Dr W Stassen
Division of Emergency Medicine
F-51 OMB
Email: willem.stassen@uct.ac.za
Student: caleb.gage@gmail.com

Dear Dr Stassen

PROJECT TITLE: STUDY 4: A QUALITATIVE INTERVIEW STUDY OF THE PERSPECTIVES OF SA PALLIATIVE PATIENTS CONCERNING EMS USE IN THEIR CARE.
(DOCTORAL CANDIDATE-MR. CALEB GAGE)

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

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 April 2024.

Please submit a progress form, using the standardised Annual Report Form (FHS016) 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/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Mr Caleb Gage will also be involved in this study.

Please quote the HREC REF 221/2023 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.

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007

HREC/ref 221.2023

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18 July 2024

HREC REF: 453/2024

A/Prof Willem Stassen
Division of Emergency Medicine
F51, Old Main Building
Groote Schuur hospital
Email: willem.stassen@uct.ac.za
Student Email: caleb.gage@gmail.com

Dear A/Prof Stassen

PROJECT TITLE: STUDY 5: A NOMINAL GROUP TECHNIQUE (NGT) STUDY TO DEVELOP AND PRIORITISE APPROACHES FACILITATING PALLIATIVE CARE AND EMERGENCY MEDICAL SERVICES (EMS) SYSTEM INTEGRATION WITHIN THE CONTEXT OF SOUTH AFRICA (SA). (DOCTOR OF PHILOSOPHY IN EMERGENCY MEDICINE - MR. CALEB GAGE).

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review and approval.

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 July 2025.

Please submit a progress report, using the standardised Annual Progress Report Forms (FHS016) **or** (FHS 017) if the study continues beyond the approval period. Please submit a Standard Closure form (FHS 010) when the study has been completed, this includes after publication or thesis submission and final completion.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

*The HREC acknowledges that **Mr Caleb Gage** will also be involved in the study.*

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.

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

Please quote the HREC reference number 453/2024 in all your correspondence.

Yours sincerely

Signed by candidate

PROFESSOR MARC BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.

HREC REF NO. 453/2024

Appendix 3: Scoping Literature Review Search String

CINAHL Search String

("Palliative" OR "Palliative care" OR "Palliative medicine" OR "Palliative management" OR "Palliative nursing" OR "Palliative care nursing" OR "Palliative care nurse" OR "Palliative care nurses" OR "Palliative patient" OR "Palliative patients" OR "Palliation" OR "Palliative situation" OR "Palliative situations" OR "Palliative emergency" OR "Palliative emergencies" OR "Palliative care protocol" OR "Palliative care protocols" OR "Emergency palliative care" OR "Emergency palliation" OR "Early palliation" OR "Early palliative care" OR "Early hospice care" OR "Palliative unit" OR "Palliative units" OR "Palliative care unit" OR "Palliative care units" OR "Hospice care" OR "Hospice" OR "Hospice and palliative care nursing" OR "Hospice and palliative nursing" OR "Hospice and palliation" OR "Hospice nurse" OR "Hospice nurses" OR "Hospice physician" OR "Hospice physicians" OR "Hospice service" OR "Hospice services" OR "End of life care" OR "End of life" OR "Terminal care" OR "Terminal patient" OR "Terminal patients" OR "Terminal illness" OR "Terminal illnesses" OR "Terminally ill" OR "Dying patient" OR "Dying patients" OR "Chronic patient" OR "Chronic patients" OR "Chronic illness" OR "Chronic illnesses" OR "Chronic care" OR "Palliative home care" OR "Home based care" OR "Home care" OR "Home based palliative care" OR "Home palliative care" OR "Home palliation" OR "Palliative care team" OR "Palliative care teams" OR "Palliative care service" OR "Palliative care services" OR "Palliative service" OR "Palliative services" OR "Palliative specialist" OR "Palliative specialists" OR "Palliative physician" OR "Palliative physicians" OR "Palliative care physician" OR "Palliative care physicians" OR "Palliative doctor" OR "Palliative doctors" OR "Palliative care doctor" OR "Palliative care doctors" OR "Palliative care giver" OR "Palliative caregiver" OR "Palliative care givers" OR "Palliative caregivers" OR "Advance care plan" OR "Advance care planning" OR "Advanced disease" OR "Advanced diseases" OR "Prehospital palliative care" OR "Out of hospital palliative care") AND ("Emergency medical services" OR "EMS" OR "EMS staff" OR "EMS system" OR "Emergency medical system" OR "Emergency medical services system" OR "Emergency medical service system" OR "Emergency medical service protocol" OR "Emergency medical services protocol" OR "Emergency medical service protocols" OR "Emergency medical services protocols" OR "EMS protocol" OR "EMS protocols" OR "Emergency medical service" OR "Emergency health service" OR "Emergency health services" OR "Emergency services" OR "Emergency care" OR "Emergency medical care" OR "Emergency healthcare" OR "Emergency treatment" OR "Emergency treatments" OR "Emergency medical treatment" OR "Emergency management" OR "Emergency medical management" OR "Out of hospital emergency care" OR "Prehospital care" OR "Prehospital emergency care" OR "Pre hospital" OR "Prehospital" OR "Out of hospital" OR "Out-of-hospital" OR "Paramedic" OR "Paramedics" OR "Emergency paramedic" OR "Emergency paramedics" OR "Ambulance" OR "Ambulances" OR "Ambulance staff" OR "Emergency medical provider" OR "Emergency medical providers" OR "Emergency medical technician" OR "Emergency medical technicians" OR "Emergency medical practitioner" OR "Emergency medical practitioners" OR "Emergency provider" OR "Emergency providers" OR "Emergency technician" OR "Emergency technicians" OR "Emergency practitioner" OR "Emergency practitioners" OR "Prehospital emergency provider" OR "Prehospital emergency providers" OR "Emergency responder" OR "Emergency responders" OR "First responder" OR "First responders" OR "Emergency doctor" OR "Emergency doctors" OR "Emergency medical doctor" OR "Emergency medical doctors" OR "Emergency physician" OR "Emergency physicians" OR "Emergency medical physician" OR "Emergency medical physicians" OR "Emergency clinician" OR "Emergency clinicians" OR "Emergency medical clinician" OR

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Embase (Scopus) Search String

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PsycInfo Search String

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MEDLINE (PubMed) Search String

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Web of Science Search String

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Appendix 4: Scoping Literature Review Summary of Included Studies

Author, Year, Setting, Country Income Status	Aim(s)	Methodology	Population and Sample Size	Outcomes and Significant Findings	Limitations
Anderson, et al. 2022 New Zealand - HIC	*"To explore bereaved family members' experiences of emergency ambulance care at the end of life."*	Qualitative Individual Interviews	38 Family Caregivers	Key themes: 1) Supporting living and dying at home. 2) Urgent and unexpected events. 3) Reluctance in calling an ambulance. EMS providers play a vital role in providing palliative care. This should be integrated into policy, practice and training.	Possibility of self-selection and recall biases. Limited external validity.
Ausband, et al. 2002 USA - HIC	*"To determine the prevalence of palliative care protocols among EMS agencies in the United States, and to estimate the percentage of the U.S. population covered by such protocols".*	Descriptive 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.	Response rate 60.5%. 'Palliative Care Protocol' was not defined. Thus, EMS palliative care protocols may be more or less prevalent than 5.8%.
Boaventura, et al. 2022 Brazil - LMIC	*"To identify the perception of health professionals regarding the concept of PC* [Palliative Care] *and their care experiences with this type of patient in a pre-hospital care (PHC) service in Brazil."*	Qualitative Individual Interviews	25 EMS Providers	Key themes: 1) Unpreparedness of the team. 2) Decision Making. 3) Dysthanasia. There is a need for EMS provider palliative care training and policy development in Brazil.	Possibility of self-selection and recall biases. Limited external validity.
Breyre, et al. 2021 USA - HIC	*"To provide a descriptive analysis of hospice and comfort care patient EMS utilization in Alameda County* [California, USA]*".*	Retrospective Cohort	534 Patient Records	0.2% (n=534) of EMS calls were for hospice patients. Of these, 468 (87.6%) were transported to hospital. Most commonly encountered symptoms:	Some hospice patients potentially missed due to incomplete/inaccurate documentation and an inability to identify serial

				respiratory distress, altered mental status. Fentanyl administration was the most common intervention. Although EMS encountered hospice patients infrequently, they should be prepared for such cases.	EMS calls from a single patient.
Breyre, et al. 2021 USA - HIC	*"To evaluate the effect of a Mobile Integrated Hospice Healthcare (MIHH) program including hospice education and expansion of paramedic scope of practice to use hospice medication kits".*	Retrospective Cohort	523 MIHH Cases	MIHH program reduced emergency department transport rates from 80.3% to 19.6%. The expanded scope medication kit was used only once. This collaboration between hospice and EMS systems was successful in reducing hospice patient transport to the emergency department, possibly improving hospice patient and family care.	No comparison with transport rates in non-hospice patients over the study period. Reasons for patient transport inconsistently documented. Method of screening for hospice patients may not have identified all eligible patients.
Breyre, et al. 2022 USA - HIC	*"To explore EMS provider challenges, self-perceived roles and training experiences caring for patients and families with life-limiting illness."*	Qualitative Individual Interviews	15 EMS Providers	Key themes: 1) In the moment decision making dilemmas. 2) Respond to varied grief reactions. 3) Disadvantaged/vulnerable populations have less access to care and advance care planning. 4) Transport people. 5) Holistic care. 6) Lack of formal training. Formal training of EMS providers in palliative care principles would empower them to care for patients with life-limiting illness.	Possibility of self-selection and recall biases. Limited external validity.
Burnod, et al. 2012 France - HIC	*"To evaluate whether patient's wishes were respected by prehospital*	Retrospective Cohort	40 Patients	Collaboration between prehospital emergency teams and palliative care networks	No limitations listed by the authors; however, the sample size was small.

	emergency medical teams after implementing collaboration and a standardized process between a community-based palliative network and the Emergency Medical Service (EMS) system".			allows prehospital teams to access information relevant to their patients and results in greater respect of palliative patient wishes (83% of the time compared with 40% where no collaboration exists).	
Carron, et al. 2014 Switzerland - HIC	To highlight *"end of-life and palliative care situations that may be encountered by prehospital emergency services".*	Retrospective Case Series	4 Cases	Palliative and prehospital emergency care may be complimentary approaches. Analysed cases demonstrate the need for palliative education in prehospital emergency teams and collaboration between EMS and palliative systems.	Limited review of 4 cases. Findings and suggestions are open to biased interpretations.
Carter, et al. 2022 Canada - HIC	*"To describe the essential elements, barriers, and facilitators for implementation, spread, and scale of the Program* [Paramedics Providing Palliative Care at Home] *from two perspectives: one system that implemented the Program and one system that had not, using the Consolidated Framework for Implementation Research (CFIR)."*	Qualitative Deliberative Dialogues	20 stakeholders (9 EMS Providers, 7 Palliative Providers, 2 Program Administrators, 1 Primary Care Provider, 1 Emergency Medicine Provider)	Key elements for implementation of the *Paramedics Providing Palliative Care at Home Program*: 1) Cosmopolitanism (outer setting). 2) Adaptability (intervention). 3) Implementation climate (inner setting). 4) Engagement and Planning (processes). Scaling this program would be beneficial for patient satisfaction and further paramedic confidence in caring for patients with palliative needs.	Possibility of self-selection and group biases. Lack of member-checking. Limited external validity.
Carter, et al. 2022 Canada - HIC	*"To explore, from the perspectives of paramedics and palliative health care providers, the alignment of a palliative care role with*	Qualitative Focus Group Interviews	11 Paramedics, 20 Health Care Providers	Key themes concerning EMS provider role: 1) Patient centeredness and job satisfaction. 2) Bridging. 3) Advocate and educator. 4)	Possibility of self-selection and group biases. Limited external validity.

	paramedic professional identity."			Psychosocial support. Key themes concerning EMS provider identity: 1) Evolution of paramedicine as a skilled clinical profession. 2) Helping people and communities. 3) Paramedic skill set aligns with work in palliative care. 4) Changing paramedic mindset. Palliative care provision is well-aligned with EMS provider identity.	
Carter, et al. 2019 Canada - HIC	*"To determine the impact of the program* [Paramedics Providing Palliative Care at Home] *in two parts: Part A examined patient and family/caregiver satisfaction, and Part B measured paramedic comfort and confidence with the delivery of palliative care support".*	Mixed Methods: Part A: Telephonic Interviews, Surveys. Part B: Pre- vs. Post-Intervention Surveys.	Part A (Patients/Families): 18 Telephonic Interviews and 67 surveys. Part B (Paramedics): 235 Pre-Intervention Surveys and 267 Post-Intervention Surveys.	After programme implementation, paramedic comfort and confidence providing palliative and end-of-life care improved. Paramedics viewed palliative care as important and rewarding in their work. Furthermore, patient/family satisfaction was high. Families particularly highlighted paramedic compassion and professionalism.	Small sample size and low survey response rates. Time-lapse between paramedic arrival and patient/family interview.
Clemency, et al. 2019 USA - HIC	To *"describe a terminal extubation performed by a paramedic under the direct supervision of an Emergency Medical Services (EMS) physician".*	Case Report	1 Case	With guidance, terminal extubation is possible out-of-hospital. Allowing for EMS involvement in this and other palliative interventions would simplify logistics and allow patients the option of a home death.	Single case description.

Dent, et al. 2020 UK - HIC	To *"report the patient characteristics and outcomes of a 24-hour hospice nursing telephone advice service to support an ambulance service".*	Retrospective Cohort	45 Telephonic Calls	Telephonic advice service was associated with low rates of patient transport to hospital (16%, n=7). Access to palliative advice can support ambulance clinicians and is feasible. Ambulance clinicians viewed this as an invaluable resource.	Quality of advice not studied. Small sample size in a paramedic-led system limiting external validity. Telephonic advice may not have been sought in all cases as EMS do not have a palliative care call-out category.
Donnelly, et al. 2018 USA - HIC	*"To assess the knowledge, attitudes, and experiences of EMS providers in the hospice care setting".*	Mixed Methods Cross-Sectional Survey	182 EMS Providers	Majority of EMS providers (84.1%, n=153) have managed a hospice patient at least once. 29.1% (n=53) reported receiving formal education on hospice patient care. EMS providers expressed a need for education and difficulties with communication and information in managing hospice patients.	Single-centre study, limiting external validity. Unvalidated survey.
Eaton-Williams, et al. 2020 UK - HIC	*"To assess whether ambulance paramedics currently identify EoLC patients, are aware of identification guidance and believe this role is appropriate for their practice".*	Cross-Sectional Online Survey	1643 Paramedics	Majority of paramedics (97.0%, n=1594) felt they should contribute to identifying end-of-life care needs. Current barriers to this role: lack of access to patient medical records, insufficient education and communication difficulties. Establishing end-of-life referral pathways and receiving education were identified as facilitators of this role.	Possibility of self-selection bias. Impossible to verify participants' qualifications and experience.
Fitzpatrick, et al. 2022 USA - HIC	*"To provide structured, evidence-based palliative and hospice education to CPs* [Community Paramedics]*."*	Pre- and Post-intervention Study	14 Community Paramedics	Paramedics play a role in the care of terminal patients. Formal palliative training within community paramedic programs	Small sample size. Unclear survey questions.

				should be implemented. The educational intervention of this study increased community paramedics' knowledge regarding EoL communication.	
Gage, et al. 2020 South Africa - LMIC	*"To gather the perspectives 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."*	Qualitative Individual Interviews	6 Paramedics	Key themes: 1) Need for pre-hospital palliative care. 2) Function of pre-hospital healthcare providers concerning palliative care. 3) Challenges to pre-hospital palliative care. 4) Ideas for implementing pre-hospital palliative care. Pre-hospital palliative care is needed in South Africa and EMS may play a valuable role.	Possibility of self-selection bias. Limited external validity.
Goodwin, et al. 2021 UK - HIC	*"To explore staff stakeholder views on the role of UK paramedics in advance care planning, including the use of the Gold Standards Framework Proactive Identification Guidance for screening and referral of patients".*	Qualitative Individual Interviews	17 Stakeholders (8 Paramedics, 4 General Practitioners, 2 Emergency Department Doctors, 2 Emergency Department Nurses, 1 Community Nurse)	Key themes: 1) A lack of advance care planning. 2) Variation across health conditions. 3) A lack of joined-up care. 4) Poor-quality end of life conversations. UK paramedics are well positioned to screen patients for advance care planning.	Possibility of self-selection and recall biases. Limited external validity.
Hauch, et al. 2021 Germany - HIC	To answer the questions: *"Which EMS operations occurred in the patients cared for in the SPHC* [Specialized	Retrospective Cohort	172 Paediatric Patient Records	Despite existence of a 24/7 specialised palliative home care service, some parents of children with palliative needs still	Small sample size. Limited external validity.

	Home Palliative Care]*, and how frequent were they? What treatments were given, and what was the outcome? Which possible associated factors can be identified that triggered the emergency call?"*			contacted EMS in emergency situations (12%, n=20). Within this group, EMS were contacted 27 times. These patients were less likely to have a do not resuscitate order, required more home visits and were under SPHC care for longer when compared to the non-EMS group. Collaboration between palliative and emergency services is needed.	
Hoare, et al. 2018 UK - HIC	*"To understand the role of ambulance staff in the admission to hospital of patients close to the end of life".*	Qualitative Individual Interviews	6 Ambulance Staff	Ambulance staff play an important role in end-of-life patient hospital admissions. Their ability to keep patients at home is hindered by: 1) The limited availability and accessibility of additional care support in the community. 2) The limited information ambulance staff had about the patient and their condition. 3) A perceived ambulance service emphasis on hospital care.	Possibility of self-selection and recall biases. Limited external validity.
James, et al. 2021 Australia - HIC	*"To understand paramedics' intentions to use a hypothetical Specialist Palliative Care telehealth service, based on their perceptions of the service (i.e. usefulness, ease of use, and attitude toward to the service) and their palliative care self-efficacy".*	Descriptive Online Survey	112 Paramedics	All variables were positively correlated with an intention to use a Specialist Palliative Care telehealth service apart from age and palliative care self-efficacy, which was negatively correlated. Thus, paramedics displayed a desire to use the service despite high palliative care self-efficacy ratings.	Possibility of self-selection bias. Desirability/positivity bias in that attitudes are often positive to new technology in a hypothetical scenario.

Juhrmann, et al. 2022 Australia - HIC	*"To examine the quality and content of existing Australian palliative paramedicine guidelines with a sample of guidelines from comparable Anglo-American ambulance services."*	Guideline Quality Appraisal and Qualitative Analysis	8 Palliative Care EMS Guidelines	Overall, guideline quality was poor to moderate according to the AGREE II instrument, however, this does not refer to clinical validity. Key themes from guideline analysis: 1) Audience and approach. 2) Communication is key. 3) Assessing and managing symptoms. 4) Looking beyond pharmaceuticals. 5) Seeking support. 6) Care after death.	Potentially relevant information may have been missed as EMS guidelines not palliative/EoL specific were excluded.
Juhrmann, et al. 2021 Australia - HIC	*"To review and synthesise the empirical evidence regarding paramedics delivering palliative and end-of-life care in community based settings."*	Systematic Literature Review	23 Articles	Key themes: 1) Broadening the traditional role. 2) Understanding patient wishes. 3) Supporting families. Paramedics can play an important role in facilitating home-based death and reducing unnecessary hospital admissions.	Selected articles limited to English. Some relevant articles potentially omitted.
Kamphausen, et al. 2019 Germany - HIC	*"To investigate challenges faced by emergency physicians (EPs) who provide prehospital emergency care to patients with advanced incurable diseases and family caregivers in their familiar home environment".*	Qualitative Individual Interviews	24 Emergency Physicians	Key themes: 1) Structural conditions of prehospital emergency care. 2) Medical documentation and orders. 3) Finding optimal and patient-centred therapy. 4) Uncertainty about legal consequences. 5) Challenges at the individual (EP) level. 6) Challenges at the emergency team level. 7) Family caregiver's emotions, coping, and understanding of patient's illness. 8) Patient's wishes, coping, and understanding of patient's illness.	Possibility of self-selection and recall biases. Limited external validity.

				9) Social, cultural, and religious background of patients and families.	
Knighting, et al. 2017 UK - HIC	To answer the questions, *"do paramedics view end-of-life care as a key part of their role and are they confident in managing this aspect of their clinical practice? Further to this, what are the underlying concerns of paramedics when managing end-of-life care"?*	Descriptive Online Survey	182 Paramedics	Paramedics saw end-of-life care as essential to their function. Fear of litigation and conflict with patient family members were identified as challenges in palliative care provision. Education is needed for paramedic confidence.	Impossible to verify participants' experience and qualifications. Low response rate.
Lamba, et al. 2013 USA - HIC	*"To 1) review four case scenarios that relate to palliative care and may be commonly encountered in the out-of-hospital setting and 2) provide a road map by suggesting four things to do to start an EMS-palliative care initiative in order to optimize out-of-hospital care of the seriously ill and increase preparedness of EMS providers in these difficult situations".*	Collaborative Plan of Action (IPAL-EM project) with Case Discussions	Plan of action to integrate palliative and prehospital care. 4 Case Discussions.	Four steps to begin an EMS-palliative initiative: 1) Identify EMS 'champions'. 2) Review protocols and literature. 3) Needs assessment. 4) Create action plan. Ideally, palliative care begins out-of-hospital. This study represents a guideline for the integration of palliative and EMS care.	Requires implementation in various settings as well as study to determine effectiveness. Limited case review.
Leibold, et al. 2018 Germany - HIC	*"To determine whether or not a paramedic's decision-making in end-of-life situations is influenced by his/her religious beliefs, how they decide given the current judicial framework, and how they would decide were there legal certainty".*	Descriptive Online Survey	429 Paramedics	Religious beliefs play a role in influencing paramedic decision-making, however, experience, background, special training and legal framework conditions, appear to have greater influence.	Possibility of self-selection bias. Unvalidated survey. Limited religions and beliefs represented across sample.

Lord, et al. 2019 Australia - HIC	*"To describe the incidence and nature of cases attended by paramedics and the care provided where the reason for attendance was associated with a history of palliative care".*	Retrospective Cohort	4348 Patient Records	Identified cases were 0.5% of caseload during study period. Most common assessments by paramedics were 'respiratory' (20.1%), 'pain' (15.8%) and 'deceased' (7.9%). Majority of patients were transported (74.4%, n=3237) with hospital the most prevalent destination (99.5%, n=3221).	Emergencies and reasons for paramedic calls may have been unrelated to palliative condition.
Lord, et al. 2012 Australia - HIC	*"To identify paramedics' knowledge, beliefs, and attitudes related to the care of patients requiring palliative care in community health settings".*	Qualitative Focus Group Interviews	3 focus group interviews with a total of 26 paramedics	Key themes: 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. Possibility of self-selection and group biases.
McCormick, et al. 2019 New Zealand - HIC	*"To understand the role New Zealand paramedics have as providers of community and pre-hospital palliative and EOL care, as well as to ascertain whether paramedics are suitably equipped and educated to provide quality palliative care to an increasingly elderly population with non-curable life-threatening illnesses".*	Rapid Literature Review	4 Articles	No New Zealand articles or guidelines were found. New Zealand Ministry of Health documents provide minimal reference to pre-hospital emergency medical providers. Paramedics already provide palliative and end-of-life care. They are willing to continue this provision, with improved education and better integration with other care providers.	Small sample of articles. Two databases searched. Lack of quality appraisal.
McGinley, et al. 2017 USA - HIC	*"To describe how medical orders inform EMS providers' decision making during emergencies involving*	Mixed-Methods: Descriptive Cross-Sectional	239 Surveys and 48 Interviews of EMS Providers	Many EMS providers (62.7%) had treated a patient with both an intellectual disability and medical orders directing end-of-life care. Key themes: 1) Provider	Possibility of self-selection bias. Limited external validity. Unvalidated survey.

	people with intellectual disabilities who are near life's end by considering the multiple (individual, organizational, sociocultural) contexts within which these decisions occur".	Survey and Individual Interviews		familiarity. 2) Organizational processes. 3) Sociocultural context.	
Mott, et al. 2020 Australia - HIC	*"To explore the experiences and attitudes of ambulance officers in managing pediatric patients with palliative care needs".*	Descriptive Online Survey	22 Ambulance Officers	Many ambulance officers found these cases to be challenging and their confidence levels varied. They were most likely to use correspondence provided by the family as a guide for management. Half of participants felt paediatrics receiving palliative care should have a 'not for resuscitation' order. They suggested support for themselves could be improved through increased patient documentation.	Small sample size. Possibility of self-selection and recall biases.
Murphy-Jones, et al. 2016 UK - HIC	*"To explore how paramedics make decisions when asked to transport nursing home residents nearing the end of their lives".*	Qualitative Individual Interviews	6 Paramedics	Key themes: 1) The challenges in understanding patients' wishes. 2) Evaluating patients' best interests. 3) The influence of others on decision making.	Possibility of self-selection and recall biases. Limited external validity.
Patterson, et al. 2019 UK - HIC	To investigate *"the extent to which access to, and quality of, patient information affects the care paramedics provide to patients nearing end-of-life, and their views on access to a shared electronic record as a means of*	Qualitative Individual Interviews	10 Paramedics	Key themes: 1) Access to information on patients nearing end-of-life. 2) Views on the proposed Electronic Palliative Care Coordination System (EPaCCS). Lack of access to patient information is a barrier to paramedics delivering end-of-life care. Access to EPaCCS may	Possibility of self-selection and recall biases. Limited external validity.

	improving the information flow around end-of-life care".			assist, but practical and technical challenges must be overcome for implementation.	
Pease, et al. 2019 UK - HIC	To *"describe the delivery, outcomes and potential impact of the Serious Illness Conversation project delivered to Welsh Ambulance Service Trust (WAST) staff".*	Mixed-Methods: Open-Ended Question Surveys, Pre- vs. Post-Intervention Surveys, Patient Care Record Review	218 Paramedics and 150 Paramedic Students	Participants view themselves as playing several roles in end-of-life care: 'facilitators' to patient-centred and seamless care, providing support, link between services and practical help. Barriers to providing end of life care centred around communication challenges. The Serious Illness Conversation training resulted in increased participant confidence handing these situations.	Self-assessment of confidence. Review of patient care records not specific to training participants.
Pentaris, et al. 2019 UK - HIC	To explore *"current knowledge and evidence about paramedics' attitudes and perceptions about end-of-life care".*	Systematic Literature Review	11 Articles	Key themes: 1) Critical incidents and emotional resilience. 2) Decision making. 3) Communicating death. 4) Recognising dying patients. 5) Death education. A dearth of literature exists concerning paramedics and end-of-life practice.	Selected articles limited to English. Some relevant articles potentially omitted.
Peran, et al. 2021 Czech Republic - HIC	To answer the question, *"What is the role of ambulance EMS, EMS dispatch centres, paramedics and emergency medical physicians in the provision of palliative care to terminally ill patients"?*	Scoping Literature Review	31 Articles	Three EMS roles and one contextual factor were identified: 1) Providing complex care. 2) Adjusting patient's trajectory. 3) Being able to make decisions in a time and information limited environment. 4) Health care professionals are insufficiently supported in palliative care.	Selected articles limited to English and German. Some relevant articles potentially omitted.

Rogers, et al. 2015 Australia - HIC	*"To identify and measure paramedics' perspectives and educational needs regarding palliative care provision, as well as their understanding of the common causes of death".*	Mixed Methods Survey	29 Paramedics	Paramedics have a good understanding of palliative care. They particularly identified terminal cancer as requiring palliation. Paramedic education is needed in end-of-life communication practices, ethical issues and illnesses requiring palliation.	Low response rate. Possibility of self-selection and recall biases.
Rosa, et al. 2021 Canada - HIC	*"To understand the current state of community paramedicine and palliative care"* in Canada.	Rapid Literature Review	Unspecified Number of Articles	Expanded scope of community paramedic practice that provides palliative care has potential benefit in alleviating healthcare system strain while simultaneously improving patient outcomes. Pilot community paramedic palliative care programs in Canada have demonstrated the benefits of reduced emergency department visits and improved patient satisfaction with community paramedic use.	Small sample. Lack of quality appraisal.
Stone, et al. 2009 USA - HIC	*"To ascertain paramedics' attitudes and beliefs about end-of-life decision-making; To measure the frequency with which practicing paramedics encounter various end-of-life situations…and the importance they assign to them; To assess the extent to which paramedics report they were trained to address end-*	Descriptive Cross-Sectional Survey	235 Paramedics	Participants perceived end-of-life issues as important, however, they did not feel adequately trained for these situations. Most (95%) agreed that paramedics should honour advance directives. Over half (59%) felt that paramedics should honour verbal wishes to limit on-scene resuscitation. Most (95%) had previously questioned intervention appropriateness in	Small sample size. Possibility of self-selection and recall biases.

	of-life situations; To compare the importance paramedics place on end-of life issues".			terminal patients. Some (26%) reported using personal judgement to withhold or terminate resuscitation in a terminal patient.	
Surakka, et al. 2020 Finland - HIC	To answer the questions, *"What is the frequency, reasons and timing of paramedic visits via the end-of-life protocol and do these visits differ between the areas with and without around the clock (24/7) palliative care services"?*	Retrospective Cohort	252 Patients, 306 Paramedic Visits	Most frequent reasons for paramedic visits were symptom control (38%) and transportation (29%). Paramedics visited 43% and 70% of the patients in areas with and without 24/7 palliative home care services, respectively. Over half (58%) of all paramedic visits were done outside office hours. Integration of paramedics into end-of-life care at home is reasonable particularly in rural areas without around the clock palliative care services and outside of office hours.	Efficacy of paramedic management and patient/family perceptions not assessed.
Surakka, et al. 2022 Finland - HIC	*"To describe experiences and educational needs of the paramedics included in the end-of-life care protocol."*	Mixed Methods Survey	192 Paramedics	Over 80% of paramedics agreed the protocol helped with care for patients with palliative needs and improved EoL care quality. Patient visits were considered useful (76.5%) and EoL care meaningful (62.5%) by paramedics who expressed challenges in psychosocial aspects, communication, symptom management, and their role in EoL care. They identified symptom management	Some respondents (28%) were inexperienced with the protocol. Potential for self-section and recall biases. Limited external validity.

				and communication as areas for education.	
Swetenham, et al. 2013 Australia - HIC	*"To explore the introduction of a rapid response team as outlined in the South Australian Palliative Care Services Plan 2009–2016".*	Mixed Methods: Call Log Data, Patient Records, Surveys and Individual Interviews	40 Patients attended by extended care paramedics, 24 Carer Interviews, 2 Patient Interviews, 22 Extended Care Paramedic Surveys	During the study period there were 40 paramedic visits. Of these, 90% received an after-hours visit and remained at their site of care; 5% attended an emergency department and 5% were directly admitted to hospice. Paramedics found palliative care rewarding and contributory towards job satisfaction, however, also demanding. Paramedics appreciated the specialist palliative care service's telephonic support.	Methodology lacking adequate description. Qualitative data without thematic analysis.
Taghavi, et al. 2011 Germany - HIC	*"To determine paramedics' practices in regard to withholding and terminating resuscitation, as well as to examine reports of their practical experiences with advance directives and special palliative crisis cards".*	Prospective Self-Administered Survey	728 Paramedics	End-of-life decision-making is challenging for paramedics. Guidelines for these situations are desired. Advance directives should be legally reinforced. Education in palliative care a need for paramedics.	No comparison of respondents vs. non-respondents – possibility of self-selection bias exists. Questionnaire was self-administered and unvalidated.
Waldrop, et al. 2014 USA - HIC	*"To identify how a sample of prehospital providers learned about EOL care, their perceived confidence with and perspectives on improved preparation for such calls".*	Mixed Methods Cross-Sectional Survey	178 Prehospital Providers	Key themes: 1) Prehospital provider education. 2) Public education. 3) Educating health care providers on scope of practice. 4) Conflict resolution skills. 5) handling emotional families. 6) Clarification of transfer protocols. Majority of paramedics received formal training on DNR orders (92%) and MOLST (72%). Majority of	Small sample size. Limited external validity.

				paramedics confident in ability to uphold DNR orders (87%) and resolve family conflict (87%).	
Waldrop, et al. 2015 USA - HIC	*"To explore prehospital providers' perceptions of (1) the frequencies of different types of end-of life calls, (2) the signs and symptoms of dying in prehospital care, and (3) medical orders for life sustaining treatment (MOLST)".*	Descriptive Cross-Sectional Pilot Survey	178 Prehospital Providers	Calls to nursing homes and dying patients were frequent. MOLST documentation was infrequently encountered. There is synergy between prehospital and palliative medicine, however, further research is needed to develop prehospital end-of-life decision-making and understand how prehospital providers operate when confronted with palliative situations.	Open to participant information recall bias and perceptions. Convenience sampling at a single institution limiting external validity. Unvalidated survey.
Waldrop, et al. 2019 USA - HIC	"*To explore prehospital providers' perspectives on how the awareness of dying and documentation of preferences influence decision-making on emergency calls near the end of life".*	Qualitative Individual Interviews	43 EMS Providers	Key themes: 1) Aware of Dying-Wishes are Documented. 2) Aware of Dying—Wishes are Undocumented. 3) Unaware of Dying-Wishes are Documented. 4) Unaware of Dying Wishes are Undocumented. 5) Discordance. EMS providers are well aware of the impact of their decisions at the end of life. EMS providers play a critical role at the end of life.	Possibility of self-selection and recall biases. Limited external validity.
Waldrop, et al. 2018 USA - HIC	*"To investigate prehospital providers' perceptions of emergency calls at life's end."*	Qualitative Individual Interviews	43 EMS Providers	Key themes: 1) Care crises. 2) Dying-related turmoil. 3) Staffing ratios. 4) Organizational protocols. EMS providers become mediators between nursing homes and emergency	Possibility of self-selection and recall biases. Limited external validity.

				departments by handling tension, conflict and challenges in patient management.	
Waldrop, et al. 2015 USA - HIC	*"To explore and describe how prehospital providers assess and manage end-of-life emergency calls".*	Qualitative Individual Interviews	43 EMS Providers	Key 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.	Possibility of self-selection and recall biases. Limited external validity.
Wenger, et al. 2022 USA - HIC	*"To survey the state of Michigan's EMS providers regarding encounters with hospice patients to better understand challenges caring for this population and to identify any need for additional education."*	Self-Administered Survey	706 EMS Providers	Most EMS providers (96%) had at least one encounter with a hospice patient. Only 24% had received formal education in this area. Most (86%) indicated interest in this training. Identified challenges included inaccessible advance directives (72%), pressure from family for aggressive treatment (61%), and difficulty contacting hospice personnel (48%). Empowering EMS providers with training in these areas would bridge the gaps.	Possibility of self-selection and recall biases. Questionnaire was self-administered and unvalidated. Limited external validity.
Wiese, et al. 2013 Germany - HIC	*"To determine international recommendations for the treatment and prevention of palliative emergencies".*	Mixed Methods: Prospective Self-Administered Survey	92 Experts	Four standards in the management of palliative emergencies were recommended: 1) Early integration of "Palliative Care Teams" and basic outpatient	Possibility of self-selection bias. Limited external validity. Unvalidated survey.

				palliative care systems. 2) End-of-life discussions. 3) Defined emergency medical documents, drug boxes, and "Do not attempt resuscitation" orders. 4) Emergency medical training for physicians and paramedics.	
Wiese, et al. 2012 Germany - HIC	*"To determine paramedics' understanding of their role in withholding or withdrawing resuscitation/EoL-treatment of palliative care patients when an advance directive is present".*	Prospective Self-Administered Survey	728 Paramedics	Majority of paramedics (71%) have dealt with palliative emergencies. Improved training and guidelines for paramedics are necessary. Ethical and legal obligations may conflict for paramedics faced with palliative emergencies.	Possibility of self-selection and recall biases. Questionnaire was self-administered and unvalidated.
Wiese, et al. 2010 Germany - HIC	*"To provide information about the strategic and therapeutic approach employed by EMTs in outpatient palliative care patients in cardiac arrest".*	Retrospective Cohort	88 Patient Records	Approaches to prehospital palliative patients with cardiac arrest differ based upon EMS provider qualification. Many resuscitations are initiated contrary to patient wishes due to lack of advance directives. These should be more readily available.	Small sample size. Limited external validity.
Wiese, et al. 2009 Germany - HIC	*"To show the importance of palliative medical care competence in the pre-hospital emergency medical care of patients with advanced cancer diseases* [and] *to describe basic approaches to improve the current situation in Germany".*	Prospective Cohort	361 Emergency Calls	Prehospital palliative care improves when prehospital physicians have palliative care expertise. Prehospital palliative care education is recommended.	Limited external validity.
Wiese, et al. 2009 Germany - HIC	To interview prehospital emergency physicians (EP) *"about their knowledge of*	Retrospective Self-	104 Emergency Physicians	Most participants (89%) had been confronted with palliative emergencies and expressed	Possibility of self-selection and recall biases. Questionnaire was self-

	palliative care, about their experiences in dealing with palliative care patients in out-of-hospital emergency situations and about their beliefs and interests in palliative care".	Administered Survey		uncertainties in managing these situations. Psychosocial and social care represented frequent challenges. Most participants (80%) were interested in further palliative care training.	administered and unvalidated.
Wiese, et al. 2009 Germany - HIC	To investigate and compare *"the emergency medical treatment of acute dyspnoea in palliative care patients affected by advanced (palliative) stages of cancer disease on basis of emergency medical therapy schemes".*	Retrospective Cohort	116 Patient Care Records	Significant relief of acute dyspnoea when using opioids compared to standard treatment. This should be included in emergency physician training. Most emergency physicians (>70%) were uncertain about palliative patient management.	Small sample size. Limited external validity.

Appendix 5: Palliative Care Provider Interview Discussion Schedule

Discussion Schedule

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 elicit further explanation.

FACILITATION: *Before the interview, refer to this discussion schedule to ensure familiarity with the content. Lead the discussion, take notes and operate the audio recording device.*

PREPARATION: *Audio recording equipment should be tested from various positions within the room before the interview in the case of in person interviews. In the case of virtual interviews, confirm stable internet connectivity and correct operation of the recording function on the chosen platform. Ensure that participant consent forms and note-taking materials are prepared. 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 perspectives. All of your answers will be kept strictly confidential. I would also like to remind you that your consent may be withdrawn at any time, including during this process.** *(Give opportunity for questions concerning confidentiality)*

SESSION INTRODUCTION: *Briefly introducing yourself. Ask the participant to introduce themselves. You may start the session as follows:*

Identify participant on the recording by interview number.

Thank you very much for taking the time to discuss the topic of palliative care and EMS in South Africa. EMS are typically used for life-threatening, emergency situations with the goal of saving life and limb, primarily in the out of hospital setting (for example in patient homes). In this setting, EMS providers often encounter palliative patients in emergent and non-emergent situations requiring care. Thus, EMS and palliative care overlap in these situations. The purpose of this interview is to gather your perspectives on EMS use in palliative care in terms of its utility, barriers and concerns with use and feasibility in the South African setting.

I will begin by briefly asking about yourself and your experience in South African palliative care. I will then ask six main 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. *Re-iterate during this introduction that this process is less of a formal interview and more of a discussion to gain the*

interviewees valuable and informed perspectives. In addition, mention that notes will be taken during the interview, but this is nothing to worry about.

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

PROMPTS AND PROBES:

- Demographics: Age, Gender, Qualification, Current Position, Area of Work (rural vs. urban).

- Years of experience.

- Previous experience/positions.

2. **In a previous study we gathered data on the intersection between EMS and patients with palliative needs. With regards to your setting, how do these findings compare?**

PROMPTS AND PROBES:

- In a state district hospital, 51% of patients with palliative needs used EMS, and 27% in a state tertiary hospital.

- This resulted in up to 36 such EMS palliative cases per month at a single hospital.

- The vast majority of patients with palliative needs (84%) were from rural areas and were cared for primarily by family (89%).

- The leading chief complaint was dyspnoea (36%) while the leading diagnosis was cancer (32%).

3. **What are your thoughts surrounding EMS involvement in palliative situations?**

PROMPTS AND PROBES:

- Helpful vs. Harmful.

- Any personal experience with EMS use in palliative care?

- Could EMS potentially be utilised? If so, where?

- Opportunity for EMS use in palliative care (after hours, palliative emergencies, home care).

- EMS perspective from previous study: they often encounter palliative patients, but have limited management options due to system, mindset, resource and education problems. However, they see palliative care as important to their role.

4. **Would you have any concerns with using EMS in palliative care situations?**

PROMPTS AND PROBES:

- Particularly in the out of hospital setting.

- System concerns: lack of integration and communication.

- Legalities.

- Ethical considerations.

- Concerns with EMS: knowledge, education, skill, role/function.

- Concerns for palliative patients: standards of care, inappropriate care

- (Note: answers to this question may naturally flow into the next question).

5. **What barriers exist (if any) in your setting to the potential use of EMS in palliative situations?**

PROMPTS AND PROBES:

- Resources

- Communication

- Uncertainty regarding EMS systems and capabilities

- Palliative care system constraints

6. **Taking all of our discussion into account, would you please provide your thoughts on the feasibility of EMS use in palliative situations?**

PROMPTS AND PROBES:

- Potential solutions to concerns/barriers.

- *Summary statement: Can/should it be done and how? (or why not?)*

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

Thank you so much for spending your valuable time discussing this topic with me and taking part in this study. Your perspectives are incredibly helpful, and I have thoroughly enjoyed our discussion. Your contribution is much appreciated.

After the session has been concluded, answer any further questions the interviewee may have concerning the study.

Appendix 6: Patient and Family Member Interview Discussion Schedule

Discussion Schedule

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 elicit further explanation.

FACILITATION: *Before the interview, refer to this discussion schedule to ensure familiarity with the content. Lead the discussion, take notes and operate the audio recording device.*

PREPARATION: *Audio recording equipment should be tested from various positions within the room before the interview in the case of in person interviews. In the case of virtual interviews, confirm stable internet connectivity and correct operation of the recording function on the chosen platform. Ensure that participant consent forms and note-taking materials are prepared. 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 perspectives. All of your answers will be kept strictly confidential. I would also like to remind you that your consent may be withdrawn at any time, including during this process.** *(Give opportunity for questions concerning confidentiality)*

SESSION INTRODUCTION: *Briefly introducing yourself. Ask the participant to introduce themselves. You may start the session as follows:*
Identify participant on the recording by interview number.
Thank you very much for taking the time to discuss the topic of palliative care and EMS in South Africa. EMS are typically used for life-threatening, emergency situations with the goal of saving life and limb, primarily in the out of hospital setting (for example in patient homes). In this setting, EMS providers often encounter palliative patients in emergent and non-emergent situations requiring care. Thus, EMS and palliative care overlap in these situations. The purpose of this interview is to gather your perspectives on EMS use in your care in terms of reasons for use, effectiveness of care received, satisfaction with and confidence in EMS providers.

I will begin by briefly asking about yourself. I will then ask four main 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. *Re-iterate during this introduction that this process is less of a formal interview and more of a discussion to gain the interviewees valuable and informed perspectives. In addition,*

mention that notes will be taken during the interview, but this is nothing to worry about.

1. **Could you please begin by telling me about yourself?**

PROMPTS AND PROBES:
- *Demographics: Age, Gender.*
- *Years of hospice enrolment/palliative care.*
- *Chronic medical conditions (interviewee should only state what he/she is comfortable with sharing)*

2. **You have previously experienced care from EMS/paramedics. What was the reason for EMS involvement?**

PROMPTS AND PROBES:
- *Elaborate on the situation.*
- *Emergency vs. non-emergency.*
- *Symptom control or procedure.*
- *Lack of access to palliative care provision.*
- *Were you or your loved one transported by EMS to a medical facility? (if so, where? - ED, hospice, clinic)*

3. **How satisfied would you say you were with the care received from EMS providers?**

PROMPTS AND PROBES:
- *Elaborate on reasons for poor or good satisfaction levels.*
- *EMS Professionalism, attitude, competence.*
- *Confidence in EMS providers.*
- *Were needs met (patient and family)? (Symptom control/management: physical, mental, emotional, spiritual, social; Fulfilment of care goals and wishes.)*

4. **Taking all of our discussion into account, in what areas could EMS providers improve?**

PROMPTS AND PROBES:
- *Knowledge/education, affect, holistic care.*
- *Summary: Would you currently recommend/use EMS providers again? (why or why not?)*

SESSION CONCLUSION: *Once all the questions have been asked and answered you may conclude the session as follows:*
Thank you so much for spending your valuable time discussing this topic with me and taking part in this study. Your perspectives are incredibly helpful, and I have thoroughly enjoyed our discussion. Your contribution is much appreciated. *After the session has been concluded, answer any further questions the interviewee may have concerning the study.*

Appendix 7: NGT Procedural Schedule

NOTES TO FACILITATOR: Statements in *ITALICS* are instructions to the facilitator. Items to be read out are in **BOLD.** Prompts contained in textboxes may also be read out during the clarification phase to elicit further explanation.

FACILITATION: *Before convening the nominal group, refer to this procedural schedule to ensure familiarity. Lead the group through the below steps, take notes and operate the online platform including audio-recording and transcription.*

PREPARATION: *Online platform, audio-recording and transcription functions should be tested prior to convening the nominal group. Confirm stable internet connectivity and prepare note-taking materials. Ensure participants are as comfortable as possible before beginning. Confirm that the participants have signed consent forms and that they consent to being audio recorded.*

CONFIDENTIALITY STATEMENT: **There are no right or wrong answers to the question we will be discussing. Rather, we are here to generate ideas. All discussions will be kept strictly confidential within this group and identities anonymised. I would also like to remind you that your consent may be withdrawn at any time, including during this process.** *(Give opportunity for questions concerning confidentiality)*

SESSION INTRODUCTION: *Briefly introducing yourself. Ask the participant to introduce themselves. Start the session by reading and visually presenting the following introduction:*

<u>Study Aim</u>

The aim of this study is to develop and prioritise approaches facilitating palliative care and EMS system integration within the context of SA.

<u>Context</u>

SA suffers from a quadruple burden of disease from high rates of maternal/neonatal mortality, communicable diseases (i.e. HIV and TB), non-communicable diseases and traumatic injury. The ensuing chronic, life-limiting illnesses have resulted in an increased need for palliative care. However, supply of palliative care is currently inadequate to meet demand resulting in a lack of access to this care for patients and their families. As a result, palliative providers have recognised the need to integrate with additional services. This maintains political support as SA previously supported a World Health Assembly (WHA) resolution to strengthen palliative care and prioritise its development. Furthermore, palliative care is an essential service in the National Health Insurance (NHI) bill and is considered a human right.

<u>EMS</u>

One additional service yet to be formally involved in SA is EMS, despite their frequent intersection with palliative situations. Within the country EMS are called to palliative situations for both emergency and non-emergency needs. Patients and their families use EMS in such situations to enhances access to palliative care through conveyance and 24/7 availability. However, due to the current lack of EMS and palliative care integration, EMS providers frequently mismanage palliative situations through unnecessary hospital conveyance and procedural interventions, often disregarding patient and family wishes.

EMS and palliative providers, along with patients and families with palliative needs, have all viewed EMS and palliative care integration positively, however, several barriers have been identified:

Barriers to Integration	
Challenging out-of-hospital environment for EMS (safety, limited time and information)	**Fear of litigation**
Compelled EMS conveyance	**Limited EMS scope of practice**
Unreliability of EMS service delivery	**EMS and palliative care cultures**
Lack of alternative care pathways	**Lack of education**

NOMINAL GROUP: *Explanations of the below steps should be provided before commencing. Allow time for clarifying questions.*

QUESTION: **Taking this information into account, what do you think should or could be done to most effectively integrate EMS and palliative services in South Africa?**

STEP 1: SILENT IDEA GENERATION: *Approximately 5 minutes given for each participant to silently and individually record as many answers as possible to the question posed. The facilitator should remain silent.*

STEP 2: ROUND ROBIN DISCUSSION: *Approximately 30 minutes for each participant to present their ideas. These should be recorded by the facilitator for all to see.*

STEP 3: CLARIFICATION: *Approximately 1 hour for discussion and clarification of ideas. Participants should be given the opportunity to ask questions about the ideas and clarify their meaning. Similar ideas should be combined. Ideas may also be excluded, or new ideas generated.*

STEP 4: RANKING: *Participants should be asked to individually rank ideas in order of priority from highest to lowest. A scoring system should be applied to the top 5 ideas. The scores for each idea should be summed and presented to the group for discussion and re-ranking pro re nata. Scoring system: The top ranked idea should be scored five points, the second four points and likewise for the remainder.* (Note: this step was completed online).

SESSION CONCLUSION: *Once all ranking has been concluded, any further questions or items for clarification should be addressed. The facilitator should thank all participants, stop the recording and close the session.*

Appendix 8: NGT Idea Categories

Phase 2: Round Robin Discussion

Funding	
Alternative Pathways/Approaches	
Communication	
Education	
Governance	
Information Sharing	
Collaborations	
Research	
Awareness	
Stakeholder Management	
Other	

Appendix 9: NGT Ranking Survey

Impact and Feasibility Rankings

Please rank each item generated in the previous phases according to its potential impact and feasibility within the South African context.

1.Please state your name (this will be anonymized in the final report and is simply being captured to ensure all participants have completed the form)

Enter your answer

2.Please state your qualifications and years of post-graduate experience.

Enter your answer

3.Budget allocations for palliative care within EMS – education, policy and guideline development, service provision

	Low-1	Moderate-2	High-3
Impact			
Feasibility			

4.Adjusting private sector EMS funding models relating to medical insurance.

	Low-1	Moderate-2	High-3
Impact			
Feasibility			

5.Allocating finances for EMS in palliative care in the public sector.

	Low-1	Moderate-2	High-3
Impact			
Feasibility			

6.Develop a model for EMS and palliative care integration at various healthcare system levels and EMS environments.

	Low-1	Moderate-2	High-3
Impact			
Feasibility			

7.Ongoing EMS and palliative care research concerning efficacy.

	Low-1	Moderate-2	High-3
Impact			
Feasibility			

8.EMS and palliative care integration cost-benefit analyses.

	Low-1	Moderate-2	High-3
Impact			
Feasibility			

9.Palliative care awareness and education for the public.

	Low-1	Moderate-2	High-3
Impact			
Feasibility			

10.Palliative care awareness for the EMS community.

Low-1 Moderate-2 High-3

Impact

Feasibility

11.Palliative care awareness for in-hospital healthcare providers, particularly emergency medicine.

Low-1 Moderate-2 High-3

Impact

Feasibility

12.Development of care packages for EMS in palliative situations based upon scope of practice.

Low-1 Moderate-2 High-3

Impact

Feasibility

13.Policies for EMS to independently prescribe medications.

Low-1 Moderate-2 High-3

Impact

Feasibility

14.Policies for EMS administering medications in palliative situations.

Low-1 Moderate-2 High-3

Impact

Feasibility

15.EMS ability to administer already prescribed medications.

Low-1 Moderate-2 High-3

Impact

Feasibility

16.Defined alternative care pathways for EMS in palliative situations.

Low-1 Moderate-2 High-3

Impact

Feasibility

17.Defined processes for EMS linking palliative situations with outpatient services, community healthcare, and community oriented primary care.

Low-1 Moderate-2 High-3

Impact

Feasibility

18.Specialist out-of-hospital palliative care team – inclusive of EMS and/or non-EMS staff.

Low-1 Moderate-2 High-3

Impact

Feasibility

19.Development of EMS palliative care networking team.

Low-1 Moderate-2 High-3

Impact

Feasibility

20.Mechanisms for EMS to handover patient care in palliative situations to family members.

Low-1 Moderate-2 High-3

Impact

Feasibility

21.EMS community care approach.

Low-1 Moderate-2 High-3

Impact

Feasibility

22.Palliative care advice for EMS at point of care.

Low-1 Moderate-2 High-3

Impact

Feasibility

23.Development of telehealth systems for patients, family members and EMS.

Low-1 Moderate-2 High-3

Impact

Feasibility

24.Development of palliative care committees inclusive of EMS, hospice, in-hospital management at all levels of care.

Low-1 Moderate-2 High-3

Impact

Feasibility

25.Community engagement concerning specific palliative care needs.

Low-1 Moderate-2 High-3

Impact

Feasibility

26.Recognition of signs of dying.

Low-1 Moderate-2 High-3

Impact

Feasibility

27.Training in subcutaneous medication administration.

Low-1 Moderate-2 High-3

Impact

Feasibility

28.EMS patient and family member communication.

Low-1 Moderate-2 High-3

Impact

Feasibility

29.EMS undergraduate training in palliative care – principles of palliative care, relevant medications, paeds and adults.

Low-1 Moderate-2 High-3

Impact
Feasibility

30.Improved understanding of palliative care for EMS – including legal and ethical implications, DNRs, ACPs, qualification levels.

Low-1 Moderate-2 High-3

Impact
Feasibility

31.Post-graduate palliative care training for EMS providers.

Low-1 Moderate-2 High-3

Impact
Feasibility

32.Post-graduate palliative care training for EMS educators.

Low-1 Moderate-2 High-3

Impact
Feasibility

33.Early recognition of palliative cases.

Low-1 Moderate-2 High-3

Impact
Feasibility

34.Include EMS in inter-disciplinary palliative care education.

Low-1 Moderate-2 High-3

Impact
Feasibility

35.Ongoing education in palliative care for EMS (i.e. CPDs)

Low-1 Moderate-2 High-3

Impact
Feasibility

36.EMS palliative care curriculum development.

Low-1 Moderate-2 High-3

Impact
Feasibility

37.Development of palliative care teams at hospital level to identify patients with palliative needs.

Low-1 Moderate-2 High-3

Impact
Feasibility

38.Development of guidelines, SOPs for EMS at point of care – including who to call.

Low-1 Moderate-2 High-3
Impact
Feasibility

39.EMS palliative care case reviews, debriefs for quality improvement..

Low-1 Moderate-2 High-3
Impact
Feasibility

40.Recognition of palliative care trained EMS providers.

Low-1 Moderate-2 High-3
Impact
Feasibility

41.Registration of advanced EMS providers in palliative care.

Low-1 Moderate-2 High-3
Impact
Feasibility

42.Improved EMS scope of practice for EMS from HPCSA.

Low-1 Moderate-2 High-3
Impact
Feasibility

43.Legal and ethical support for EMS in palliative situations.

Low-1 Moderate-2 High-3
Impact
Feasibility

44.Advanced care plan availability for EMS at point of care.

Low-1 Moderate-2 High-3
Impact
Feasibility

45.Support for EMS to fulfil advanced care plans by including information (instructions, contact details) specific to EMS in the plans.

Low-1 Moderate-2 High-3
Impact
Feasibility

46.Include EMS within advanced care plans.

Low-1 Moderate-2 High-3
Impact
Feasibility

47.Cross-disciplinary communication and information-sharing – EMS, palliative care, in-hospital providers.

Low-1 Moderate-2 High-3
Impact
Feasibility

48.EMS providers spending time in palliative care practices.

Low-1 Moderate-2 High-3

Impact

Feasibility

49.EMS and palliative care networking with locally available resources.

Low-1 Moderate-2 High-3

Impact

Feasibility

50.Include EMS in palliative care policies to link services and prioritise palliative care cases.

Low-1 Moderate-2 High-3

Impact

Feasibility

51.Collaboration between EMS and palliative care societies.

Low-1 Moderate-2 High-3

Impact

Feasibility

52.Collaboration between EMS and palliative care decision-makers at a national level.

Low-1 Moderate-2 High-3

Impact

Feasibility

53.Palliative care contacts for patients and family members – 24/7 availability.

Low-1 Moderate-2 High-3

Impact

Feasibility

54.EMS support tools to assist in the identification of patients with previously unrecognized palliative needs.

Low-1 Moderate-2 High-3

Impact

Feasibility

Appendix 10: NGT Prioritisation Matrix

Impact	Low	Moderate	High
High	- Allocate finances for EMS in palliative care in the public sector. - Improve EMS scope of practice for EMS at the Health Professions Council of South Africa (HPCSA).	- Allocate budget for palliative care within EMS – education, policy and guideline development, service provision. - Adjust private sector EMS funding models relating to medical insurance. - Develop mechanisms for EMS to handover patient care in palliative situations to family members. - Define processes for EMS linking palliative situations with outpatient services, community healthcare, and community oriented primary care. - Develop palliative care teams at hospital level to identify patients with palliative needs. - Develop EMS support tools to assist in the identification of patients with previously unrecognized palliative needs. - Enable early EMS recognition of palliative cases. - Post-graduate palliative care training for EMS providers. - Train EMS in patient and family member communication. - EMS palliative care curriculum development. - Improve EMS understanding of palliative care – including legal and ethical implications, DNRs, ACPs, qualification levels. - Post-graduate palliative care training for EMS educators. - Ongoing education in palliative care for EMS (i.e. Continual Professional Development) - Establish EMS palliative care case reviews and debriefing sessions for quality improvement. - Make advance care plans available for EMS at the point of care. - Include EMS within advance care plans. - Establish cross-disciplinary communication and information-sharing – EMS, palliative care, in-hospital providers. - Support for EMS to fulfil advance care plans by including information (instructions, contact details) specific to EMS in the plans. - Provide palliative care advice for EMS at the point of care. - Develop EMS palliative care networking teams. - EMS and palliative care networking with locally available resources. - Develop palliative care committees inclusive of EMS, hospice and in-hospital management at all levels of care. - Develop a model for EMS and palliative care integration at various healthcare system levels and within various EMS environments. - Develop guidelines and standard operating procedures for EMS at the point of care – including who to contact for advice. - Develop policies for EMS medication administration in palliative situations. - 24/7 availability of palliative care contacts for patients and family members.	- Enable EMS to administer already prescribed medications. - EMS undergraduate training in palliative care. - Improve EMS recognition of signs of dying at the end of life. - Palliative care awareness for the EMS community. - Palliative care awareness for in-hospital healthcare providers, particularly those in emergency medicine.
Moderate	- Develop telehealth systems for patients, family members, and EMS. - Register advanced EMS providers in palliative care at HPCSA. - EMS and palliative care decision-maker collaboration at a national level. - Develop policies for EMS to independently prescribe medications.	- Develop an EMS community care approach. - Create specialist out-of-hospital palliative care teams inclusive of EMS and/or non-EMS staff. - Define alternative care pathways for EMS in palliative situations. - Develop care packages for EMS in palliative situations based upon scope of practice. - Include EMS in inter-disciplinary palliative care education. - Provide legal and ethical support for EMS in palliative situations. - Recognize palliative care trained EMS providers. - Have EMS providers spend time in palliative care practices. - Perform EMS and palliative care integration cost-benefit analyses. - Perform ongoing EMS and palliative care research concerning efficacy of integration. - Include EMS in palliative care policies to link services and prioritise palliative care cases. - Engage community concerning specific palliative care needs. - Provide palliative care awareness and education for the public.	- EMS training in subcutaneous medication administration. - Collaboration between EMS and palliative care societies.
Low			

Feasibility