

PALLIATIVE SUPPORT BY EMERGENCY MEDICAL SERVICES FOR PERSONS
AT THE END OF LIFE:
A POPULATION BASED ANALYSIS OF NEED

by

Andy Muise

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ABSTRACT

Emergency Medical Services (EMS) are often involved in providing care to individuals at the end of life. Despite this, the development of EMS palliative support has been limited. This thesis utilized a linked administrative database describing Nova Scotia decedents between 1995 and 2009, and EMS patient care records (PCRs) from January to March 2014 to describe the need for EMS palliative support and determine if EMS patient demographics differ between end of life and non-end of life related calls.

In-hospital death rates were found to be high, supporting the need for improved home based care. Palliative care services (PCS) enrollment increased over study duration for both cancer and non-cancer decedents. Comorbidities were found to be common among individuals at the end of life. Overall, individuals with non-cancer conditions appeared to be more complex, and were enrolled in PCS less often and later than cancer decedents.

EMS PCRs suggested that EMS is frequently involved in providing care to older adults and individuals with conditions that may benefit from palliative support. EMS providers did not often record advanced directives (ADs) and do not resuscitate orders (DNRs) on scene. The development and application of a Palliative Support Composite Measure (PSCM) to estimate the frequency of calls where palliative support may have been beneficial suggested 1% of EMS calls had a probable palliative purpose. A further 22.5% of calls were categorized as potential palliative, 45.6% were low potential palliative, while 30.9% of calls were categorized as non-palliative. The further refinement and validation of this measure is recommended.

To address the limitations of this thesis, it is proposed that EMS and death certificate data be linked to further describe EMS utilization in the final year of life. As well, it is hoped that this linkage will help validate and refine the PSCM via Classification and Regression Tree (CART) analysis.

EMS palliative support has the potential to address a gap in the delivery of out-of-hospital palliative care, as there are few options available in emergency situations. Improved emergency palliative support appears to be warranted as there is an increasing trend in the frequency of individuals requesting palliative care and wishing to receive care in the home. Considerations in the delivery of EMS palliative support include comorbidities at the end of life, the limited frequency of AD/DNRs, and the increasing prevalence of individuals with non-cancer conditions requesting palliative care.

LIST OF ABBREVIATIONS USED

ACP- Advanced Care Paramedic

AD- Advance Directive

AIDS- Acquired Immunodeficiency Syndrome

ALS- Amyotrophic Lateral Sclerosis

CART- Classification and Regression Tree

CCP- Critical Care Paramedic

CI- Confidence Interval

CIHI- Canadian Institute of Health Information

COPD- Chronic Obstructive Pulmonary Disease

CTAS- Canadian Triage and Acuity Scale

DHA- District Health Authority

DNR- Do Not Resuscitate Order

ECP- Extended Care Paramedic

ED- Emergency Department

EHS- Emergency Health Services Nova Scotia

EMS- Emergency Medical Services

ePCR- Electronic Patient Care Record

HCN- Health Card Number

IQR- Interquartile Range

MLR- Multiple Logistic Regression

NELS-Network for End of Life Studies

NSDHW- Nova Scotia Department of Health and Wellness

NSVS- Nova Scotia Vital Statistics

PCS- Palliative Care Service

PCR- Patient Care Record

PSCM- Palliative Support Composite Measure

WHO-World Health Organization

GLOSSARY

Advance Directive: Documentation of a person's wishes regarding medical treatment in the event the individual is unable to communicate these decisions directly (MedlinePlus 2014a).

Do Not Resuscitate Order: A medical order that instructs healthcare providers to not perform cardiopulmonary resuscitation (CPR) if the patient's heartbeat or breathing stops (MedlinePlus, 2014b).

Emergency Medical Services (EMS): Medical services provided in a pre-hospital environment under emergency situations. EMS providers are typically responsible for the transport of patients from the location of their emergency to hospitals or other care centres.

End of Life Care: Health care received by an individual during the final days, weeks and months of life when suffering from a terminal disease (Johnston, 2014). Care provided during this phase of life can be palliative and/or curative in intent.

Home Care: Medical or personal care provided to an individual within their own home.

Palliative Care: Care that focuses on improving quality of life through the provision of symptom relief, spiritual and psychological support from diagnosis to the end of life for patients and their families (World Health Organization (WHO), 2015).

Palliative Care Service (PCS): A formal comprehensive palliative care program providing care for persons in District Health Authorities in Nova Scotia, Canada. They are described in more detail in Lavergne et al. (2015).

Palliative Support: A holistic concept that involves the provision of care that improves the quality of life and respects the goals of care for persons living with life limiting disease. In this paper, palliative support is used to describe the potential role of emergency medical services in the coordinated delivery of palliative care.

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CHAPTER 1: INTRODUCTION

Given the aging of our population, increased emphasis on the delivery of palliative care and the need to improve the delivery of community based health care; this thesis was developed to improve the understanding of the role of Emergency Medical Services (EMS), in providing palliative support. Nova Scotia, Canada is a leader in the provision of quality EMS and EMS innovation; and provides an ideal location for this research, as the system is in the process of implementing new palliative care protocols.

End of Life Care

End of life care can be defined as care received by an individual during the final days, weeks and months of life when suffering from a terminal disease (Johnston, 2014). Care provided at this stage of life can consist of both palliative and curative care. Palliative care is a holistic concept which involves the provision of care that is of a supportive nature, improving the quality of life and preparation for death (Stone, 2001; Cairstairs, 2010). Palliative care also emphasizes the provision of spiritual and psychosocial support for individuals at the end of life and considers supporting family and loved ones after the individual has passed (WHO, 2015; Stone, 2001; Teno et al., 2004; Singer et al., 1999; Lamba et al., 2013). In comparison, curative care focuses on the treatment of chronic disease and resolution from the disease state.

For individuals at the end of life, the provision of palliative and curative care should not be mutually exclusive. The delivery of concurrent palliative and curative care should be

based on an individual's preferences, often with the delivery of palliative care increasing as a life limiting chronic disease progresses.

Overall, the ability to meet individual preferences during the end of life may be improved through early advance care planning and preparation for death (Institute of Medicine, 2014). However, reluctance in western society to discuss death and palliative care has traditionally impacted palliative care delivery, as there has been apprehension for both a caregiver to accept that an individual is nearing the end of life and for an individual to accept they are nearing the end of life (Carstairs, 2010).

Major Themes in Palliative Care

Effective end of life care should be person centred and be provided in conjunction with psychosocial and spiritual support in order to improve outcomes at the end of life (Institute of Medicine, 2014). Key components of palliative care include providing adequate pain and symptom management, avoiding the use of life supporting interventions that would prolong life when there is little hope for recovery or restoration of functional abilities, allowing individuals at the end of life to have a sense of control throughout the proceedings, relieving the burden on family and loved ones, strengthening relationships and allowing individuals at the end of life to achieve a sense of completion (Singer et al., 1999; Heyland et al., 2006; Steinhauser et al., 2000). Effective communication and the ability to build a level of trust with care providers has also been noted as a core component associated with quality end of life care (Hanson et al., 1997).

Home Based Palliative Care: A Solution?

The majority of individuals at the end of life express the wish to die in the home environment (Higginson & Sen-Gupta, 2000; Brazil et al., 2005; NELS News, 2011; Gomes et al., 2013). Due to the prevalence of this request, location of death is often viewed as a measure of quality of end of life care, as high in-hospital rates of death can be seen as an indicator of poor access to home-based services and advance care planning (Earle et al., 2003; Grunfeld et al., 2008; Lawson et al., 2009). If proper resources and supports are in place, receiving palliative and hospice care at home has been linked with improved patient and family member satisfaction (Teno et al., 2004; Brumley et al., 2003; Brumley et al., 2007). Individuals at the end of life often prefer to die at home due to the comfort associated with receiving care and dying in a familiar environment with the opportunity to have loved ones present (Gott et al., 2004; Miccinesi et al., 2012).

Individuals enrolled in home-based palliative care were more likely to die at home than those not enrolled in home based programs (Brumley et al., 2003; Brumley et al., 2007; Gomes et al., 2014). Additionally, home based palliative care programs have been shown to reduce medical system usage during the final months of life, as individuals enrolled in these programs exhibit fewer Emergency Department (ED) visits and in-hospital days (Brumley et al., 2003; Brumley et al., 2007; McNamara et al., 2013). Furthermore, home-based palliative care had lower associated healthcare costs than traditional hospital-based palliative care programs (Brumley et al., 2003; Brumley et al., 2007).

Despite the home environment frequently being considered the preferred location of death, concerns do persist regarding the delivery of end of life care and dying at home (Gott et al, 2004). Focus group discussions and interviews with older adults identified

that many did not want to become a burden for loved ones during their final days and often expressed concerns about having an able caregiver at home (Fried et al., 1999; Gott et al., 2004). Individuals also had apprehension with respect to the quality of care that could be provided in the home, specifically relating to ensuring adequate symptom relief (Gott et al, 2004).

A Nova Scotia Mortality Follow Back study interviewed family members after their family member had died to ascertain concerns with care provided at the end of life. Findings included concerns about knowing what to expect during the end of life (67.7%), having unmet emotional and spiritual needs (64.4%), and not being able to obtain adequate information (43.1%) (Burge et al., 2014). Clinical care issues, such as pain management (9.0%) and dyspnea (9.5%), were less prevalent (Burge et al., 2014). Death in the home environment was identified by family members as associated with higher levels of overall satisfaction in comparison to death in hospital or long term care environments. However, despite these findings, 51.0% of the family members of decedents who died in the home were not completely satisfied with home-based care (Burge et al. 2014).

Quality Palliative Care: A System Perspective

From a system perspective, the development and delivery of palliative care programs has been a difficult challenge. The Romanow Report noted that while it is the right of Canadians to die in the location of their preference, many do not have to opportunity to do so due to a lack of effective infrastructure and support mechanisms (Romanow, 2002).

Despite the majority of individuals noting the home as their preferred place of death, the majority of deaths continue to occur in-hospital (Brink & Frise-Smith, 2008).

Increased efforts have been undertaken to improve the understanding and integration of palliative care into the continuum of care. The development of coordinated and interprofessional palliative care programs and initiatives has been shown to improve quality of life for individuals at the end of life (Bakitas et al., 2009; Institute of Medicine, 2014). In response to the increased discussion on palliative care, the World Health Organization (WHO) has tabled a resolution emphasizing the importance of the development of palliative care policy and improved palliative care education (WHO, 2014).

The province of Nova Scotia is a jurisdiction that has implemented an integrated palliative care strategy to improve the delivery of palliative care (Nova Scotia Department of Health and Wellness (NSDHW), 2014). The initiative focuses on allowing individuals to receive care and die in the location of their choice, emphasizing a system of care that is centred around the individual, not the system (NSDHW, 2014). To achieve this, the strategy focuses on promoting the utilization of interprofessional teams in the delivery of care, and when possible promoting early planning and preparation (NSDHW, 2014). Specifically, this initiative notes the importance of bringing together all individuals involved in providing in-hospital and out-of-hospital care to improve the delivery of palliative care (NSDHW, 2014).

Emergency Medical Services Involvement in End of Life Care

Emergency medical services (EMS) are often involved in providing care to individuals with chronic disease who are nearing the end of life (Stone et al., 2009; Lamba et al., 2013). Despite these findings, there has been limited development of EMS best practices in the provision of palliative support (Stone et al., 2009; Jensen et al., 2013). Palliative support involves the provision of supportive interventions at the end of life and is a component of the larger definition of palliative care that encompasses all formal and informal care provided at the end of life.

EMS often serves as the default care providers in the out-of-hospital environment, available at all times of day or night in all communities. EMS providers may be requested in palliative situations when patients or family are having difficulty and/or when other palliative services are unavailable (Lamba & Quest, 2011; Weise et al., 2009).

Speaking to the frequency of EMS involvement, Lawson et al. (2009) found that a majority of individuals enrolled in a palliative care program who arrive at the ED arrived via EMS. EMS is often called to assist when there are symptom control issues, complications with medical devices and at times when caregivers are unsure of care options or unable to care for the individual due to caregiver burnout or care exceeding their abilities (Meishke et al., 2009; Lamba & Quest, 2011). Additionally, EMS may be requested by family or caregivers to confirm that the individual is in the dying process or deceased and sometimes due to the belief that calling EMS or emergency services is required by law (Meischke et al., 2009).

From a policy perspective, the role of EMS in palliative care is important to consider as EMS often provides care to individuals approaching the end of life and is uniquely positioned to provide emergency support in the out-of-hospital environment. EMS is well established within North American and European health systems to provide a rapid response to out-of-hospital emergencies. As well, the scope of practice within EMS has been expanding in respect to medication administration and invention support. The role of EMS has also expanded into primary care in some jurisdictions, and is seen as an area of expansion for future EMS practice (Ball, 2005; EMS Chiefs of Canada, 2006). The increasing EMS scope of practice and capacity to provide primary care, and its frequent involvement in the provision of care to individuals at the end of life, supports the consideration of the role of EMS in palliative care, as EMS is uniquely position to provide palliative care in emergency situations in the out-of-hospital environment. With that said it is important to note that EMS involvement in palliative care should not usurp the care provided by other palliative care providers. Palliative care when possible should be provided by other health care providers, including family physicians, community hospice and /or home care services as these individuals are often more suited to provide ongoing care and will have a greater understanding of the individual's needs through their prior interactions with these individuals.

Barriers in the Involvement of EMS in Palliative Support

Challenges arise in the development of EMS palliative support as the concepts of palliative care do not integrate well within EMS, which has traditionally been focused on providing lifesaving interventions to critically ill individuals, usually in the paradigm of

transporting patients to the ED for care to be continued or completed (EMS Chiefs of Canada, 2006; Stirling et al., 2007, Jensen et al. 2013). The need for improved EMS palliative support has been identified, but few initiatives have been implemented to date (Ausband et al., 2002; Jensen et al., 2013; Lamba et al., 2013). The development and delivery of EMS palliative support has been constrained by several factors, including limited research in this area, a lack of EMS palliative care training and continuing education, and EMS provider perceptions that palliative care is a variation from traditional practice (Stone et al., 2009; Jensen et al., 2013; Waldrop et al., 2014a; Waldrop et al., 2014b).

Ramifications of EMS Involvement

The role of EMS in the care of individuals requesting palliative support is of importance, as EMS can markedly affect the trajectory of care (Lamba & Quest, 2011). As well, EMS providers are often an individual's first point of contact with the medical system in emergency and urgent situations and have the potential to offer life prolonging interventions and affect the transport location of an individual (Lamba & Quest, 2011).

Based on traditional practice, individuals at the end of life with medical emergencies are usually transported to EDs to receive care (Hjermstad et al., 2013). However, this care may not be the most appropriate care for individuals at the end of life. Frequently, individuals at the end of life with medical emergencies require non-complex medical interventions that often do not require ED admission if resources are available to treat these conditions in the out-of-hospital environment (Hjermstad et al., 2013; Barbera et

al., 2010). One study found that 23% of ED visits by individuals with advanced cancer were avoidable (Delgado-Guay et al., 2014). Individuals at the end of life presenting at EDs were commonly admitted for pain, gastrointestinal distress, lung and breathing difficulties, fatigue, dehydration and reduced level of consciousness (Hjermstad et al., 2013; Barbera et al., 2010). Hjermstad et al., (2013) and Barbera et al., (2010) noted that if proper resources were in place, many visits to the ED could be reduced.

This may be a potential area where EMS can assist with palliative support. Improved EMS support for individuals experiencing palliative related emergencies may allow these individuals to remain in the home and/or potentially avoid a trip to the ED. Palliative support by EMS could include areas such as providing symptom support and assisting individuals at the end of life experiencing medical complications and supporting family members when necessary.

An important aspect in the delivery of palliative support by EMS is the presence of advance directives (AD) or a do not resuscitate order (DNR) on scene. Jeukar et al., (2012) noted that the presence of an AD was associated with dying at home among those who had a preference to die at home. Without an AD or DNR on scene, EMS providers in many situations are mandated to provide lifesaving interventions (Feder et al., 2006, Lord et al., 2012). The initiation of lifesaving procedures on individuals who wish to receive palliative interventions but cannot produce AD/DNRs or recognized documentation creates an ethical dilemma for EMS personnel and creates tension with family members and caregivers at the scene (Guru et al., 1999; Lord et al., 2012).

Traditional EMS Scope of Practice

The development of palliative care protocols in EMS has traditionally been limited; a 2002 report found that 5% of polled American EMS agencies had a palliative care protocol in place (Ausband et al., 2002). The Paramedic Association of Canada sets National Occupancy Competency Profiles which define the necessary competencies for paramedics and first responders in Canada (Paramedic Association of Canada, 2012). The National Occupancy Competency Profiles have defined palliative care competencies. However, these competencies are broad and include transport as a component of the care provided to individuals requesting palliative care (Paramedic Association of Canada, 2012).

Although EMS agencies have increased awareness of the importance of developing palliative protocols, further education and policy development is required (Stone et al., 2009; Waldrop et al., 2014a). Stone et al. (2009), noted that EMS providers often feel they are not prepared to deal with situations related to end of life care, such as interpreting AD's or talking with the family about an out-of-hospital death. Waldrop et al., (2014a) further noted that in addition to EMS providers feeling they need more end of life care education, further education must also be made available for other health care providers and the public to provide a better understanding of the role of EMS in providing palliative support. As well, EMS providers felt more education on conflict resolution and protocol education would improve palliative support delivery (Waldrop, 2014a).

Expanded EMS Practice: A Potential Solution

In order to provide effective palliative support within EMS, the focus should consider moving away from providing transport to the ED, since many individuals at the end of life wish to remain in the home. Although a fairly new innovation, some EMS agencies are beginning to implement expanded models of care that allow EMS providers to provide on scene “treat-and-release” care. Expanded care paramedicine (also known as community paramedicine) has been identified as an area with an increasing role in EMS (Ball, 2005; EMS Chiefs of Canada; 2006). Community paramedicine involves EMS providing treatment to individuals with low-acuity conditions within the community (Bigham et al., 2013). To date, there has been limited investigation into the efficacy of community paramedicine (Bigham et al, 2013). However, some models have shown potential; having found that community paramedicine can reduce transport and ED admission among the target populations (Mason et al., 2008; Jensen et al., 2013; Bigham et al., 2013).

In Nova Scotia, Emergency Health Services (EHS) had implemented an Extended Care Paramedic (ECP) program, in which a single specially-trained paramedic responds to calls for long term care patients with emergency care needs. The goal of this program is to provide tailored care that meets the needs of each patient, in consultation with their long term care physician, nursing staff, EHS physician and family (Jensen et al., 2013). Within this program an ECP can recommend immediate transport to the ED, schedule a transport for a pre-arranged time, request a follow-up health care provider visit at a later date or provide treat-and-release care without further treatment (Jensen et al., 2013).

Further information regarding the scope of practice of ECPs and the other paramedic roles within Nova Scotia can be found in Table 1.

The ECP model has reduced ED transports among the target population, allowing a majority (70%) of individuals to stay in the nursing home environment with no transport to hospital (Jensen et al., 2013). Additionally, an important finding of this program was the potential benefit of EMS in providing expanded scope end of life care. Due to the population demographic seen within this program, ECPs are provided end of life care training (Jensen et al., 2013; Jensen et al., 2014). ECPs found the expanded model of care was more effective than the traditional transport focused model in attaining the wishes of those who were at the end of life (Jensen et al., 2014).

Building on the results of the ECP program, as well as taking into consideration the Nova Scotia Palliative Care Strategy, EHS has begun to examine the potential for expanding the scope of EMS practice in providing palliative support. In 2014, EHS in collaboration with Cancer Care Nova Scotia and Health Prince Edward Island were awarded an Enhancing End of Life Care Grant from the Canadian Partnership Against Cancer (Cancer Care Nova Scotia, 2014). The goal of this program is to enable EMS to provide palliative support to individuals who are at the end of life, potentially under a treat-and-release paradigm to better meet the wishes of individuals with life limiting diseases to remain in the home (Office of the Provincial Medical Director, EHS Nova Scotia, 2015). To support this objective, EHS has developed an evidence based Palliative Care Clinical Practice Guideline for ground EMS providers to guide the delivery of palliative support (Office of the Provincial Medical Director, EHS Nova Scotia, 2015).

Conclusion, Research Purpose and Questions

Providing care that meets individual wishes is a key tenet in providing patient-centred end of life care. Despite individual differences in the preference for care delivered, quality end of life care is based upon the ability to provide support to a dying individual and their family by providing symptom control and promoting clear lines of communication during this stage of life.

This thesis provides an analysis to improve the body of knowledge associated with EMS involvement in palliative support. This thesis has two primary research questions. The first question is: what are the potential considerations for expanded EMS involvement in providing palliative support, as estimated by analysis of the size and characteristics of the end of life population? The second question is: what has been the frequency of EMS involvement in potentially providing palliative support to individuals at the end of life and does the support provided and the demographics served vary from EMS calls that do not appear to be palliative? The first study question is addressed in Chapter Two of this thesis, while the second question is answered in Chapter Three.

Manuscript Development

Chapters two and three of this thesis are written as manuscripts for publication. At the time of writing, the manuscripts are being prepared for submission and written per the guidelines of *Prehospital Emergency Care*, an EMS focused peer reviewed journal. If unsuccessful in submission to this journal, other journals in the EMS, emergency care or the Canadian healthcare and healthcare policy fields may be considered.

Chapter Two co-authors include: Grace Johnston, Lynn Lethbridge, Alix Carter, Jan Jensen, Paul McIntyre, David Henderson, and Ann Frances d'Intino. The student was responsible for the primary development of the manuscript, including the presentation of results, literature review and development of the discussion and conclusions. The student did not conduct data collection and initial analysis, as this work is a secondary analysis of the 3x3 Network for End of Life Studies (NELS) database. Co-authors (GJ, LL, PM, DH and AF) supported the initial collection and analysis of the data. As well co-authors (GJ, JJ and AC) reviewed the manuscript and provided feedback regarding content, structure and format.

Chapter three co-authors include: Grace Johnston, Alix Carter, Jan Jensen, and Saleema Karim. The student was responsible for manuscript development including development of methods, data collection and cleaning, literature review, analysis and presentation of data and formatting of the discussion and conclusions. Co-authors assisted with methods development, data interpretation, and providing feedback on manuscript content, format and style.

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Table 1. Nova Scotia Paramedic Levels and Role

Paramedic Level	Role
Primary Care Paramedic (PCP) ¹	Paramedics trained to provide symptom relief including, oxygen support, establishment of intravenous lines, performing semi-automated and external defibrillation and cardiac monitoring
Advanced Care Paramedic (ACP) ¹	Scope of a PCP in addition to interpretation of 12-lead ECGs, performing advanced airway management and can provide an expanded scope of medications.
Critical Care Paramedic (CCP) ¹	Scope of an ACP in addition to being able to provide complex procedures associated with critical care. Most typically CCPs work with Air Ambulance/Critical care transport programs transporting high acuity patients.
Extended Care Paramedic (ECP) ²	ACP or CCPs who have received additional training in geriatric assessment and management, primary wound closure techniques as well as point-of-care testing and end of life care. ECPs focus on providing care to long term care residents with low acuity injuries with the goal of providing patient-based care within the community.

1. Source: EHS (2014)
2. Source: Jensen et al. (2013) and Jensen et al. (2014)

Chapter 2: Estimates of Potential Need for Emergency Medical Services Palliative Support

Abstract

Objective

To provide a descriptive analysis of the Nova Scotia (NS) end of life population to assist emergency medical services (EMS) in the development of protocols that will optimally serve end of life patients and their families.

Methods

Study subjects were retrospectively identified from death certificates and linked to data from three district palliative care services (PCS) and three provincial disease registries. Population characteristics, including causes of death, enrolment in PCS, enrollment in disease registry, and location of death were compared between cancer and non-cancer decedents. A method developed by Rosenwax et al. (2005) was utilized to estimate the overall need for palliative care.

Results

Between 1995 and 2009, there were 121,458 deaths; 32.2% of decedents died of cancer. Non-cancer causes of death included cardiovascular disease (31.6%), chronic obstructive pulmonary disease (11.5%), and diabetes (10.6%). Median number of causes of death on the death certificate was 3 (IQR 2-4) for all decedents. Cancer decedents had fewer median causes of death than non-cancer decedents.

Cancer decedents were more likely to die in hospital (70%) and less likely in a nursing home (8.9%), than non-cancer decedents (58.4% and 21.3% respectively). In districts with PCS data, 28.8% of decedents were enrolled in PCS, with cancer decedents being more likely to be enrolled than non-cancer decedents. Cancer decedents were less likely to experience late PCS enrollment. PCS enrollment among non-cancer decedents has been increasing; in 1995, 4.9% of PCS enrollees did not have cancer, compared to 28.5% in 2009. An estimated 59.6% of decedents as a minimum and maximum of 94.5% may have benefited from palliative care.

Enrollment of cancer decedents in the Nova Scotia cancer registry was high (97.8%). Enrollment was lower in the Nova Scotia diabetes and cardiovascular disease registries but improved over time.

Conclusions

High rates of in-hospital deaths demonstrate the need to improve home-based palliative support. Low and late PCS enrollment may limit the identification of persons needing EMS palliative support and impact the ability to deliver support. Comorbidities were common at the end of life. Individuals dying of non-cancer diseases may require more complex support.

Introduction

Emergency medical services (EMS) regularly provide care to individuals with chronic disease who are nearing the end of life (Guru et al., 1999; Stone et al., 2009; Lamba et al., 2013). Despite this, few EMS agencies have implemented palliative protocols to date (Ausband et al., 2002; Jensen et al., 2013; Lamba et al., 2013). A 2002 study reported that only 5% of sampled American EMS agencies had implemented palliative care protocols (Ausband et al., 2002). Barriers to expanding the EMS role in palliative support includes EMS perceptions of palliative care and the public's perception of EMS scope of practice, an absence of relevant research, and a lack of EMS palliative care training and education (Stone et al., 2009; Jensen et al., 2013; Waldrop et al., 2014).

EMS may be requested by individuals at the end of life in emergency situations when home-based palliative support is unavailable. In these situations EMS can provide symptom control; support individuals with medical device complications; or offer support when caregivers are either unsure of their care options, experiencing burnout, or if the care needed exceeds their abilities (Weise et al., 2009; Meishke et al., 2009; Lamba & Quest, 2011). EMS may also be called if family or caregivers want confirmation that a person is dying or deceased (Meischke et al., 2009).

With an aging population and an increasing focus on patient-centered care, home-based services are expected to increase. This may impact the frequency of calls and role of EMS in caring for persons who are living at home with palliative needs. Given these changes, EMS should consider how to optimally meet palliative patients' care objectives. This may involve the development of protocols that will allow palliative patients to

remain in the home and avoid a trip to the emergency department (ED). Frequent ED admissions among persons nearing the end of life is viewed as an indicator of poor quality end of life care, poor advance care planning, and limited access to palliative care services (PCS) (Earle et al., 2003; Grunfeld et al., 2008; Lawson et al., 2009).

This study aims to assist the development of effective EMS palliative support protocols by providing a description of the end of life population. The objectives of this study are to 1) utilize a population based method to describe the end of life population who may request EMS palliative support and 2) describe the characteristics of the end of life population in the relation to the development of EMS palliative support. Definitions of palliative care, palliative support, PCS, and end of life care are provided in Figure 1.

Methods

Study Design

This retrospective, population-based study is an epidemiological descriptive analysis of Nova Scotia residents who died in the province between 1995 and 2009. This study is a secondary analysis of the 3x3 Network for End of Life Studies (NELS) linked administrative database.

Secondary Data Utilization

NELS researchers linked seven administrative databases within Nova Scotia through probabilistic record linkage. Death certificate data for 1995-2009 from Nova Scotia Vital

Statistics were used to define and describe study subjects. Enrolment data from three District Health Authority PCS and three provincial disease registries (cancer, cardiovascular, diabetes) were linked to the decedents to create the 3x3 NELS dataset. This linkage included both cancer and non-cancer decedents using the methodology that had been developed previously to investigate access to palliative care for persons dying of cancer (Johnston et al., 1998; Johnston et al., 2001; Burge et al., 2003; O'Brien et al., 2007; Burge et al., 2008; Gao et al., 2011). Further details on the 3x3 NELS dataset are in the protocol (<http://www.dal.ca/sites/nels/research/3x3.html>) and published papers (Laverne et al., 2015; Johnston et al., 2014).

The Nova Scotia Cancer Registry was established in the mid-1960s (Band et al., 1993). The diabetes registry was established about three decades later (Johnston et al., 2015) around the same time that the cardiovascular registry was established. PCS enrollment data were collected within each of the nine District Health Authorities in the province; as there was no provincial PCS database. Only three of the PCS districts had sufficient data in electronic form across the time span of the deaths of the study subjects. Two of the three PCS (Capital Health and Cape Breton) utilized data from 1996-2009, while the PCS enrollment data from the third dataset (Colchester East Hants) was linked in from 2003-2009. The three PCS districts in this study encompassed almost 65% of the Nova Scotia population (Laverne et al., 2015). Research ethics approval was provided by the District Health Authorities of all three PCS that provided data to the 3x3 NELS linked dataset.

Study Population and Variables

Study variables included: age, sex, year of death, PCS and disease registry enrollment, and location and cause(s) of death. For cause of death, the ninth edition of the International Classification of Disease was used for 1995-1999, while the tenth edition was used from 2000-2009. Up to 13 causes of death could be recorded for each decedent. Cause of death information was utilized to understand the frequency of comorbidities at the end of life which may have attributed to death. Disease registry and PCS data were included to assess the extent to which the PCS and disease registries might be able to help prospectively identify individuals with chronic diseases who might benefit from EMS palliative support.

The study population was categorized as cancer and non-cancer decedents. This separation was made as historically palliative care has focused on persons dying of cancer, while access was more difficult for individuals with non-cancer conditions (Addicott, 2012). However, persons dying of diseases other than cancer are increasingly being recognized as also needing palliative support. Therefore the subdivision of cancer and non-cancer decedents was made to describe the potentially different experiences of these two groups at end of life.

Data Analysis

Descriptive statistics and temporal trends were reported. Statistical significance testing was not carried out as the 3x3 NELS data represents a population (all decedents in NS), and not a random sample. Since the 3x3 NELS population size is very large, all tests are

expected to be significant due to the large population size, in other words, not useful in indicating precision of values in a sample. Beyond this, univariate (unadjusted) findings are reported, some of which would attain statistical significance in univariate analysis but which could be non-significant if controlled for confounding variables. However, the counts and percentages reported in this chapter are meaningful for describing the population at end of life in Nova Scotia that might benefit from a palliative approach to care.

Palliative care need was estimated by utilizing a method developed by Rosenwax et al. (2005) to predict the maximum and minimum size of the population who may have benefitted from palliative care. The Rosenwax et al method was developed through focus group discussions held with care providers involved in providing end of life care, supported by a review of the palliative care literature (Rosenwax et al., 2005). The minimum estimate identified individuals that may have benefitted from palliative care as decedents who suffered from at least one of 10 chronic diseases identified as potentially needing palliative care (Table 1), while the maximal estimate was defined as all decedents who died from a non-sudden cause of death (Rosenwax et al., 2005). This classification used all causes of death on the death certificates to develop these estimates.

Results

Between 1995 and 2009, there were 121,458 deaths. Mean age at death was 74.5 years, with males accounting for 50.5% of all decedents (Table 2). Cancer decedents were on

average younger and more likely to be male than non-cancer decedents. Cancer decedents accounted for 32.2% of decedents, while 67.8% of decedents died of a non-cancer cause.

The median number of causes of death on the death certificate was 3 with an interquartile range (IQR) of 2-4. Non-cancer decedents (who were the larger proportion of the decedents) had this same median and IQR, while the corresponding values were lower for the cancer decedents (median: 2, IQR: 1-3). Non-cancer decedents were more likely to have multiple causes of death listed on their death certificates than cancer decedents (Figure 2). For cancer decedents, 39.3% had one cause of death listed on the death certificate in comparison to 17% of non-cancer decedents. Among all decedents, only 5.5% were sudden deaths (Table 2). The most common causes of death were cancer (32.2%) and cardiovascular disease (31.6%). Other common causes of death were chronic obstructive pulmonary disease (11.5%), diabetes (10.6%) and dementia (10.2%).

Application of the Rosenwax et al. (2005) method to the death certificate data showed that a minimum of 59.6% and a maximum of 94.5% of decedents may have benefitted from palliative care. Both the minimum and maximum estimates for cancer decedents was 99.2%, since the Rosenwax et al. method classifies all non-sudden cancer deaths as potentially benefiting from palliative care, regardless of whether the maximum or minimum value is calculated. In contrast, the minimum and maximum estimates of palliative care need were 40.8% and 92.3%, respectively, for non-cancer deaths, reflecting wider range of views on the need for palliative support for persons dying of chronic diseases other than cancer.

In health districts where PCS data were available, 28.8% of decedents were enrolled in a PCS (Table 2), but this rate varied by cause of death and over time. Overall, 66.1% of cancer decedents were enrolled in PCS, in comparison to only 9.2% of non-cancer decedents. PCS enrollment increased steadily over the study duration for both cancer and non-cancer decedents (Figure 3). In 1995, 47.8% of cancer decedents were enrolled in PCS in comparison to 73.5% in 2009. In 1995, 1.8% of non-cancer decedents were enrolled in PCS in comparison to 15.2% in 2009. Figure 4 shows the growth in PCS enrollment rate for cardiovascular, chronic obstructive pulmonary disease, diabetes and renal causes of death. Rates for dementia were lower but increased more rapidly. In contrast, rates of pneumonia as a cause of death for PCS enrollees slowly decreased over time. From a separate analysis, it was observed that in 1995, 95.1% of PCS enrollees had cancer, compared to 71.5% in 2009. Late PCS enrolment (within two weeks of death) occurred in 29.3% of PCS referrals; with non-cancer decedents having higher rates of late referral (49.9%) compared to cancer decedents (22.9%) (Table 2).

Decedents were also enrolled in Nova Scotia disease registries. Almost all (97.8%) of the cancer decedents were enrolled in the provincial cancer registry. Overall, rates were lower in the cardiovascular (52.8%) and diabetes (55.5%) registries for cardiovascular and diabetes causes of death, respectively. However, non-cancer registry enrollment of persons who later died increased over time; as by 2009 74.9% of cardiovascular decedents and 76.1% of diabetes decedents were included in their respective provincial registries.

The majority of the decedents died in hospital (62.1%); 17.3% died in a nursing home and 20.6% died in a location labelled “other” which was considered in most cases being

the home environment (Figure 5). Cancer decedents died in-hospital more frequently (70%) than non-cancer decedents (58.4%). Cancer decedents were less likely to die in a nursing home (8.9%) than non-cancer decedents (21.1%). Meanwhile, the proportion of decedents dying in their own home was similar at just over 20% for both cancer and non-cancer decedents.

Over the study duration, there was a slight increase in the proportion of individuals dying out-of-hospital. In 1995, 36.1% of decedents died out-of-hospital compared to 41.2% in 2009 (Figure 6). This trend was apparent among both cancer and non-cancer decedents.

Discussion

Location of Death

A majority of individuals wish to die at home if adequate resources are available (Higginson & Sen-Gupta, 2000; Brazil et al., 2005; NELS News, 2011; Gomes et al., 2013). However, in Nova Scotia, the study data show that only 37.9% of individuals died at home or in a nursing home over study duration. Other Canadian provinces during the same time period reported similar out-of-hospital death rates when death certificates were used for this calculation (Neutel et al., 2005; Canadian Institute of Health Information (CIHI), 2007). Persons at the end of life may be unable to remain in the home due to a lack of resources to provide supportive interventions, an absence of family caregiver support, and caregiver burnout (Gott et al., 2004; Vassal et al., 2011).

With increasing trends in the number of individuals projected to die out-of-hospital, as our population ages, EMS may increasingly be requested to provide palliative support (Gomes & Higginson, 2008; Weise et al., 2009). Effective EMS involvement in palliative support may provide improved care in emergency situations, better allowing individuals to receive care and die in the location of their preference.

Palliative Care Services Enrollment

Persons dying of cancer in Nova Scotia have been reported as having a median of one ED visit in their last six months of life (Burge et al., 2003). Also, it has been reported that the majority of out-of-hospital PCS enrollees in the Halifax area who went to the ED were transported by EMS (Lawson et al., 2009). Thus, it is realistic to assume that at least some persons living at home at end of life may call EMS in emergency situations.

Therefore, EMS should consider collaborating with PCS to develop a plan for the delivery of EMS emergency palliative support that can complement PCS service. Also, knowing the proportion of the decedent population who were enrolled in a PCS is one way to estimate a possible minimum need or demand for palliative support from EMS.

However, there is reason to believe that not all persons needing EMS palliative support are enrolled in a PCS. Gao et al. (2011) found that persons who die soon after a cancer diagnosis, were a nursing home resident, living at a greater distance from a PCS and who were not receiving oncology care were less likely to be enrolled in PCS. Urquhart et al. (2015) found that being frail was associated with dying quickly regardless of the stage of colorectal cancer diagnosis.

Data from our study showed that a high proportion of persons dying of cancer were enrolled in a PCS program. On the other hand, individuals with non-cancer diseases were less likely to be enrolled in PCS and more likely than cancer decedents to experience late PCS enrolment. However, the individuals with non-cancer diseases were increasingly being referred to PCS over study duration.

Application of the Rosenwax method suggested that actual palliative care enrollment among decedents was lower than the determined potential PCS need within Nova Scotia. The method was utilized as it provided an evidence-based method to estimate the size of the end of life population that may have benefited from palliative care by using population-based death data. Using the Rosenwax et al (2005) method, 99.2% of cancer decedents could have benefited from palliative support. This contrasts with 66.1% that were enrolled in a PCS. Among non-cancer decedents, using the Rosenwax et al (2005) method, a minimum of 40.8% and a maximum of 92.3% are estimated to have had palliative needs. In contrast, Figure 3 shows that by 2009, only about 15% of non-cancer decedents were enrolled in PCS.

Therefore, EMS may respond to many calls where individuals approaching the end of life are not enrolled in a PCS at the time of a call. In these situations it may be difficult for EMS to provide effective palliative support to individuals without PCS support. For example, these individuals may not have advance directives and may not have discussed and decided on their goals of care as death approaches. Also, EMS is structured to provide emergency, not ongoing care. Therefore, EMS personnel may not be able to clearly identify to whom people being seen at home should be referred for coordinated ongoing palliative care, after EMS clears the scene.

Chronic Disease Registries Enrollment

Given that some persons living with advanced chronic disease at home at end of life are not enrolled in a PCS, and that late PCS enrollment is common, chronic disease registries might be able to help identify additional persons who might call EMS and who might benefit from palliative support. Cancer registry data had almost all cancer decedents included. The cardiovascular and diabetes program registration of individuals with their respective registries was lower but increased over the study duration. Therefore in the future the information within these databases may be helpful to EMS to help plan timely access to palliative support for persons with advanced chronic disease.

Nova Scotia has four provincial chronic disease programs (cancer, cardiovascular, diabetes, renal). The provincial renal program was established approximately five years ago and as a result was not able to provide data for this study, but may in future studies. In addition to surveillance and monitoring the frequency of their respective diseases, these programs are also responsible for setting and monitoring guidelines for disease management including supporting the implementation palliative care guidelines and education. Therefore, collaboration with these chronic disease programs seems worthy of consideration to support further development of home-based care strategies for individuals dying with chronic diseases. A next step might also be consideration of the development of an end of life registry spanning all chronic disease such as that developed in Sweden (Martinsson et al., 2012).

Comorbidities

This study found that comorbidities were common among individuals at the end of life. Comorbidities at the end of life can contribute to difficulties in providing palliative care (Currow et al., 2007 O'Brien, 2011). Comorbidities in individuals approaching the end of life should be considered in the design and delivery of EMS palliative support. A particular concern is the effects of poly-pharmacy and adverse events associated with the administration of medications to end of life patients with comorbidities (Currow et al., 2004; O'Brien, 2011). Also, knowledge is needed on what to do if the individual being seen by EMS for palliative support is presenting with contraindications for medication administration. Increased medication administration training may be necessary for EMS providers.

Scope of Practice

Standard EMS practice in caring for individuals at the end of life has traditionally involved providing symptom support and transport to the Emergency Department (ED). However, the needs of individuals at the end of life can often be addressed in an out-of-hospital environment without ED transport, especially given that a majority prefer to remain at home if support is available (Higginson & Sen-Gupta, 2000; Brazil et al., 2005; Barbera et al., 2010; Hjermstad et al., 2013; Gomes et al., 2013). EMS should consider developing palliative support protocols that can provide treat-and-release care for persons with palliative needs wishing to remain at home, as opposed to transport to the ED.

Expanded EMS scope of practice could lead to the provision of EMS palliative support that is more appropriate and in line with patient wishes. EMS in Nova Scotia has implemented an Extended Care Paramedic (ECP) program in which specially trained paramedics may provide treat-and-release care to nursing home residents in the provincial capital of Halifax (Jensen et al., 2013). This program has allowed 70% of the patients seen by ECPs to avoid a trip to the ED, with a low (6%) relapse rate requiring further EMS intervention within 48 hours (Jensen et al., 2013). Due to the nature of the patients seen within this program, ECPs were provided training in end of life care (Jensen et al., 2014). ECPs noted that this non-traditional EMS scope of practice allowed for improved communication and support provided to individuals at the end of life (Jensen et al., 2013; Jensen et al., 2014).

Limitations

Although the method of palliative care estimation developed by Rosenwax et al. (2005) is helpful in providing an overall population estimate of palliative need, it does not account for individual preferences regarding palliative care. Some persons may need but not want palliative support. It also does not quantify the level of palliative care need as it was designed to only estimate whether individuals may have needed palliative care. As well, the method was developed to estimate the overall need for palliative care, not the need for EMS palliative support specifically. Furthermore, in addition to maximal and minimal estimates, Rosenwax et al. (2005) also developed a mid-range estimate. However it could not be utilized in this study as the mid-range estimate requires hospital admissions data,

which were not available in the 3x3 NELS linked administrative database. Since its publication, the Rosenwax et al. (2005) method has been utilized by other sources to estimate the need for palliative care and to help develop other methods to estimate palliative care need (Naylor, 2011; Murtagh et al., 2014; Johnston et al., 2015). Other methods developed to estimate palliative care service need (Murtagh et al., 2014), were not considered for this study as most of these methods utilize hospital admissions records.

The 3x3 NELS data did not include the location of care in the final weeks of life.

Location of care as death approaches is important to consider (Lawson et al., 2010) as in many cases individuals may be transported to hospital only in the final days of life when care becomes impossible in the home. Utilizing location of death does not adequately account for this. Further limitations were that the 3x3 NELS dataset did not include EMS data. As well, more recent data would have been useful as the study data was only available until 2009. Furthermore, a multivariate analysis of the 3x3 NELS data was not undertaken and may have been helpful in better identifying characteristics of the end of life population. As well, PCS data were limited, especially for rural areas and the three districts utilized only provided service for approximately 65% of the population (Lavergne et al., 2015).

Future Research

As a follow-up to this study, linkage between death certificate, PCS, disease registry, hospital, and EMS records may further inform our understanding of the role of EMS in

palliative support. Linkage between administrative and EMS records have been performed for research purposes elsewhere (Mumma et al., 2014).

Conclusions

This study provides description of the end of life population in Nova Scotia to inform EMS of potential considerations in the development of palliative support protocols. In describing the characteristics of this population, we found that out-of-hospital death rates were lower than surveys indicate that these people want. Furthermore, some persons at the end of life were not enrolled in a PCS or only enrolled close to the time of their death. To help address this challenge, the study findings indicate that collaboration with provincial chronic disease programs, as well as PCS, may be beneficial. Comorbidities were common among individuals at the end of life and may increase the complexity of providing EMS palliative care. As well, individuals with non-cancer diseases appeared to be more complex, and were enrolled in PCS less often and later than cancer decedents, however non-cancer decedent PCS enrollment is increasing.

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TABLE 1. Chronic diseases potentially needing palliative care¹

Cancer
Heart Failure
Renal Failure
Liver Failure
Chronic Obstructive Pulmonary Disease
Motor Neurone Disease/Amyotrophic lateral sclerosis
Parkinson's Disease
Huntington's Disease
Alzheimer's Disease
HIV/AIDS

¹As defined by Rosenwax et al. (2005)

TABLE 2. Demographic, causes of death and palliative care enrollment characteristics

Characteristics	Decedents' Cause of Death		
	Cancer (n=39,091)	Non-Cancer (n=82,367)	Total (n=121,458)
Mean age (years)	72.1	75.7	74.5
Age 90 years and over	6.5%	18.3%	14.5%
Males	53.6%	49.0%	50.5%
Median (interquartile range) of number of causes of death	2 (1-3)	3 (2-4)	3 (2-4)
Causes of death ¹			
Sudden death	0.8%	7.7%	5.5%
Cancer	100%	--	32.2%
Cardiovascular disease	11.6%	41.0%	31.6%
Chronic obstructive pulmonary disease	7.9%	13.2%	11.5%
Dementia	3.4%	13.5%	10.2%
Diabetes	6.6%	12.7%	10.6%
Renal disease	4.6%	10.2%	8.8%
Potentially could have benefited from a palliative approach to care ²			
Minimum estimate ³	99.2%	40.8%	59.6%
Maximum estimate ⁴	99.2%	92.3%	94.5%
PCS enrollment ⁵	66.1%	9.2%	28.8%
PCS enrollment ⁵ in final two weeks of life	22.9%	49.9%	29.3%

¹ Causes of death are not mutually exclusive

² Estimated using method of Rosenwax et al. (2005)

³ Had any of ten causes of death in Table 1 and was not a sudden death.

⁴ 100% minus % sudden death above

⁵ Deaths in only three District Health Authorities (Capital Health, Cape Breton, Colchester East Hants)

Palliative care Care that focuses on improving quality of life through the provision of symptom relief, spiritual and psychological support from diagnosis to the end of life for patients and their families (World Health Organization (WHO), 2015).

Palliative support is a holistic concept that involves the provision of care that improves the quality of life and respects the goals of care for persons living with life limiting disease. In this paper, palliative support is used to describe the potential role of emergency medical services in the coordinated delivery of palliative care.

Palliative care service (PCS) is a formal comprehensive palliative care program providing care for persons in District Health Authorities in Nova Scotia, Canada. They are described in more detail in Lavergne et al. (2015).

End of life care is health care received by an individual during the final days, weeks and months of life when suffering from a terminal disease (Johnston, 2014). Care provided during this phase of life can be palliative and/or curative.

FIGURE 1. Terminology used in this paper

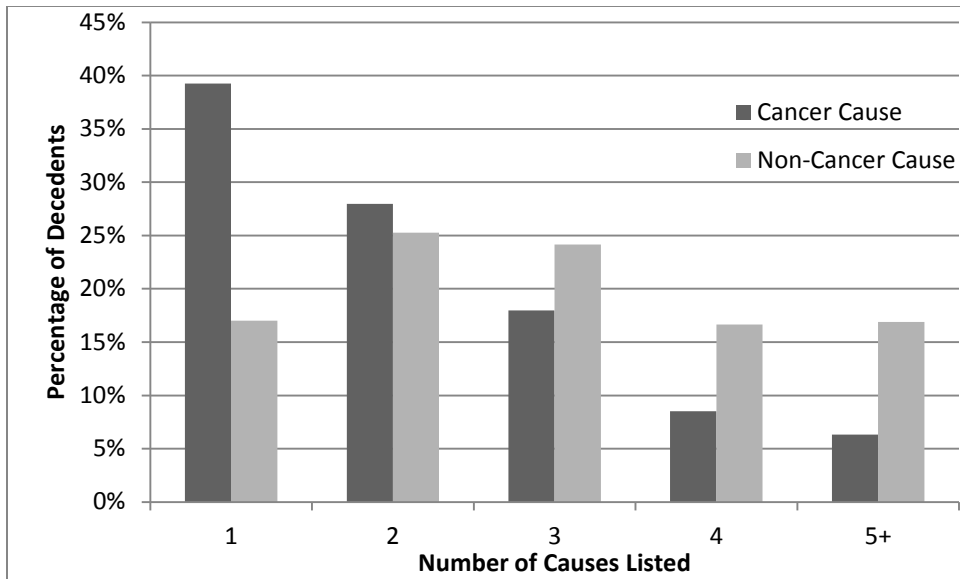
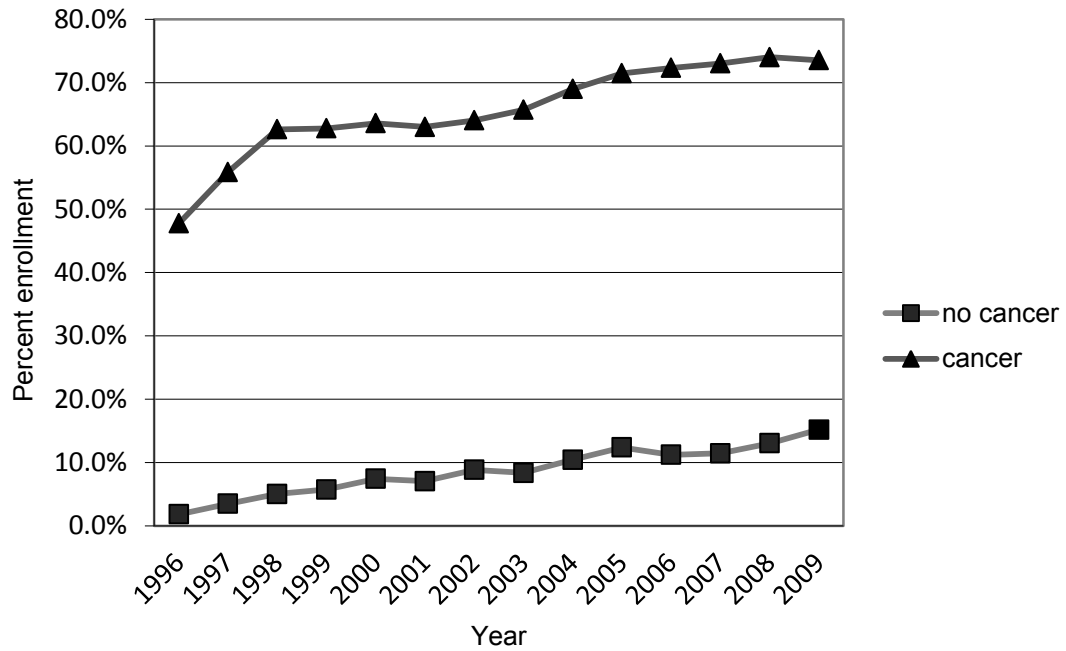
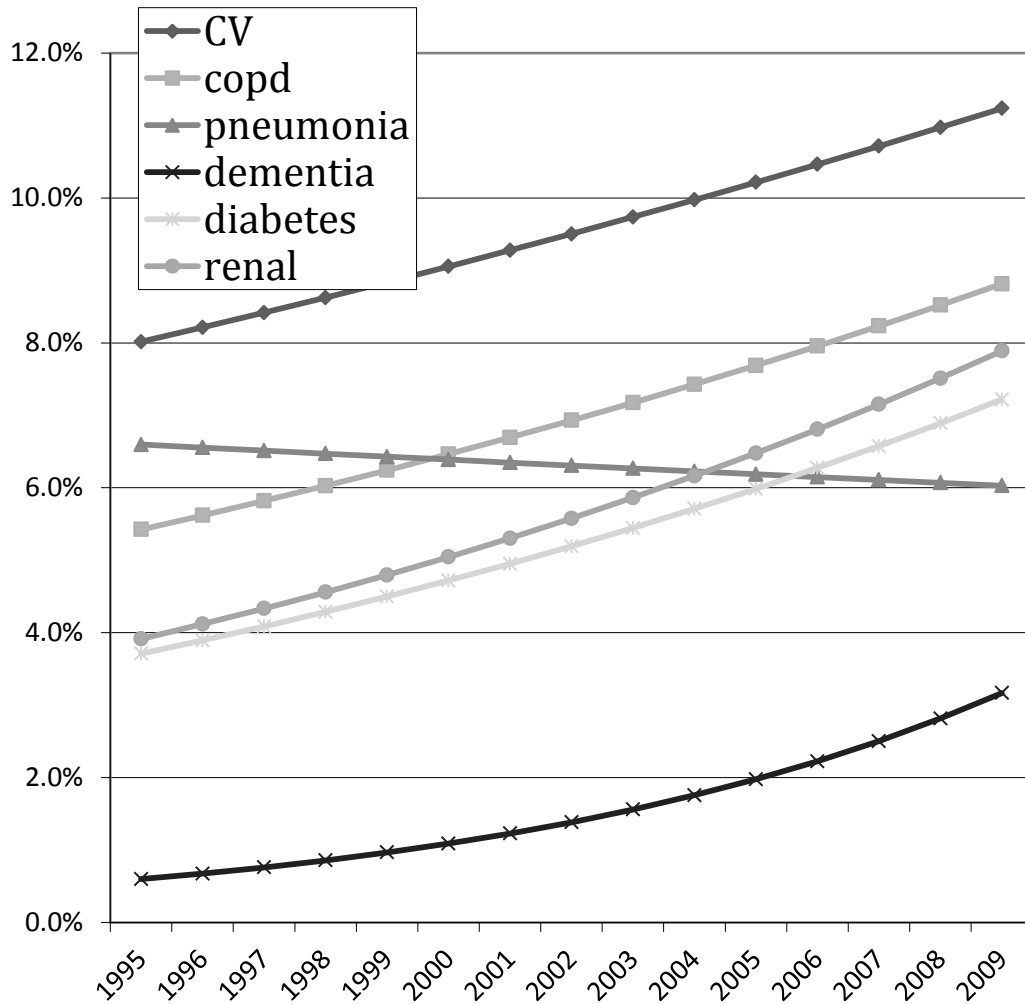


FIGURE 2. Percentage of decedents by number of causes of death for cancer and non-cancer deaths



1. Enrollment for Capital Health and Cape Breton PCS 1996-2009, Colchester East Hants PCS 2003-2009.

FIGURE 3. Percent palliative care service (PCS) enrollment by year (1995-2009) for cancer and non-cancer decedents



Note: CV is cardiovascular disease; COPD is chronic obstructive pulmonary disease

FIGURE 4. Percent palliative care service (PCS) enrollment by year (1995-2009) for selected non-cancer causes of death

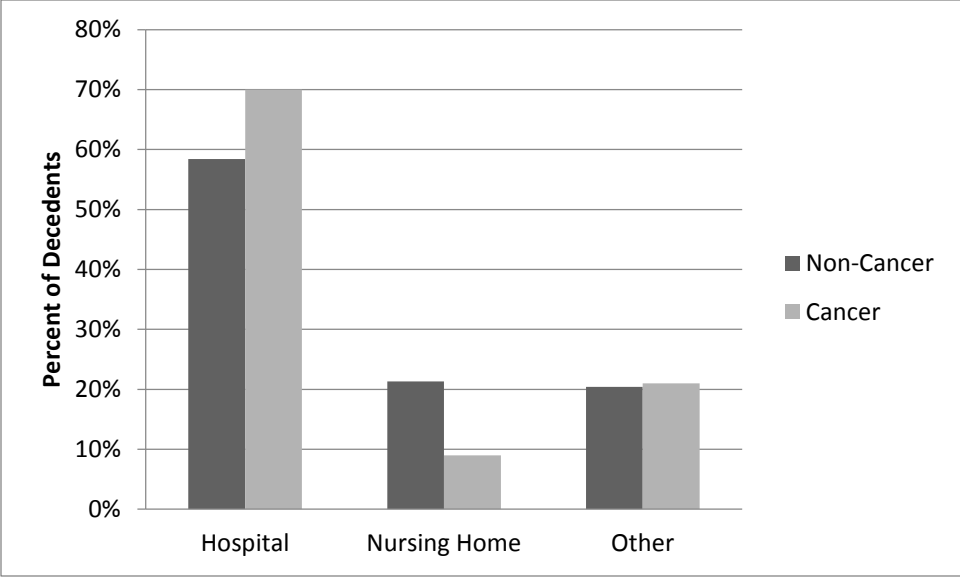


FIGURE 5. Percentage of decedents by location of death for cancer and non-cancer deaths

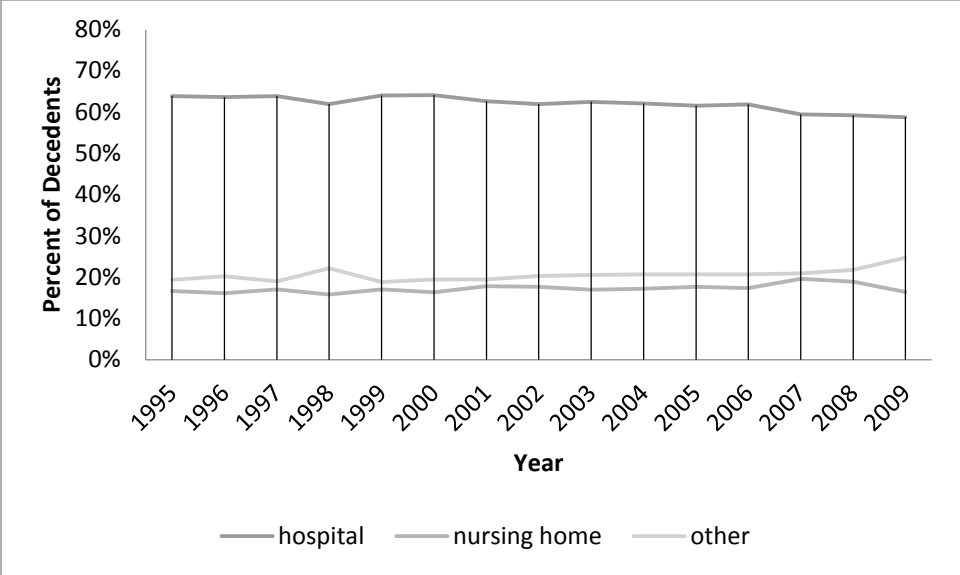


FIGURE 6. Percentage of decedents by location of death by year (1995-2009)

Chapter 3: Estimating Emergency Medical Services Utilization by Patients that could potentially benefit from Palliative Support

Abstract

Objective

This study aims to describe the potential need for EMS palliative support. EMS call data was utilized to: 1) describe the demographics of patients who request EMS, to assist in describing the potential need for EMS palliative support, 2) develop a measure to estimate the frequency of calls for patients who may have benefited from palliative support and 3) to identify patient and care differences among calls in each of four categories of the developed palliative support composite measure (PSCM).

Methods

This study was a retrospective review of EMS patient care records from a provincial ground EMS system between January-March 2014. To estimate the proportion of EMS calls potentially related to palliative support, a PSCM was developed that coded calls based on the presence of three criteria: 1) history of a condition that may benefit from palliative care 2) a chief complaint associated with palliative care and 3) an advance directive (AD) or do not resuscitate order (DNR). Calls were grouped into four categories based on these criteria and compared using descriptive statistics.

Results

There were 19,487 calls between January and March 2014. Average patient age was 59.6 years, with 40.7% of calls involving patients 70 years or older. Approximately 32.8% of

calls involved patients with a condition that could potentially benefit from palliative care. Less than 2% of calls had an AD/DNR documented.

The PSCM estimated that 1% of calls were probable palliative, 22.5% potential palliative, 45.6% low potential palliative and 30.9% non-palliative. Probable palliative calls consisted of older patients, who were more likely to be long term care residents and more likely to die on scene; these calls were also more likely to involve advanced life support EMS providers in comparison to other categories of the measure.

Conclusions

EMS was frequently involved in providing care to older individuals with conditions that might benefit from palliative care even though few had AD/DNRs. The existence of these demographic trends supports the need for improved protocols and training regarding the role of EMS in palliative support.

The development and application of the PSCM provided an estimate and description of the proportion of calls potentially related to palliative support. Further research to refine and validate the PSCM is required.

Introduction

Individuals approaching the end of life frequently utilize emergency medical services (EMS) (Lamba & Quest, 2011; Weise et al., 2009). Despite the request for assistance, many may not wish to receive the aggressive lifesaving interventions traditionally provided by EMS, but rather may prefer palliative support. These situations can create concern as palliative support is not within the scope of training or practice of many EMS providers. This may be associated with the limited development of EMS palliative protocols to date (Stone et al., 2009; Lord et al., 2012; Jensen et al., 2013). Barriers hindering the development of an EMS role in palliative support include limited research, a lack of EMS training in palliative practices, and perceptions of palliative care among EMS providers (Stone et al., 2009; Jensen et al., 2013; Waldrop et al., 2014a; Waldrop et al., 2014b).

Despite these barriers, there is potential for EMS to improve its ability to provide support for individuals at the end of life. To date, EMS scope of practice in relation to palliative support has been limited primarily to treat and transport to the emergency department (ED) for definitive care. However, this model of care may not be ideal for promoting a good death and for meeting patient wishes at the end of life.

A majority of individuals enrolled in a palliative care program who visited the ED were transported to the ED by EMS (Lawson et al., 2009). This care path may pose a concern, as time spent in the ED is not what a majority of individuals at the end of life prefer as many wish to receive care and die in the home environment, if adequate resources are accessible (Higginson & Sen-Gupta, 2000; Brazil et al., 2005, NELS News, 2011; Gomes

et al., 2013). Despite this wish, a majority of deaths continue to occur in-hospital, as evident by the findings of Chapter Two.

Despite the frequency of transport to the ED by EMS, many individuals at the end of life have needs that often can be managed in the home or out-of-hospital environment (Hjermstad et al., 2013; Barbera et al., 2010). Delgado-Guay et al. (2014) found that 23% of ED visits by individuals with advanced cancer were avoidable and could have been treated by other areas of the healthcare system. Another study focusing on individuals enrolled in a palliative care program found that a majority of study subjects who visited the ED were released without hospital admission (Lawson et al., 2009).

EMS may be requested for a variety of reasons by an individual at end of life. At times, EMS may be called when other sources of home-based palliative care are delayed or unavailable. EMS often provides assistance with symptom control, complications with medical devices and offers support when caregivers are unsure of other care options, are experiencing burnout or the level of care exceeds their abilities (Meishke et al., 2009; Lamba & Quest, 2011). Additionally, EMS is sometimes requested to confirm that an individual is in the process of dying or has died (Meischke et al., 2009).

The inability to meet patient wishes regarding location of care and death, in conjunction with the increasing prevalence of palliative care enrollment found in Chapter Two supports the need to improve home based palliative support. As EMS provides care to individuals in the out-of-hospital environment in emergency situations, including palliative support crises, the optimal role of EMS should feature meeting patient wishes and promoting optimal outcomes for palliative patients.

To our knowledge, neither the utilization of EMS by individuals at the end of life nor the frequency of EMS involvement in palliative support has been described in the literature. This study attempts to address this gap. This study has three objectives: 1) describe the demographics of patients who request EMS, to assist in describing the potential need for EMS palliative support, 2) develop a measure to estimate the frequency of calls for patients who may have benefited from palliative support and 3) to identify patient and care differences among calls in each of four categories of the developed PSCM.

Methods

Study Context

This study was undertaken in Nova Scotia, Canada. Nova Scotia has a population of approximately 950,000 with a sole EMS provider for the province: Emergency Health Services (EHS). The service consists of approximately 1,000 paramedics who operate from close to 70 bases throughout the province in urban, suburban and rural locales. The EMS workforce in Nova Scotia consists largely of primary care and advanced care paramedics with smaller numbers of intermediate and critical care paramedics. EHS responds to approximately 80,000 emergency requests per year. All clinical documentation by EHS is recorded in an electronic patient care record (ePCR). Information on a patient's medical history, demographic information, complaints and symptoms, treatments provided, as well as call location information and outcome data are collected in the ePCR. The ePCR record is call based as opposed to patient based;

meaning that for every call a new record is created. Linkage of ePCRs to ascertain an individual's use of EHS over time does not occur in the current system.

In addition to traditional EMS services, EHS has implemented a community paramedicine program known as the extended care paramedic (ECP) program, which operates in Halifax, Nova Scotia. The program allows specially trained paramedics with an expanded scope of practice to provide personalized care to long term care residents who present to EMS with low acuity complaints. To date, the program has allowed 70% of patients seen by ECPs to forego emergency transport to the ED (Jensen et al., 2013). Due to the population demographic served by this program, specialized end of life care training was provided to ECPs.

Study Population

The study population includes all EMS calls from January to March 2014, excluding interfacility transfers, air ambulance involved calls, calls where EMS did not arrive on scene, and calls where paramedics provided care in EDs or non-emergency environments. ECP calls were included as they provided emergency out-of-hospital care to a population that may request and benefit from palliative support. Data cleaning was performed by the lead investigator to remove incomplete ePCRs and duplicate ePCRs that occurred when a crew transferred care to another unit during a call.

EMS Palliative Support Composite Measure Development

Using literature on the characteristics of persons at end of life, three ePCR data fields were identified which may indicate whether a call is for a person who may have benefitted from a palliative approach to care: 1) a history of a condition that could benefit from palliative care, 2) a chief complaint that may be associated with palliative care, and 3) the presence of an advanced directive (AD) or do not resuscitate order (DNR) on scene.

Chronic diseases were considered palliative if they matched a disease from a list adapted from a population based method developed to estimate palliative care need by Rosenwax et al. (2005) and refined by Murtagh et al. (2014) (Table 1). Some alterations and additions were made to the list due to EMS coding that differed from that of Rosenwax et al. (2005) and Murtagh et al. (2014). In the ePCR past medical history (conditions and diseases) data field, multiple entries were possible. To limit the complexity in capturing these data, only the first 10 entries in the past medical history field in the ePCR were monitored.

Chief complaints associated with palliative care were compiled from a review of the literature consisting of 1) reasons why individuals enrolled in palliative care or at the end of life visited the ED (Hjermstad et al., 2013, Barbera et al., 2010; Delgado-Guay et al., 2014), 2) reasons why EMS had been requested in cardiac arrests (Guru et al., 1999; Meischke et al., 2009), and 3) to include the violent/agitated complaint common among individuals with dementia at the end of life (Eustace et al., 2002; Rodger, 2006) (Table 2).

The presence of either an AD or a DNR was considered as an indicator that the call may be for a person at end of life and thus the potential need for palliative support. In the ePCR, only DNR or AD option can be selected, not both, from a drop down menu.

Based on the three end of life indicators identified, calls were classified into one of four categories of the PSCM created for this study:

Category	Description of Category of Composite Measure
Non-Palliative	No condition that could benefit from palliative care, no palliative related complaint, and no AD/ DNR present
Low Potential Palliative	One indicator was present (palliative condition/disease or palliative chief complaint or AD/DNR)
Potential Palliative	Two but not three indicators were present
Probable Palliative	All three indicators were present.

The EMS PSCM was developed to create a generalizable standard utilizing EMS data that could help estimate and describe the potential size and characteristics of the EMS population who may request palliative support.

Descriptive Variables

Age, sex, and call location were utilized to describe the study population. Nursing home and senior centre location of call options were combined into one variable to represent ongoing care provided in a non-hospital facility: long term care. EMS system indicators included: the highest level paramedic on scene, whether an on-scene consult with another

medical professional was made, whether the call was an ECP call and call outcome (transported to ED or not, or deceased on scene).

EHS uses the Canadian Triage and Acuity Scale (CTAS) to describe patient acuity. The CTAS is a standardized score utilized to indicate patient acuity and need of care (Canadian Association of Emergency Physicians, 2014). The score ranges from 1-5 with one representing a patient that requires immediate resuscitation and intervention, while a score of five indicates that the patient requires non-urgent care (Canadian Association of Emergency Physicians, 2014). Distribution of CTAS scores were utilized to determine if acuity varied between groups of the PSCM.

Data Analysis

The analysis consisted of two phases. The first phase described the population demographic which utilized EMS. The second phase focused on the development and application of the PSCM to estimate the frequency of calls that may have benefited from EMS palliative support. Descriptive statistics were reported using counts, means, and percentages, for this analysis.

To determine if age was significantly different between categories of the PSCM, a one way Analysis of Variance was utilized. To determine if there was a difference in the distribution of CTAS scores among the PSCM categories, a Kruskal-Wallis test was utilized. For all other descriptive statistics, chi-square tests were utilized to test for significance. Microsoft® Excel 2010 was utilized to perform the statistical tests.

Ethics Approval

Ethics approval for this study was provided by Capital District Health Authority (REB # CDHA-RS/2015-106) which provides ethics review for research undertaken by EHS.

Results

Population Characteristics

Between January and March 2014, there were 19,487 calls. Female patients accounted for 52.6% of calls (Table 3). The average patient age was 59.6 years, with 40.7% of calls involving patients 70 years or older (Figure 1). Of total calls, 49.5% originated in the home, while 8.9% of calls originated from long term care. Of all calls, 15.6% involved high acuity patients with a CTAS of 1 or 2. EMS provided transport in 76.7% of calls, while no patient transport occurred in 22% of calls. A further 1.3% of calls involved situations where resuscitation efforts were ceased on scene or where the patient was deceased upon the arrival of EMS. Approximately, 67.6% of calls involved an advanced care or critical care paramedic (ACP or CCP). ECP calls accounted for 0.9% of calls. Medical consult was requested by EMS providers in 4.9% of calls.

Patients had a past medical history with at least one condition that could benefit from palliative care in 32.8% of calls. Frequent conditions identified were chronic obstructive pulmonary disease (COPD) (11.7%) (including emphysema and chronic bronchitis), cancer (10.4%), cerebrovascular accident (ischemic and hemorrhagic) (5.2%) and congestive heart failure (5.0%) (Table 1).

The recording of AD/DNRs was minimal, as 1.7% (326) of calls had an AD/DNR present. Of the 326 calls with an AD/DNR, 67.8% originated from long term care.

The most common chief complaints included minor trauma (11.3%), respiratory distress (7.4%), wellness check (7.0%), chest pain (6.8%) and abdominal/flank pain (6.6%) (Table 2, Table 4). The EHS end of life chief complaint was seldom recorded, being entered in only 0.1% (24) of calls. Trauma (minor trauma, major trauma, barotrauma and head/neuro injury) accounted for 12.8% of chief complaints. No chief complaint was listed in 2.5% of calls (Table 4).

Palliative Support Composite Measure

Only 1.0% (201) of calls were coded as probable palliative. Approximately 45.6% (8,880) were low potential palliative and 22.5% (4,388) of calls were potential palliative, while 30.9% (6,018) of calls were coded non-palliative. Among low potential palliative calls, 79.2% (7035) had a chief complaint related to palliative care, 20.6% (1832) had the presence of a condition that may benefit from palliative care and 0.2% (13) had an AD/DNR. Among the potential palliative calls, 97.4% (4276) were for a condition and chief complaint associated with palliative care, 1.7% (76) involved a condition associated with palliative care and an AD/DNR, and 0.8% (36) involved a chief complaint related to palliative care and an AD/DNR.

The distribution of calls involving female patients was found to be significant across categories of the measure ($p < 0.001$). Female patients outnumbered males for probable

palliative (58.2%), potential palliative (53.3%) and non-palliative categories (49.9%), while male patients outnumber females for low potential palliative calls (45.6%).

Patient age was associated with the PSCM, as calls that were probable palliative involved patients who were on average 81.3 (95% confidence interval (CI): 79.7-82.9) years old in comparison to an average age of 48.7 (CI: 48.1-49.3) years for non-palliative calls (Table 3). Difference in age across categories was statistically significant ($p < 0.001$).

A majority (64.7%) of probable palliative calls were in long term care, while 25.4% originated in the home. In comparison, non-palliative calls had few (3.2%) calls from long term care, while 42.9% occurred in the home. Just over half of the low potential and potential palliative calls occurred in the home. The association between location of the call and PSCM categories was significant ($p < 0.001$).

Probable palliative calls had a higher frequency of high acuity calls than potential, low potential or non-palliative calls. Among probable palliative calls, 25.4% were CTAS 1 or 2 in comparison to 13.8%-17.7% for the other three PSCM categories. The distribution of CTAS scores was significant across categories ($P < 0.001$).

The rate in which EMS requested medical consultation ranged from 6% for probable and 5.7% low potential palliative calls, to 4.2% for both non-palliative and potential palliative calls ($p < 0.001$) (Table 3). Transport rates for probable palliative (72.1%) and non-palliative (72.0%) calls were lower than low potential (76.0%) and potential (84.9%) calls (Table 3) ($p < 0.001$). Obvious death and termination of resuscitation calls were more common for calls with a higher likelihood of palliative support, as 4.5% of probable

palliative calls had involved a termination of resuscitation or obvious death in comparison to 0.1% of non-palliative calls.

Discussion

This study described the demographics of patients who requested EMS, to help identify the potential need for EMS palliative support. As well, the PSCM was developed and applied to estimate the number of EMS calls that may have benefited from palliative support. Differences were reported among the calls in the four PSCM categories.

Population Characteristics

Population demographics among the EMS population, including an older population, high frequency of conditions that could benefit from palliative care, and limited frequency of AD/DNRs support the need for an increased understanding and integration of EMS with palliative care providers and a greater role for EMS in providing palliative support. A large proportion of the population who utilize EMS were over the age of 70, a stage of life where palliative support is more likely to be requested. Further research is necessary to determine how EMS is utilized by older adults to ascertain if the high levels of utilization among this population are due to acute care reasons and/or are for situations where palliative support may be beneficial.

The finding that a large proportion of EMS calls involve older adults is congruent with other research (Dickinson et al., 1996; Abe et al., 2013; Pittet et al., 2014). Our study

found that 40.7% of EMS calls involve patients 70 and older. This suggests a disproportionate amount of EMS calls are received from this age group based on population size, as only 11.3% of the population within Nova Scotia were over the age of 70 according to 2011 census data (Statistics Canada, 2013) (Figure 3). High proportions of EMS calls involving older adults requires consideration as older adults are more likely to require advanced life support, and on average have longer on-scene times (Dickinson et al., 1996).

The frequency of conditions that could benefit from palliative care within the study population supports recommending an improved understanding of palliative support among EMS providers. Cancer and COPD were both present in >10% of EMS calls suggesting that EMS providers might benefit from increased support to ensure the effective management of these conditions in the out-of-hospital environment. Further research is necessary to describe the utilization of EMS by individuals with chronic diseases to determine how EMS is utilized as progression of a life limiting chronic disease occurs.

Despite the high frequency of conditions potentially benefiting from palliative care, AD/DNRs were seldom reported. The frequency of AD/DNRs within the EMS population appears to be low in comparison with the overall population, as a recent Canadian Institute of Health Information report found that 29% of Nova Scotians over the age of 55 surveyed had written plans regarding their end-of-life care (CIHI, 2015). Ensuring that EMS providers are given AD/DNRs when on scene is important as they can clarify patient wishes (Lord et al., 2012; Lamba et al., 2013). The limited frequency of AD/DNRs reported by EMS may mean either that their use among the population

requesting EMS is low or that these documents may not be seen as relevant by patients, family or EMS providers during a call. The finding that a majority of AD/DNRs were completed by long term care residents was not surprising, as in many cases long term care facilities request individuals provide AD/DNRs upon admission.

Palliative Support Composite Measure

Both probable and potential palliative calls had a higher rate of on-scene death than non-palliative and low potential calls. This finding supports that the PSCM may differentiate among calls associated with caring for persons at end of life. The inclusion of on-scene death was not included in the development of the PSCM due to the potential for capturing traumatic deaths. Further investigation is necessary to determine the frequency of traumatic versus non-traumatic deaths within EMS, and thereby might provide a variable for consideration in refinements of the PSCM.

The application of the PSCM estimated that approximately 1% of EMS calls have a probable palliative goal, while 22.5% percent have a potential palliative goal. From our review of the literature, this study appears to be the first time a method has been developed to estimate the proportion of calls that may benefit from palliative support within EMS. Measures have been developed to estimate the overall need for palliative support at the population level, typically utilizing death certificate or hospital based data (Murtagh et al., 2014). However, the application of these measures may not be suitable for the estimating palliative care use within the EMS environment.

The lower frequency of transport among the non-palliative and probable palliative groups was expected, though it occurred for potentially different reasons. The low transport rate among the non-palliative population is likely explained by many of these calls involving low acuity patients where EMS care/transport was not necessary. In comparison, the probable palliative group had higher acuity patients (more CTAS 1 and 2's), but transport may have been less likely among this population due to the potential of AD/DNRs that helped clarify patient wishes and care objectives for treat and release care, or due to the high frequency of ECP calls among this population.

Patients were older on calls that were more likely to be palliative (Figure 2). Among non-palliative calls there was a higher tendency for calls with no age recorded. These calls potentially represent situations where paramedics were on scene for a short period of time, or where EMS was either not needed or not requested to provide treatment to the patient on scene.

Implications for EMS Practice

Results suggest that there is a potential benefit for improved integration of palliative practices within EMS. The delivery of patient centred, palliative support by EMS may provide assistance to individuals with palliative related emergencies in the out-of-hospital environment, and should be designed to allow individuals to receive care in the location of their choice.

The Nova Scotia ECP program may provide guidance in the development of a solution. ECPs have noted the benefits associated with the expanded scope of practice and being

provided end of life care training, as it has allowed ECPs to better meet the wishes of individuals at the end of life (Jensen et al., 2014). To properly facilitate this on a larger scale within a ground ambulance system, collaboration may be necessary with other palliative care providers to ensure continuity of care, as EMS remains focused on the delivery of care in emergency situations and should not be relied upon as the sole provider of palliative support.

Limitations

Variations in the charting habits of EMS providers have not been investigated and may have an impact on study results. Also, the extensive number of data fields within the EHS ePCR may mean that meaningful data were recorded in fields not examined in this analysis. As well, certain fields were incomplete. This may be due to the nature of the call, the field not applying to the situation, or the field not being a mandatory field within the ePCR.

The impact of the inclusion of ECP calls must also be considered. ECP calls were included in this analysis as the objective was to describe the population who requested EMS for emergency assistance. It is important to note the difference in the scope of care and potential disposition for these calls may have had an impact on the results.

Specifically, the frequency of transports among ECP patients may have been substantially lower for ECP calls than non-ECP calls. ECP calls may have also accounted for the high rate in which probable palliative calls were attended by an ACP or CCPs as ECPs are not

a designated position but rather are ACP/CCPs with specialized training and thus are recorded as an ACP or CCP in the ePCR on ECP calls.

Limitations are also associated with the PSCM. The measure was developed because EHS does not widely track patient information after the conclusion of a call. Therefore, it could not be determined if a patient was at the end of life when a call occurred. This led to the development of the PSCM. The ability to proactively estimate whether an individual is at the end of life is difficult, especially with certain conditions such as COPD, congestive heart failure, frailty and organ failure as functional decline at the end of life is less predictable in comparison to individuals with cancer (Lunney et al., 2003; Dalgaard et al., 2014). In addition, it is important to consider that not all individuals at the end of life may wish to receive palliative support, as the decision to receive palliative support is based on personal preference. As there is no easy method to determine patient preferences for palliative support retrospectively from the ePCR, the measure developed for this analysis estimated that all potential end of life calls could have benefited from palliative support.

Further limitations are associated with the indicators utilized to develop the PSCM. The measure assumed that all individuals with a condition that could benefit from palliative care may have benefitted from palliative support, not taking into account the stage of the disease. Therefore, this may be considered an overly liberal estimation. Similarly, the selected chief complaints included all complaints that may have been associated with palliative support. However these complaints in many situations may have had non-palliative related causes, leading to an over estimation in classifying calls as associated

with a palliative goal. Additionally some individuals may have had AD/DNRs for reasons not associated with end of life, also leading to an overestimation.

Future Research

Further research should investigate the utilization of EMS by individuals at the end of life requesting palliative support, describing EMS use by specific populations, including individuals enrolled in palliative care programs, long term care residents and by individuals with specific life limiting chronic disease. Further research should investigate the ability of EMS providers to assess if a call is related to palliative support and investigate the ability of EMS to utilize AD/DNRs to provide care. Additionally, further research should be undertaken to validate the PSCM developed within this study and to determine which combination of variables can best predict that an individual requesting EMS is at the end of life and may benefit from palliative support.

Conclusions

EMS is frequently involved in providing care to older adults and individuals with conditions that may benefit from palliative support. With the prevalence of these patient characteristics in the EMS population, improved protocols and training regarding the role of EMS in providing palliative support is recommended. Despite the frequency in providing care to this population, the rate in which AD/DNRs is encountered by EMS is low.

The development and application of a PSCM provides an estimate of the frequency of utilization and characteristics of the end of life population that may benefit from EMS palliative support. Further refinement and validation of this measure is recommended.

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Table 1. Frequency of diseases that may have benefitted from palliative care in EHS (n= 8,589)

Condition^{1,2}	Frequency	Proportion of Calls
Chronic Obstructive Pulmonary Disease (COPD)	2,112	10.8%
Cancer	2,031	10.4%
Cerebrovascular Accident	1,021	5.2%
Congestive Heart Failure	964	5.0%
Dementia	868	4.5%
Alzheimer's	323	1.7%
Renal failure	281	1.4%
Parkinson's	189	1.0%
Kidney Disease	178	0.9%
Emphysema	173	0.9%
Multiple Sclerosis	172	0.9%
Chronic Bronchitis	169	0.9%
Liver Disease³	48	0.3%
Cirrhosis	44	0.2%
Liver Failure	16	0.1%

1. Conditions as reported by Murtagh et al. (2014) refined from Rosenwax et al. (2005). Huntington's, Amyotrophic lateral sclerosis (ALS), and Acquired Immune Deficiency Syndrome (AIDS) are omitted from reporting in this table because their frequency counts were less than 10 in the EHS ePCR data, but were included in the proportion of calls calculation.

2. Conditions are not mutually exclusive. Up to 10 conditions per call were tracked for this analysis

3. Liver disease does not include hepatitis

Table. 2. Frequency and justification for inclusion of EHS chief complaints as potentially palliative or common for persons at the end of life (n=11,543)

Complaint	Frequency	Percent	Source/Justification
Respiratory Distress	1,437	7.4%	Delgado-Guay et al., 2014 “dyspnea”; Weise et al., 2009 “Dypsnea”; Hjermstad et al., 2013 “Dypsnea, pleural effusion, pneumonia, embolism”, Barbera et al., 2010 “pneumonia, dyspnea, Pleural effusion”; Lawson et al., 2009 “Shortness of Breath”
Wellness Check	1,368	7.0%	Hjermstad et al., 2013 “social causes care needs”; Meischke et al., 2009 notes frequent reasons why EMS requested: “didn’t know what to do”, “called because scared”
Chest pain	1,316	6.8%	Barbera et al., 2010
Abdominal/ Flank Pain	1,287	6.6%	Lawson et al., 2009; Barbera et al., 2010
General Malaise	1,187	6.1%	Lawson et al., 2009; Barbera et al., 2010; Delgado-Guay et al., 2014 “weakness”
Weakness/ Fatigue	740	3.8%	Lawson et al., 2009; Delgado-Guay et al., 2014 “weakness”; Barbera et al., 2010 “fatigue”
No Apparent Illness/ Injury	650	3.3%	Hjermstad et al., 2013 “social causes/care needs”; Meischke et al., 2009: notes frequent reasons why EMS requested: “didn’t know what to do”, “called because scared”
Nausea/ Vomiting	590	3.0%	Lawson et al., 2009; Barbera et al. 2010; Delgado-Guay et al., 2014; Hjermstad et al., 2013
Syncope	558	2.9%	Weise et al., 2009 “unconsciousness”
Altered Mental Status	536	2.8%	Barbera et al., 2010 “altered consciousness”; Delgado-Guay et al., 2014
Seizures	484	2.5%	Barbera et al., 2010 “convulsions”; Weise et al., 2009
Back Pain- Non-Traumatic	409	2.1%	Barbera et al., 2010
Vertigo/ Dizziness	259	1.3%	Lawson et al., 2009
Cardiac Arrest	187	1.0%	Guru et al., 1999: Cardiac arrest involving palliative patients occurs in about 10% of EMS arrest calls.
Obvious Death	152	0.8%	Meischke et al., 2009: EMS often requested to confirm death.

Complaint	Frequency	Percent	Source/Justification
GI Bleed	131	0.7%	Delgado-Guay et al., 2014 “other GI Symptoms”; Barbera et al., 2010
Sepsis	108	0.6%	Hjermstad et al., 2013 “infections”; Delgado-Guay et al., 2014 “infection”
Medical Device Complication	51	0.3%	Lawson et al., 2009; Delgado-Guay et al., 2014 “catheter related events”
Pulmonary Edema	40	0.2%	Barbera et al., 2010 “congestive heart failure”
Violent/Agitated	29	0.1%	Eustace et al., 2002, Rodger, 2006: associated with advanced dementia
End of Life Care	24	0.1%	Barbera et al., 2010
Respiratory Arrest	*	0%	Delgado-Guay et al., 2014 “dyspnea”, Weise et al., 2009 “Dypsnea”; Hjermstad et al., 2013 “Dypsnea, pleural effusion, pneumonia, embolism”; Barbera et al., 2010 “pneumonia, dyspnea, Pleural effusion”

1. To protect privacy, calls with less than 10 are given an asterisk (*)

Table 3. Population characteristics by Palliative Support Composite Measure categories

	Total Population (N=19,487)	Non- Palliative (n=6,018)	Low Potential Palliative (n=8,880)	Potential Palliative (n=4,388)	Probable Palliative (n=201)	P Value
Female	52.6%	49.9%	54.0%	53.3%	58.2%	0.000
Average Age (Years)	59.6	48.7	59.0	73.7	81.3	0.000
>70 years	40.7%	22.7%	39.2%	66.1%	84.1%	-
Call Location						0.000
Home	49.5%	42.9%	51.2%	55.6%	25.4%	-
Long Term Care	8.9%	3.2%	7.4%	17.3%	64.7%	-
CTAS 1 or 2¹	15.6%	16.2%	13.8%	17.7%	25.4%	0.000
Medical Consult	4.9%	4.2%	5.7%	4.2%	6.0%	0.000
Transport Outcome						0.000
Transport	76.7%	72.0%	76.0%	84.9%	72.1%	-
No Transport	22.0%	27.9%	22.4%	13.0%	23.5%	-
Deceased/Termination of Resuscitation	1.3%	0.1%	1.6%	2.1%	4.5%	-
ACP or Higher	67.6%	66%	67.6%	68.9%	83.1%	0.000
ECP	0.9%	0.3%	0.5%	1.6%	21.0%	-

1. Kruskal-Wallis test performed to measure statistical significance of CTAS distribution.

Table 4. Non-palliative chief complaints for EHS calls from January-March 2014 (n=7,939)

Chief Complaint¹	Frequency	Proportion of calls
Minor Trauma	2,201	11.3%
Other	1,375	7.0%
Post Fall Assessment	1,022	5.2%
Psychological Problem	617	3.2%
Null	491	2.5%
Overdose/poisoning	484	2.5%
Diabetic Problem	301	1.5%
Stroke/CVA/TIA	248	1.3%
Headache	200	1.0%
Major Trauma	144	0.7%
Head/Neuro Injury	144	0.7%
Epistaxis	119	0.6%
Allergic RXN	107	0.6%
Assault	100	0.5%
Arrhythmia	99	0.5%
ACS	67	0.3%
Wound care	58	0.3%
PV Bleed/Threatened Abortion	46	0.2%
Environmental	29	0.2%
Foreign Body Obstruction	26	0.1%
Perinatal Mother Care	20	0.1%
Childbirth/Post-Partum Care	16	0.1%
Burns	15	0.1%

1. Barotrauma, CBRN/Hazmat, Near Drowning, Neonatal Care /Resuscitation and Pre-eclampsia/eclampsia chief complaints are omitted from reporting in this table because their frequency counts were less than 10 in the EHS ePCR data, but were included in the proportion of calls calculation.

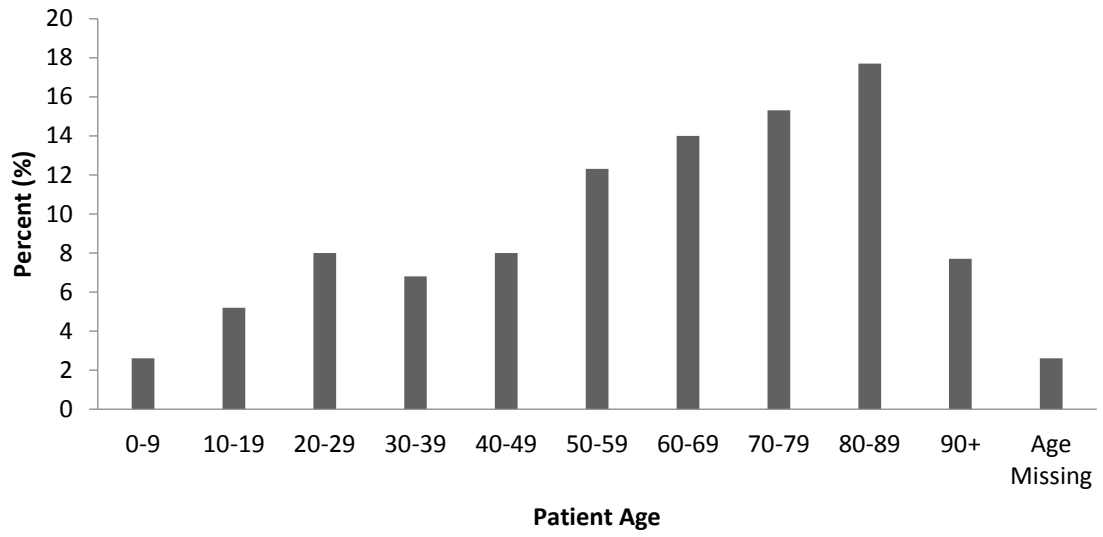


Figure 1. Distribution of age of patients for EHS calls

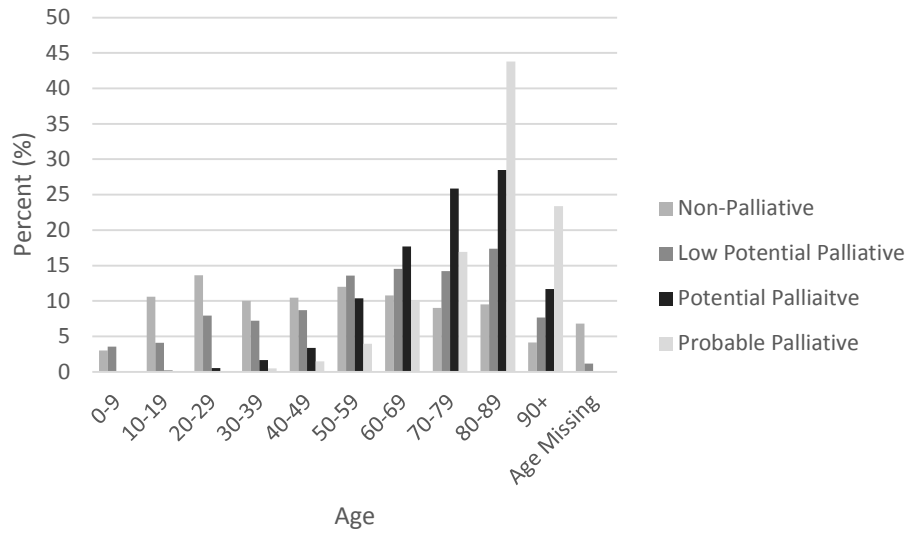


Figure 2. Distribution of age of patient for EMS calls by Palliative Support Composite Measure

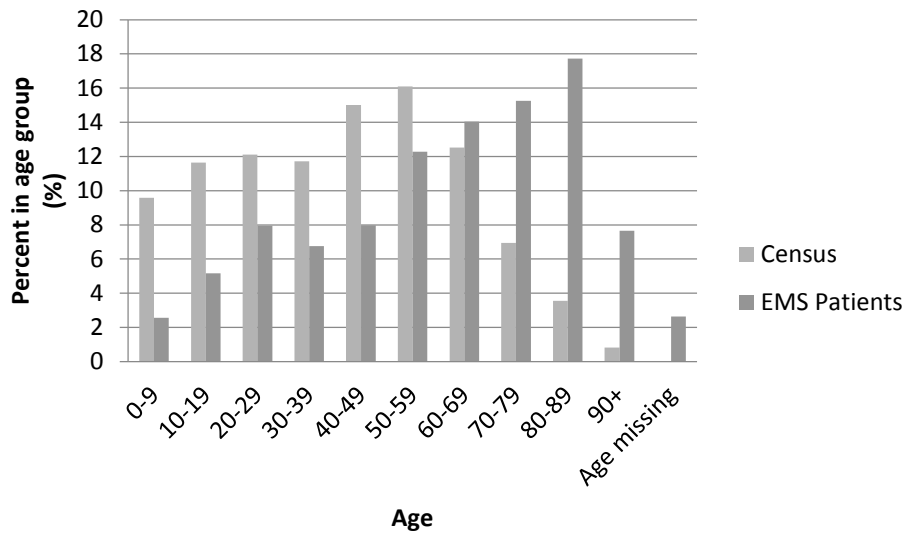


Figure 3. Age distributions for EHS patients and 2011 Nova Scotia census population

Chapter 4: Proposal for Future Research

Introduction

The previous chapters of this thesis provided insight regarding the end of life population and considerations for the involvement of Emergency Medical Services (EMS) in palliative support. A key recommendation of Chapters Two and Three was that further research was necessary to build on the results and address limitations. Further research is imperative due to the limited understanding of the role of EMS in providing palliative support and the difference between the objectives of palliative care and the traditional objectives of EMS.

Chapter Two found that the majority of deaths occur in-hospital, supporting the potential benefit of an increased involvement of EMS in providing palliative support on the premise that this will allow more individuals to die in the location of their preference.

Chapter Two also found that comorbidities were common among individuals at the end of life, and enrollment in palliative care services (PCS) often occurred late or not at all, but did increase over the study period for both cancer and non-cancer decedents. This led to the recommendation that improved collaboration between EMS and other stakeholders involved in the delivery and management of palliative services is necessary in order to develop effective EMS palliative support protocols.

Chapter Three described the demographics of the EMS population and developed a palliative support composite measure (PSCM) to estimate the number of EMS calls that may benefit from palliative support. This study found that chronic conditions which may benefit from palliative support were common, that older adults accounted for a significant

proportion of the population who utilize EMS and that EMS providers rarely recorded being provided with advance directives (AD)/ do not resuscitate orders (DNRs). The study estimated that 1% of calls had a probable palliative purpose, while 22.5% had a potential palliative purpose.

Further investigation is necessary to ensure the role of EMS palliative support is understood from a system perspective, as an emphasis on providing patient centred palliative care becomes more commonplace. Research should support the ongoing work within Nova Scotia to improve EMS palliative support, as Emergency Health Services (EHS) is in the process of implementing a new palliative care clinical practice guideline. The guideline focuses on allowing paramedics to better meet patient wishes at the end of life and reduce the frequency of transport to the Emergency Department (ED) where possible (Office of the Provincial Medical Director, EHS Nova Scotia, 2015).

A major limitation with the previous chapters of this thesis was that EMS data were not linked to death certificate data to determine which patients were at end of life or to other data that could have helped identify patients who might have benefitted from EMS palliative support. This led to the identification of future areas of research to support the development and understanding of the role of EMS in palliative support.

The linkage of the EHS electronic patient care record (ePCR) to other administrative databases would provide the ability to identify and more fully describe the end of life population and assess the pattern of individual utilization of EMS over time prior to death, providing a more comprehensive understanding to inform the optimal role of EMS palliative support. This chapter is designed as a proposal for future research based on this

linkage, with the overarching objective of describing EMS utilization in the final year of life to inform the development of EMS palliative support and assist in the refinement of the Palliative Care Support Measure (PSCM) developed in Chapter Three.

For this proposal, there are three primary components for future research. The first is to utilize linked ePCR and NSVS death certificate records to determine the validity of the PSCM and other EHS ePCR variables. The second is to utilize Classification and Regression Tree (CART) analysis to enable the refinement of the PSCM by using a data driven method to identify EMS variables that best predict who will die within a year of the EMS call versus those who do not die in this time period. The third component is to utilize the ePCR and NSVS data ideally linked to other health services databases to allow for the application of multiple logistic regression (MLR) to more fully understand the utilization of EMS by individuals at the end of life compared to other EMS users.

CART has been used previously in Nova Scotia end of life studies which utilized linked administrative data (Gao, et al., 2011; Roach et al., 2014; Urquhart et al., 2015). MLR has also been used for similar investigations (Burge et al., 2003; Johnston et al., 1998; O'Brien et al., 2007; Burge et al 2008; Gao et al, 2011; Lavergne et al., 2011).

Future Research Questions

This case-control study for proposed study has three research questions.

1. What is the validity of EHS ePCR variables, particularly the PSCM in comparison to EHS patients being within a year of death, as determined by linkage of NSVS data to the EHS ePCR?
2. Using CART, what EMS variables are the best predictors of identifying patients who will die within one year of an EMS call?
3. Using MLR, what variables are significant in differentiating between those requesting EMS who are in the last year of life versus those who are not?

Proposed Time Frame of the Study Data

This proposed study is a multi-year population-based study utilizing Nova Scotia Vital Statistics (NSVS) Death Certificate data from 2012-2014 to define the decedents. To describe the utilization of EMS in the final year of life, Emergency Health Services (EHS) ePCR data from 2011-2014 will be linked to the 2012-2014 decedents. Additional data sources that may also be linked will require data from 2011-2014. The additional year (2011) prior to the NSVS death certificate data years is necessary to describe utilization of health care services in the final year of life.

Data Linkage

Linkage between NSVS death certificate records and the EHS ePCR is the primary linkage within this analysis. It shall form the basis for answering study questions one and two and is also needed to help answer study question three. Data linkage variables to be

used from both the NSVS and ePCR data are health card number (HCN), first and last name, date of birth, date of death (or date last alive), sex, and postal code (Table 1).

NSVS data will be utilized in the linkage to identify which EHS patients died within a year of the last EHS call. Death certificate completion is mandated by law, thus helping to ensure that all decedents are captured for this study.

EHS ePCR will be linked to identify the study population and to determine EMS utilization. Prior to the linkage between EHS ePCR and NSVS records, EHS ePCR records will be internally linked to form a patient based record from the call based records. The utilization of probabilistic record linkage software is recommended, for both the internal linkage of EHS ePCR records and subsequent linkage of ePCR and NSVS data.

To answer study question three in addition to data from the EHS ePCR-NSVS linkage, data from other databases could potentially be linked including, provincial chronic disease registries, hospital discharge and other health services data if available.

Probabilistic record linkage is necessary, as HCN and other identifying variables may be incorrectly entered or missing from the NSVS, EHS ePCR or other databases (Johnston et al., 2011; Johnston & Lethbridge, 2014). Probabilistic record linkage uses the probabilities of links being correct by utilizing all identifying information collected within each database (Qayad & Zhang, 2009). Probabilistic record linkage software exists and its use is best practice for record linkage when some identifying information could be missing or inaccurate. As evident by the 3x3 Network for End of Life Studies (NELS) project, probabilistic record linkage between multiple provincial administrative datasets

is feasible and the creation of such databases can be utilized to support research and foster informed decision making in the healthcare environment (Johnston & Lethbridge, 2014).

Study Population, Study Subjects and Study Year of each Study Subject

The study population is all persons with an EHS ePCR record from 2011-2014. Using NSVS data, the study population will be subdivided into those who died within a year of the last EMS call (cases) and all others. From all others who did not die within a year of their last EMS call, a sample matched to the decedents (controls) will be selected. It is proposed that the matching be by age, sex and geographic area of residence.

The study year is the last year of life for decedents (cases). For each matched non-decedent (control), the study year would be the year prior to the date of death of their matched decedent.

A matched analysis is being proposed to limit the number of EMS calls that would otherwise be included in this study. If no matching occurred, this study would include approximately 240,000 EMS calls. Therefore matching is proposed to limit the number of EMS calls to a more manageable number: only calls associated with individuals who utilized EMS in the last year of life (cases), and a similar number of individuals who utilized EMS who were not at the end of life (controls). Based on historical NSVS death data from Chapter Two it is expected that approximately 24,300 deaths would occur during the study period. For this study, the number of decedents included would be expected to be less than 24,300, as not all individuals at the end of life are expected to utilize EMS.

Based on the case-control design the maximum number of study subjects in this analysis would therefore be approximately 49,000 individuals based on if all decedents utilized EMS at the end of life.

While making the EMS data more manageable, matching creates study limitations. Because age, sex and geographic location of care are used for matching, these variables cannot be analyzed to determine their relationship with an EMS call being associated with the end of life. This is because these variables would be controlled by the matched study design and therefore cannot be meaningfully analyzed.

Statistical Methods

Study Question One: Validation of the PSCM and other EHS ePCR Variables

A cross tabulation will be developed to answer the first study question. The study subjects will be independently subdivided and compared on two variables 1) died within a year of the last EMS call (cases versus controls) and 2) the four PSCM categories as defined in Chapter Three using the chief complaint, past medical history and AD/DNR ePCR fields. A chi-square test of significance and the kappa statistic will be computed to assess the association between the categories of the PSCM and a patient dying within one year of the EMS call.

In addition, age and sex from NSVS death certificate data will be compared to the corresponding EHS ePCR data to ascertain the quality and completeness of these variables in the patient (rather than call) based EHS ePCR. EHS ePCR clinical

information such as past medical history will also be tracked and compared to NSVS cause of death data to determine the agreement in disease coding.

Study Question Two: CART analysis and refinement of the PSCM

CART will be used to identify sets of EMS variables that are the best predictors of an individual requesting EMS dying within one year of an EMS call. EMS variables (either alone or in combination) that predict if a call is for a person in their last year of life may be added to the PSCM. Additionally, if certain variables and/or values of variables are not predictive of a call being associated with end of life they will be removed from the measure.

EHS ePCR data to be extracted to answer this study question shall include number of EMS calls in the study year of each study subject; whether the call occurred in a home, nursing home or other environment; chief complaint(s); past medical history; care provided; whether the individual had an AD/DNR or was a member of the special patient program and call outcome data (whether a medical consult was made on-scene and transport outcome). Additional EHS ePCR variables may be included in the analysis based on further discussion with EHS. Age, sex and geographic location of the call may be problematic to include in the CART analysis due to the matched study design.

Study Question Three: Multiple Logistic Regression Analysis

The dependent variable for the multiple logistic regression analysis is if the patient on the EMS call died within one year of the call or not. Further analysis may also be carried out using shorter periods of time to death, such as for the last six months or last month of life.

The independent variables for this analysis are demographic, patient care, geographic, and outcome data from the ePCR database, in addition to data from chronic disease registries and other health services databases available for data linkage.

Linkage with chronic disease registries is advised to provide an understanding of the utilization of EMS by individuals at the end of life who have chronic diseases compared to those with chronic disease who are not in their last year of life. This linkage can also be used to identify disease registry variables associated with an EMS patient that are predicative of a person being at the end of life. There are four potential chronic disease registries that could be linked to the proposed new study dataset: Cancer Care Nova Scotia, the Diabetes Care Program of Nova Scotia, Cardiovascular Health Nova Scotia, and the Nova Scotia Renal Program. Cancer Care Nova Scotia, Cardiovascular Health Nova Scotia and Diabetes Care Program of Nova Scotia data were used in Chapter Two of this thesis, while Nova Scotia Renal Program data is available from 2011 onward (NSDHW, n.d.) and thus could be linked.

The linkage of hospital discharge data could address questions such as: 1) what proportion of cases and controls are admitted to hospital and for how long before (e.g. readmission rate) and after (e.g. potentially preventable admissions) EMS calls? and 2) can inclusion of hospitalization variables improve the ability of the PSCM to predict

EMS calls related to end of life? Continuing care and drug information data may also be used to further examine factors associated with being at the end of life among EMS users. These data can also be used to inform the potential for collaborations between EMS and other health care providers to optimize the delivery of collaborative integrated palliative care.

Implications of Proposed New Linked Database Study

This proposed study shall further inform the development of the role of EMS in the provision of palliative support. The study will assist by identifying the end of life population who utilize EMS and the variables that differentiate them from EMS users who were not within a year of death. An examination of the cases only will also answer why and how frequently individuals at the end of life utilize EMS. As well, the PSCM can be further refined as needed based on the validation findings with the ultimate goal of providing a method that can be applied by EMS agencies to help estimate the size and characteristics of their end of life population. The indicator may be further developed to assist EMS providers in the field to predict the likelihood that a patient may benefit from EMS palliative support.

Research Ethics Approval

Ethics approval for this study will need to be obtained. Ethics approval shall be requested from the Nova Scotia Health Authority Research Ethics Board. Research ethics must be

sought for this study as this proposal is to utilize patient information for research purposes. As the data to be collected contains personal identifiers, security and protective measures will need to be in place to obtain Research Ethics Board approval. The new Tri-Council research ethics guidelines shall be followed for this study (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014).

Next Steps: Feasibility Study

To develop this proposal further, a feasibility study should be undertaken. This feasibility study should be carried out in collaboration with relevant stakeholders to determine which data can and should be collected, how it will be collected and how it shall be utilized. Key components would include: 1) finalization of study questions, 2) determination of which databases can and should be linked for this analysis, and 3) development of the full study protocol and methodology. Key stakeholders who should be consulted would include staff from: EHS, Palliative Care Services (either individual agencies or a single agency depending on the structure after the DHA amalgamation), the provincial disease programs, NSVS and other agencies whose data may be linked for this proposed new data analysis.

Conclusion

The earlier chapters of this thesis have increased our understanding of the possible need and provided considerations for the involvement of EMS in providing palliative support. To build on these studies and provide greater understanding of the utilization of EMS at the end of life, this chapter includes a proposal for a new study linking NSVS death certificate and EHS ePCR data to assess EMS utilization in the final year of life. Chronic disease registries and other databases may also be linked to identify additional factors that may predict that a person is at the end of life, and as a result might benefit from EMS palliative support. By carrying out a feasibility study, EHS may identify key partners for collaboration in further development of the role of EMS in the provision of palliative support.

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Table 1. Variables Required for Data Linkage

Variable/Field	NSVS	EHS	Chronic Disease Registry
HCN	Yes	Yes	Yes
All Names	Yes	Yes	Yes
Date of Birth	Yes	Age	Yes
Date of Death	Yes	No, unless call involves on scene death, and date last alive	Yes/or date last alive
Postal Code	Yes	Yes (of call)	Yes
Location of Residence	County of Residence	Location of call	County/DHA

Chapter 5: Conclusion

The role of emergency medical services (EMS) in palliative support is likely to evolve and expand, due to several factors discussed in this thesis and the literature: the population is ageing, there is increased focus on providing palliative care at the end of life, EMS has become more integrated within the healthcare system and the scope of practice of EMS providers is expanding. This investigation provides evidence to inform the potential for EMS involvement in palliative support by describing the estimated size and characteristics of the population who may benefit and by also identifying differences between potential palliative and non-palliative EMS calls. The findings of this thesis provide a foundation for future research to investigate the optimal role of EMS in palliative support.

Chapter One provided a review of the literature in relation to palliative care and the role of EMS in providing palliative support. Chapter Two was a descriptive study of the characteristics of the end of life population in Nova Scotia. Chapter Three described the demographics of EMS calls. A palliative support composite measure (PSCM) was also developed to estimate the proportion of calls that may have benefited from palliative support. Differences between calls which may be related to palliative support and those that were not were identified. From the findings of these studies, a priority for research was identified and described in Chapter Four. The study proposed to link death certificate data and EMS patient care records to determine individual utilization of EMS during the end of life, while also presenting a method for validating and refining the PSCM developed in Chapter Three.

Key Findings

The results from Chapter Two indicate that the proportion of decedents enrolled in palliative care services (PCS) with both cancer and non-cancer conditions increased over the study period. PCS enrollment was often late for both cancer and non-cancer decedents as many individuals were only enrolled in the final two weeks of life. Palliative care enrollment trends provided an estimate of the population who requested palliative care, when they requested it and why. Application of the Rosenwax et al., (2005) method found that between 59.6% and 94.5% of decedents may have benefited from palliative care at the end of life.

Comorbidities were found to be common for both cancer and non-cancer decedents. An increasing prevalence of individuals with non-cancer conditions requesting palliative care has special considerations, as these individuals are typically older and have a higher number of comorbidities in comparison to cancer decedents.

The results of Chapter Three indicate that a large proportion of EMS calls involved patients over the age of 70, that advance directives and do not resuscitate orders (AD/DNRs) were often not recorded on the EMS chart and that the presence of chronic conditions that may benefit from palliative support were common. Cancer and chronic obstructive pulmonary disease were the most common conditions encountered, each being recorded for >10% of EMS calls.

The application of the PSCM developed in Chapter Three suggested that 1% of EMS calls had a probable palliative purpose, while 22.5% had a potential palliative purpose. Of all calls, 30.9% were unrelated to palliative care. The measure found that probable

palliative calls involved individuals who were older, of higher acuity, more likely to be a resident of long term care, were more likely to be seen by an advanced care or critical care paramedic. Probable palliative calls were also more likely to involve situations where on scene death occurred. The PSCM provides a method to estimate the frequency of calls within EMS that may benefit from palliative support. Further investigation of the PSCM was recommended to refine and validate the measure.

Chapter Four provided a proposal for future research to address limitations of Chapters Two and Three, while expanding on the results of these chapters by proposing the linkage of death certificate and EMS data. This would allow for an improved understanding of the utilization of EMS by individuals at the end of life. Other databases that might also be linked include hospitalization, continuing care, drug information system, and chronic disease registries. These linkages would support the investigation of sub-populations within the study population. Classification and Regression Tree (CART) analysis of the linked data could assist in the refinement and validation of the PSCM, and to better determine what variables in the EHS electronic patient care record (ePCR) are associated with a call being related to palliative support and end of life.

Thesis Strengths

This thesis provides evidence to further the understanding of the potential need for, and role of, EMS palliative support. Research in this field is vital as an ageing population, in conjunction with an increased focus to provide palliative care in the out-of-hospital environment, may mean that EMS may be requested to provide palliative support more

frequently. This work provides foundational evidence upon which future studies can be based. The findings increase our understanding of potential palliative patients in the EMS environment, an environment in which palliative care has traditionally not been considered. Furthermore, this work has shown that there is a potential need for increased consideration of the role of EMS in the provision of palliative support, as evident by the analysis of palliative care enrollment trends, and the review of the EMS demographic.

This thesis also showed the merit of utilizing a population-based approach to conduct a comprehensive analysis of the current and potential need for EMS palliative support. The utilization of linked administrative data in Chapter Two was able to facilitate a detailed analysis of the decedent population within Nova Scotia, providing a description of PCS enrollment trends, cause of death information and population demographics. This chapter presented the benefit of utilizing data sources external to EMS to inform the development and design of EMS practice. Meanwhile, Chapter Three provided a detailed analysis of the EMS population, providing evidence as to the demographic which requested EMS for assistance and why they requested it. As well, the method and type of data analyzed within this thesis is generalizable to other jurisdictions making it possible to undertake comparable studies collecting similar administrative and EMS data.

Furthermore, the development of the PSCM in Chapter Three provides a novel method to estimate the potential need for palliative support. Chapter Four describes direction for the development and refinement the PSCM, allowing EMS to better understand and define its involvement in palliative support and end of life care.

Thesis Limitations

This thesis was unable to determine patterns of individual usage of EMS during the end of life as the EHS ePCR is call based as opposed to patient based and there was a lack of outcomes data. To address this limitation, internal linkage of EHS electronic patient care record (ePCR) data by individual and improved tracking of patient outcomes must occur.

At present there are few indicators in the ePCR that can denote a call is related to palliative care. There is an end of life chief complaint in the ePCR, but it is seldom utilized. Also, there are no performance or outcomes indicators related to palliative care utilized within EMS. Indicators and measures of success associated with palliative support are potentially very different from traditional EMS performance indicators and thus it will require considerable work to define what constitutes effective EMS palliative support. In the meantime, the PSCM was developed and presented as a novel approach to estimate the potential need for EMS palliative support, but it needs further validation and refinement.

A further limitation of this thesis is associated with the determination of whether and when palliative support is needed. This thesis estimated that all individuals at the end of life, aside from sudden deaths, may have benefited and requested palliative care at the end of life. This is an over estimation as palliative support is a personal preference and not all persons at end of life will opt to request palliative support.

An additional challenge is related to the language utilized throughout this thesis, as commonly accepted terms may change as the structure and delivery of palliative care changes. At present there is a wide variation in the utilization and interpretation of terms

associated in providing care to individuals at the end of life. For example, the use of the term “patient” was limited as much as possible in this thesis, as the term classifies an individual based on their immediate medical condition (Chochinov, 2014). Furthermore, the utilization of the term “supportive care” to define the role of EMS in palliative care may be more appropriate moving forward, as supportive care is a more encompassing definition, considering all stages of disease and needs for an individual and thus may be more in line with the purpose of EMS palliative support (Hui, 2014). As well AD/DNR are common terms within EMS, however the use of Allow a Natural Death should be considered moving forward.

A further limitation of this thesis is that this work only examined reasons why EMS was activated (medical history, chief complaint), and basic outcomes data (transport outcome, and whether a medical consultation was requested). Medication management and the utilization of specific palliative and lifesaving interventions at the end of life were not reviewed.

Discussion and Recommendations

Palliative support by EMS should not be delivered in a silo but rather should be designed with an emphasis on integration and communication with other stakeholders involved in the provision of palliative care. Palliative care is an interprofessional and team based discipline, consisting of all members involved in providing care. This model of palliative care delivery has been shown to produce positive outcomes (Bakitas et al., 2009).

Integration of EMS as part of the palliative care team is imperative, as effectively

designed EMS palliative support may permit individuals to forego ED transport and remain in their home environment. With the team based approach in mind, that focuses on care in the home environment, EMS palliative support should be designed in conjunction with primary care, PCS and other care providers.

EMS palliative support should be developed to ensure that if home-based care is provided by EMS that there is a structure in place so that follow-up care is provided by other care providers, as EMS is not structured to provide ongoing care. Specifically, this will mean that EMS should ensure that PCS and primary care providers involved in providing palliative care are consulted in the decision to transport or not transport, and to confirm that appropriate follow up care can be provided if the individual remains in the home environment. As well, linkage with primary care providers and/or PCS should be considered to ensure that EMS effectively follows care plans that have been developed by these care providers.

A further recommendation is the need to improve how to identify EMS calls that are related to palliative support, to improve the delivery of care. The development of the PSCM presented herein provides an estimate of this population; however estimation of when an individual is at the end of life remains a difficult issue, especially for non-malignant conditions (Dalgaard et al., 2014). Moving forward, if the PSCM can be further refined based on the CART analysis in Chapter Four, it may present the opportunity to develop the PSCM as a potential clinical decision tool to help EMS providers predict on scene if a call may be related to end of life and may benefit from a palliative approach to care.

While the PSCM in its current form may overestimate the proportion of palliative related calls if potential and probable palliative calls are considered, it is consistent with the concept that palliative care is more than care in the last days and hours of life. This is important to consider in the development of EMS palliative support as delivery of palliative care earlier in the disease progression is emphasized within the Nova Scotia strategy for palliative care (NSDHW, 2014).

To support the improved management of EMS palliative support, linkages with PCS and chronic disease programs is advised. These collaborations could support the development of a database for individuals wishing to receive EMS palliative support, which could improve the identification of these individuals and the delivery of care. These collaborations may also be beneficial in supporting the development of EMS protocols and clinical guidelines for the management of individuals wishing to receive palliative support, as chronic disease programs are responsible for supporting the development of standards of care for individuals with the condition within their mandates.

This thesis also demonstrates the need to improve the understanding of disease management and functional decline at the end of life within EMS to support the development of EMS palliative care protocols. Improved understanding of the optimal management of chronic conditions will mean that the providers of EMS palliative support will need higher levels of education on chronic disease management, frailty and the implication of comorbidity.

Comorbidities are common at the end of life, and patients with life limiting conditions are frequently encountered within EMS. In terms of the development of EMS palliative care, this will add a level of complexity to delivering care; especially if care is being

provided in the home without transport to hospital. It will mean that paramedics may need additional education and support on effective drug administration and delivery of care.

Additionally, individuals with non-cancer conditions are increasingly receiving palliative care. EMS must consider individuals with a wide range of non-cancer conditions in the development of palliative care protocols. Of particular concern is that individuals with non-cancer conditions may present as more complex palliative cases with less predictable disease trajectories in comparison to individuals with cancer.

To improve the management of palliative support in the out-of-hospital environment an increased focus on EMS education and training is necessary. A greater emphasis on end of life care and palliative support must be built into the initial EMS training and continuing education curriculum. Developing this new education will present challenges, as the objectives of palliative support typically differs from the traditional role of EMS in providing lifesaving treatment to critically ill patients. Increased education on the use and interpretation of AD/DNRs and understanding the process for substitute decision makers at the end of life is needed to assist EMS providers in better determining patient wishes at the end of life and providing care that meets their wishes.

Closing Remarks

Improved EMS palliative support has the potential to address a gap in the delivery of out-of-hospital palliative care, as there are presently few options available for individuals requesting palliative support at home in emergency situations in Nova Scotia. However,

other options could be further developed in the province in conjunction with or in place of EMS palliative support, such as incentives for family physician home visits, greater access to palliative care nurses in the community, and community based hospice care. Thus it is recommended that EMS palliative support initiatives are undertaken in consultation with other palliative care providers, to ensure the seamless and effective delivery of care and that EMS initiatives are appropriately involved in care based on the capabilities and structure of other palliative care providers. If designed and delivered in collaboration with other care providers, EMS palliative support may assist in better meeting the wishes of individuals at the end of life in regards to location of care and type of care provided.

Evidence suggests that consideration of EMS palliative support is warranted as there is an increasing trend in the frequency of individuals requesting palliative care and wishing to receive care in the home. Considerations in the delivery of EMS palliative support include the number of comorbidities at the end of life, the limited frequency of AD/DNRs encountered within EMS, and the increasing prevalence of individuals with non-cancer conditions requesting palliative care. From a population perspective, the benefit of palliative support is evident as a large proportion of EMS calls involves patients who are at an age where palliative support may be requested. As well, patients with life limiting chronic diseases are commonly encountered by EMS. To promote the development and delivery of effective EMS palliative support, collaboration between EMS and other stakeholders involved in the delivery and management of palliative care is advised.

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