Early Palliative Care: Opinions & Attitudes of Canadian Palliative Care Physicians

by

Anna Marie Sorensen

A thesis submitted in conformity with the requirements
for the degree of Masters of Science – Medical Science

Institute of Medical Science
University of Toronto

Early Palliative Care: Opinions and Attitudes of Canadian Palliative Care Physicians

Anna Marie Sorensen

Masters of Science – Medical Science

Institute of Medical Science
University of Toronto

2016

Abstract

Our aim was to describe Canadian palliative care physicians' attitudes and opinions about early palliative care and to determine factors associated with receiving early referrals. The response rate was 71% (531/747); 48% (257/531) were SPC physicians. The majority reported that for cancer (93.9%) and non-cancer (90.2%) patients, referral to palliative care should ideally be early. Only 20.5% reported the average survival for patients referred to them was >6 months. Having completed a Masters/PhD (OR 2.5, 95% CI 1.1-5.5); providing care mainly for non-cancer patients (4.0, 1.3-12.3); and female sex (2.7, 1.2-6.2) were associated with receiving early referrals. Those agreeing that patients should have stopped all chemotherapy before palliative care referral (0.34, 0.16-0.73) were less likely to receive early referrals. We conclude that timing of referral may be related to characteristics of the receiving physician rather than only the referring physician.

Acknowledgements

The gratitude I have for the support I received to complete this Master's thesis is more than words on a page could possibly convey. First, I want to acknowledge my friends who have supported me through all of my academic career; notably Murat Görgün, Serkan Bilgi, Aaron Gough, Evrim Delen, Candice Günöven, Öner Günöven, Joey Suriano, Daniela Mason, Dom Hanlon, Bonavie Tek, Nicole Ducommun, Ruth McGeehan and many others. Your support is not unlike a loving family. I am also grateful for the friends I have made. Particularly, Samantha Fernandez, we shared in this process and the memories we have made will stay with me. I can't wait to continue to build our careers together; the Masters was just the start.

The girls of the Zimmermann team, Nadia Swami, Nanor Kevork, Ashley Pope, and Christine Moon have kept me motivated and I can't express how lucky I am to have them in my life; this Masters was not possible without a lot of their help, laughter, stories, and all the snacks to keep me fueled. Furthermore, my parents, Jessica and David Sorensen and brother Forster Sorensen are really my foundation, and one thank you would never be enough. They are really the shining stars, they are the ones who taught me to work hard, think critically, and never give up. Also, thank you to my in-laws Berkok and Sevim Baybaş for their loving support and enthusiasm.

Dr. Camilla Zimmermann, thank you for being an exceptional role model and leader, for showing me how rewarding working towards your dreams can be, you are an inspiration, and you have helped me grow professionally in more ways than one. All of my mentors on my committee Dr. Gary Rodin, Dr. Kirsten Wentlandt, Dr. Monika Krzyzanowska, as well as Lisa Le in Biostats at Princess Margaret, you have all been exceptionally helpful and encouraging. All of you have taught me a lot, your expertise made this project possible. Also, thank you to my examiners Dr. Yael Schenker, Dr. Doris Howell, and Dr. Anna Gagliardi for devoting time to evaluating my work.

Lastly, I want to thank my husband and best friend, Alkas Baybaş. This Masters is just as much yours as it is mine. You have always supported my dreams as if they are your own, I could not be more lucky. To describe all the ways you have supported me would take as many pages as there are in this thesis and more. (And of course, much love to my dog Gamma Ray for keeping me grounded.)

Contributions

The completion of this Master's thesis was made possible by many contributors.

My progress advisory committee, including Dr. Camilla Zimmermann, Dr. Gary Rodin, Dr. Kirsten Wentlandt, Dr. Monika Krzyzanowska, in addition to Lisa Le of the Biostatistics Department of Princess Margaret Cancer Centre, and I designed the study. Our study was modeled after a study designed by Dr. Kirsten Wentlandt and Dr. Camilla Zimmermann that evaluated the referral practices of Canadian oncologists (Wentlandt et al., 2012). I developed the *Early Palliative Care Survey* used in this study with the help of Dr. Camilla Zimmermann, Dr. Kirsten Wentlandt and my committee. I sourced our cohort of Canadian physicians who provide palliative care from the Canadian Society of Palliative Care Physicians. Dr. Zimmermann, the Zimmermann research team, and I wrote the Research Ethic Board proposal submitted to the University Health Network. I performed the statistical analysis with the mentorship of Lisa Le, of the Biostatistics Department of Princess Margaret Cancer Centre, and Dr. Camilla Zimmermann.

This project was funded by the Canadian Cancer Society.

Table of Contents

List of Abbreviations

ASCO – American Society of Clinical Oncology

CFPC – College of Family Physicians of Canada

CHF – Chronic Heart Failure

CI – confidence interval

CMA – Canadian Medical Association

COPD – Chronic Obstructive Pulmonary Disease

CSPCP – Canadian Society of Palliative Care Physicians

EPC – Early Palliative Care

ECOG – Eastern Cooperative Oncology Group

EIU – Economist Intelligence Unit

GI – Gastrointestinal

GU – Genitourinary

IQR – interquartile range

MDACC – University of Texas M.D. Anderson Cancer Center

mo – month

PC – Palliative Care

RCT – Randomized Control Trial

REB – Research Ethics Board

Royal College – Royal College of Physicians and Surgeons of Canada

SD – Standard Deviation

SPC – Specialized Palliative Care

WHO – World Health Organization

YAC – Year of added competence

List of Tables

List of Figures

List of Appendices

Chapter 1: Introduction

Palliative medicine is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness” (World Health Organization [WHO], 2014). Palliative care is increasingly encouraged globally and in Canada for the management and reduction of physical, psychological, social and spiritual concerns related to end of life (Canadian Hospice Palliative Care Association [CHPCA], 2013; WHO, 2014).

Early palliative care is a model of care in which palliative care is integrated into standard care and is provided longitudinally in collaboration with the primary care team, typically in outpatient ambulatory clinics (Hannon et al., 2014). In an early palliative care model, patients are ideally referred to palliative care at the diagnosis of their terminal illness, or at a prognosis of 6-24 months (Bakitas et al., 2009; Temel et al., 2010; Zimmermann et al., 2014). Studies have shown that palliative care early in the illness trajectory is effective for improving patient quality of life, mood, satisfaction with care, and symptom control (Bakitas et al., 2009; Temel et al., 2010; Zimmermann et al., 2014). These results are clinically relevant, as patients consider quality of life a high priority when faced with a terminal illness (Steinhauser et al., 2000, 2001). However, despite the benefits of early palliative care, patients are typically referred late in their illness, usually in the last weeks to months of life or not at all (Cheng, Willey, Palmer, Zhang, & Bruera, 2005; Christakis & Escarce, 1996; Costantini et al., 1999; Earle et al., 2008; El Osta et al., 2008; Hui et al., 2014; Hui, Elsayem, et al., 2010; Hui, Parsons, et al., 2010). This delayed referral to specialized palliative care leaves less time for beneficial palliative services to be implemented.

In a previous survey of Canadian oncologists, 83% of patients were referred at a prognosis of <6 months (Wentlandt et al., 2012). In the same study, enablers for early palliative care referral included satisfaction with the availability of palliative care services, having access to comprehensive teams, and palliative care services’ acceptance of patients who were receiving concurrent treatments such as palliative chemotherapy. Additional barriers to integrating referring, primary, and specialized palliative care have also been documented in the literature. Often palliative care education is limited and thought to be synonymous with only pain management; therefore, referring physicians’ knowledge and understanding of the benefits of palliative care may be scant (Mullan, Weissman, Ambuel, & Von Gunten, 2002).

Correspondingly, patients and their caregivers also have a lack of knowledge and understanding of what palliative care entails. Studies have shown that patients incorrectly understand palliative care to only be applicable at the very end of life, and that the name palliative care may be a significant barrier to referral (Dalal et al., 2011; Fadul et al., 2009; Maciasz et al., 2013; Miyashita, Hirai, Morita, Sanjo, & Uchitomi, 2008; Morstad Boldt, Yusuf, & Himelstein, 2006; Zimmermann et al., 2016)

Barriers to early palliative care have been conceptualized mainly as stemming from attitudes of referring physicians and avoidance of palliative care among patients and their families. In contrast, attitudes and opinions regarding early palliative care among palliative care physicians have not been systematically assessed. In order to improve the timely provision of palliative care, a comprehensive understanding is needed of those providing palliative care, as well as those receiving and referring to specialized palliative care services. Here we are addressing this gap in the literature.

Chapter 2: Literature Review

2.1 Palliative medicine

In the broadest sense, the term “to palliate” comes from Latin “palliare” meaning to cloak (Canadian Hospice Palliative Care Association [CHPCA], 2016). The contemporary definition of palliative care is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness” (WHO, 2014). Palliative care began its formation in the 1960s when Dame Cicely Saunders first sought to develop and build St. Christopher’s Hospice, the first modern hospice in the United Kingdom (CHPCA, 2016). Since the building of St. Christopher’s Hospice in 1967, less than 50 years from the writing of this thesis, palliative care has continued to strive to improve the quality of life of patients and their loved ones by managing and reducing the physical, psychological, social and spiritual concerns related to life-threatening illnesses.

2.1.1 World Health Organization’s definition of palliative care

In the 1980s, The World Health Organization’s (WHO) interest in palliative care began as an initiative in their cancer unit to advocate for pain relief and opioid availability (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002). Since then the WHO has expanded its definition of palliative care to be more comprehensive. The current WHO definition of palliative care is “an approach that improves quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual” (WHO, 2014). Specifically, the WHO operationalizes palliative care as:

- Providing relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intending to neither hasten or postpone death;
- Integrating the psychological and spiritual aspects of patient care;
- Offering a support system to help patients live as actively as possible until death;

- Offering a support system to help the family cope during the patients illness and in their own bereavement;

- Using a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;

- Enhancing quality of life, and may also positively influence the course of illness;

- Applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The current model of care for patients facing a life-limiting illness is one where palliative care is integrated into standard medical care, such as oncological care (Bruera & Hui, 2010). In addition to improving quality of life, the collaboration of medical teams with palliative care aids patients in making decisions and achieving goals of care.

2.1.2 Palliative medicine in Canada

In the early seventies, Canadian physician Dr. Balfour M. Mount, inspired by Dame Cicely Saunders, founded the first palliative care ward in the Royal Victoria Hospital in Montreal (Mount, 1976). Palliative care is a relatively young field of medicine and how it is practiced varies among and within countries; each country experiences unique provisional challenges and Canada is no exception. In 2015, the Economist Intelligence Unit (EIU) was commissioned by the Lein Foundation to rank the environment, availability, affordability, community engagement, and quality of end-of-life care in 80 countries. Over all, Canada ranked 11th out of 80 countries in the EIU report (The Economist Intelligence Unit, 2015). The United Kingdom, Australia, and New Zealand took the top 1-3 spots respectively. Table 1 shows Canada’s overall and per category rank.

Table 1 Canada's overall and per category Quality of Death Index for 2015 (The Economist Intelligence Unit, 2015).

2015 Quality of Death Index	
	Out of 80
Canada's Overall Quality of Death Index Score	11
Quality of Care	
Presence of accreditation and monitoring standards for organizations; availability of opioid painkillers and psychosocial support; presence of Do Not Resuscitate (DNR) policy; shared decision-making; use of patient satisfaction surveys.	6
Human resources	
Availability of specialized palliative care workers; general medical knowledge of palliative care; certification for palliative care workers; number of doctors per 1,000 PC-related deaths; number of nurses per 1,000 PC-related deaths.	6
Community engagement	
Public awareness of palliative care; availability of volunteer workers for palliative care.	9
Palliative and healthcare environment	
Healthcare spending; presence and effectiveness of government-led national palliative care strategy; availability of research-based policy evaluation; capacity to deliver palliative care services.	18
Affordability of care	
Availability of public funding for palliative care; financial burden to patients for available palliative care services; national pension scheme coverage of palliative care services.	22

*PC = palliative care

The need for high quality palliative care in Canada is growing and increasingly evident. In 2012, Statistics Canada reported that the leading causes of all deaths in Canada were cancer (30.2%), heart disease (19.7%), stroke (5.3%), chronic lower respiratory disease (4.5%), diabetes mellitus (2.8%), Alzheimer's (2.6%), and kidney disease (1.3%) (Statistics Canada, 2012). Furthermore, Canadians are living longer as medicine continues to advance. To exacerbate this issue, the baby-boomer population (1946-1965) is getting older, with increasing numbers over 65 years of age. It is estimated that by the year 2030, close to one in four Canadians will be 65 or older, amounting to at least 22% of Canada's population compared to only 15% in 2013 (Statistics Canada, 2014).

These statistics highlight the importance of prioritizing our improved understanding and provision of palliative care across Canada. However, globally few resources are allocated to palliative care research, totaling only 0.24% of £508 million of annual research funding in the United Kingdom and 1% of the United States' $5 billion of total cancer research funding (Sleeman, Gomes, & Higginson, 2012). In the Canadian Cancer Research Alliance report*, Investment in Research on Survivorship and Palliative and End-of-Life Care 2005-2008,* it was stated that $17.1 million (18.5 million average annually) was invested in survivorship and palliative and end-of-life care research between 2005-2008, 4.6% of the overall budgeted cancer research investment (Canadian Cancer Research Alliance, 2011). Palliative and end-of-life research composed only 3.4% of the yearly budget, totaling only $6.3 million average annually. In 2015, the Canadian Medical Association (CMA) published a national call to action, urging Canadian physicians and other healthcare professionals to become more actively involved in the practice of palliative care (Canadian Medical Association, 2015).

2.1.3 Palliative care needs of patients with and without cancer

In Canada, cancer is the leading cause of death, making up nearly 30% of all deaths; approximately, 78,000 Canadians died due to cancer in 2015 alone (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). Although the number one cause of death is cancer, a substantial proportion of patients die from diagnoses other than cancer, including from heart disease (19.7%), stroke (5.3%), chronic lower respiratory disease (4.5%), diabetes mellitus (2.8%), Alzheimer's (2.6%), and kidney disease (1.3%) (Statistics Canada, 2012). These patients may all benefit from palliative care earlier in their illness trajectory.

The physical and emotional needs of patients newly diagnosed with cancer were assessed in a paper published by Whelan et al., (1997). In this study, of the 129 participants, many experienced a dynamic range of physical, spiritual, psychological, and social concerns early in their diagnosis. While 42% of the participants reported currently experiencing symptoms related to pain, more than 60% reported symptoms related to fatigue, worried outlook, and social concerns. In a systematic review of the unmet needs of patients with cancer, activities of daily living, psychological, informational, and physical needs were most frequently reported (Harrison, Young, Price, Butow, & Solomon, 2009). These studies emphasize that the needs of patients with cancer are in multiple domains and arise early in their illness trajectory.

There is nothing in the literature to suggest that patients with a non-cancer diagnosis would not also experience and have multiple concerns early on in their illness. Nonetheless, palliative care research has been disproportionally designed around the needs of cancer patients; thus the unique palliative care needs of patients with a non-cancer diagnosis have not been extensively studied and significant gaps exist regarding the provision of palliative care and timing of referral for these patients (Addicott, 2012). While there are many similarities between palliative care for patients with cancer and those with a non-cancer diagnosis, such as the management of both physical and psychosocial concerns, there are unique factors that should be carefully considered for patients with a diagnosis other than cancer.

The illness trajectory for patients with cancer is often one where patients are relatively high-functioning, leading to a decline with a very clear terminal phase; in contrast, patients without cancer typically have a gradual decline with what may seem like an unexpected death or a prolonged gradual expected decline (Murray & Sheikh, 2008). For example, patients who have been diagnosed with heart failure or chronic obstructive pulmonary disease (COPD) may have episodes of exacerbated symptoms that with aggressive treatments might result in improvements in their physical well-being (Gadoud & Johnson, 2015). Patients with non-cancer diagnoses also might experience prolonged symptom burden and a very gradual decline in health, with periods of relatively good health, in this case palliative care may be particularly appropriate before the last weeks to months of life. The management of patients with advanced non-cancer illnesses demand integrated care, from early on to the time of death, in order to manage complex symptoms, medications, and devices specific to their disease (Goodlin, 2009).

2.1.4 Primary, secondary and tertiary palliative care

Comprehensive palliative care is provided at the primary, secondary, and tertiary care levels (Ferris et al., 2009). Primary palliative care is typically provided by family physicians and general internists. The role of primary palliative care is to provide the basic management of physical and psychosocial concerns while successfully managing the patient holistically. This is not to imply that primary palliative care physicians are only involved when patients are first diagnosed; they can also be involved all the way to end of life depending on the circumstance and patient's preferences (Rubin et al., 2015). Secondary palliative care is typically provided by specialists and care providers who are responsible for managing the complexities of a patient's life-threatening illness that is above the comfort of primary palliative care (Ferris et al., 2009). For example, for patients with cancer, health care providers at the secondary level include oncologists and certified palliative care and oncology nurses (Cancer Care Ontario, 2009). Lastly, tertiary palliative care is where experts in palliative care, such as specialized palliative care physicians, utilize their knowledge and skill sets to manage complex end-of-life concerns, such as unmanaged pain and distress (Ferris et al., 2009). Tertiary palliative care is involved in collaboration with primary and secondary palliative care providers, and may occur in person or through advice or consultations over the telephone (Bakitas et al., 2009; Hannon et al., 2014; Temel et al., 2010; Zimmermann et al., 2014).

This model of palliative care that integrates primary, secondary, and tertiary palliative care is encouraged by the WHO and the American Society of Clinical Oncology (ASCO), as well as in Canada by the Canadian Hospice Palliative Care Association (CHPCA); however the degree of integration between the three is variable (CHPCA, 2013; Rubin et al., 2015; T. J. C. B. Smith et al., 2012; World Wide Palliative Care Alliance, 2014). Patients are often involved with multiple levels of care at any given time and can move between them as needed and as preferred (Cancer Care Ontario, 2009). Successful collaboration and integration of primary, secondary, and tertiary palliative care is the foundation upon which high-quality palliative care is built (Fig. 1). Through the optimization of clinical infrastructure, processes, education, and research palliative care can be successfully integrative and collaborative (Hui & Bruera, 2015).

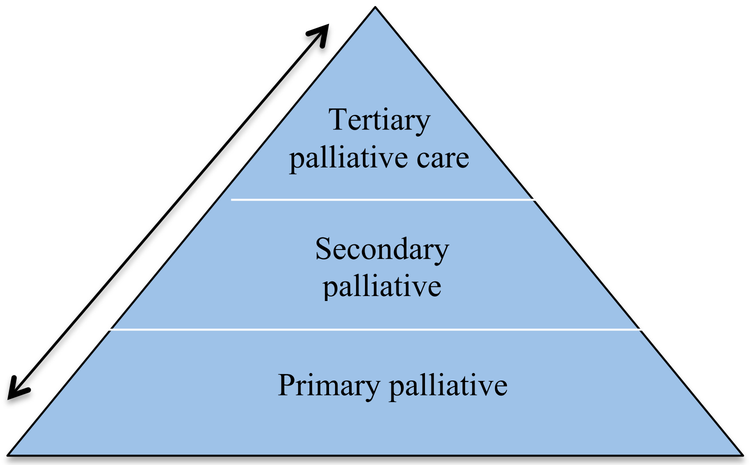


Figure 1 Model of integrated primary, secondary, and tertiary palliative care (Cancer Care Ontario, 2009).

2.1.5 Provision of palliative medicine by Canadian physicians

In November 2015, the Canadian Society of Palliative Care Physicians (CSPCP) partnered with the CMA, the Royal College of Physicians and Surgeons of Canada (Royal College), and the College of Family Physicians of Canada (CFPC) to develop the *National Palliative Medicine Survey* (Human Resources Committee of the Canadian Society of Palliative Care Physicians, 2015). The aim of this survey was to describe the current workforce of physicians providing palliative care in Canada. Of the more than 60,000 physicians to whom the survey was sent, 2,116 identified themselves as providing palliative medicine in Canada.

The CSPCP reported that Canadian palliative care practitioners represent a group of physicians from various specialties and subspecialties. Just over 50% of respondents (1,114/2116) were what the CSPCP termed “Palliative Medicine Physicians”, the other half were physicians who may provide palliative care to their own patients but are not specialized or dominantly focused in palliative medicine. In their brief report, a few key findings were described. Only 12% (128/1064) of Palliative Medicine Physicians in their study reported having completed an accredited postgraduate training program in Palliative Medicine. Currently in Canada, training in palliative medicine is available as a one-year conjoint program accredited by the Royal College and the CFPC at the post-certification level (Royal College of Physicians and Surgeons of

Canada, 2014); this program was first launched in 1999 (Monette, 2012). However, in October of 2013, the Royal College approved the development of a palliative medicine subspecialty that will have entry through internal medicine, pediatrics, neurology or anaesthesia. The first trainees will enter this program in July 2017. Thus, Canadian physicians with specialist or subspecialist training in Palliative Medicine would either have trained outside Canada, or completed their training since 2000. The CSPCP survey also reported that access to palliative care in Canada is not consistent across diagnoses. Fifty-seven percent of palliative care physicians reported that individuals with a non-cancer diagnosis made up less than 20% of their palliative patients. Furthermore, 78% of physicians stated that they did not provide care for patients under the age of 18.

2.2 Early palliative care

The timing of palliative care referral has been highlighted as a significant barrier to palliative care. When patients first receive palliative care services dictates the amount of time available for the implementation of valuable palliative interventions. For palliative interventions to be effective, an adequate amount of time is necessary to implement such services. An early palliative care model is one in which palliative care is integrated into standard care early in a patient’s illness trajectory and is provided as an outpatient service until inpatient palliative services are needed (Hannon et al., 2015).

Despite recommendations by national and international organizations that palliative care interventions begin early in the course of illness (WHO, 2014; Ferris et al., 2013), palliative care referral typically takes place in the last few months or weeks of life, or not at all (Cheng et al., 2005; Christakis & Escarce, 1996; Costantini et al., 1999; Earle et al., 2008; El Osta et al., 2008; Hui et al., 2014; Hui, Elsayem, et al., 2010; Hui, Parsons, et al., 2010). Several studies have evaluated the timing of referral to specialized palliative care (Table 2). The results from these studies show that referral timing is variable depending on palliative care consultation site; however, even outpatient palliative care referrals are consistently late and in the last few months of life.

Table 2 Time intervals between palliative care referral and death.

Publication	Population	Method	Measure	Palliative Facility	Time from referral to death
(Hui et al., 2014)	Advanced cancer patients at MDACC who died between Sep. 2009 – Feb. 2010	Retrospective Cohort Study N = 366	Median (IQR) - mo	Inpatient	0.7 (0.2-1.6)
				Outpatient	3.7 (1.6-9.6)
(Hui, Elsayem, et al., 2010)	Executive and program leaders of National Cancer Institute cancer centers in the US	Survey N = 262	Median (IQR) - days	Inpatient consultation team	7 (4-16)
				Inpatient unit	7 (5-10)
				Outpatient clinic	90 (30-120)
(Hui, Parsons, et al., 2010)	Advanced cancer patients referred to the outpatient supportive care clinic at MDACC between Jan. 2007 – Dec. 2008	Retrospective Cohort Study N = 114	Median (95% CI) - mo	Outpatient	4 (3-5)
(El Osta et al., 2008)	Advanced cancer patients at MDACC between Apr. 2003 – Sep. 2005	Retrospective Chart Review N = 2868	Median (95% CI) - days	Inpatient/ Outpatient	42 (38-46)
(Cheng et al., 2005)	Advanced cancer patients at MDACC between Sep. – Dec. 2003	Retrospective Chart Review N = 340	Median (95% CI) - mo	Inpatient/ Outpatient	1.9 (1.6-2.2)
(Costantini et al., 1999)	Terminally ill cancer patients admitted to Italian palliative care units	Multicenter prospective study N = 589	Median - days	Inpatient	37.9
(Christakis & Escarce, 1996)	Medicare patients admitted to hospice programs during 1990 in California, Florida, New York, Pennsylvania, and Texas	Retrospective Study N = 6457	Median - days	Inpatient	26
				Outpatient	39

MDACC = The University of Texas M.D. Anderson Cancer Center; mo = months; IQR = interquartile range; CI = confidence internval

2.2.1 Effectiveness of early palliative care

A systematic review published in JAMA in 2008 assessed the evidence available for the effectiveness of specialized palliative care (Zimmermann, Riechelmann, Krzyzanowska, Rodin, & Tannock, 2008). Specifically, the systematic review sought to objectively review the literature to assess the support for specialized palliative care improving patient quality of life, satisfaction with care, and economic cost. The studies which demonstrated the effectiveness of specialized palliative care to improve patient quality of life, satisfaction with care, and economic cost were very limited, both in quantity and quality. The results from this systematic review concluded that methodologically rigorous research trials demonstrating the effectiveness of specialized palliative care are needed.

Improved quality of life is arguably the primary goal of palliative care (WHO, 2014). Not only do patients consider quality of life a high priority when faced with a terminal illness, they also express a need for greater preparedness at the end of life (Steinhauser et al., 2000, 2001). In order for there to be enough time to address patients' needs, their concerns about preparation, and for beneficial palliative interventions to be implemented, patients are ideally referred to palliative care services at the diagnosis of their terminal illness, or at a prognosis of between 6 and 24 months (Bakitas et al., 2009; Temel et al., 2010; Zimmermann et al., 2014). Three large randomized control trials (RCTs) evaluating the effectiveness of early palliative care have been published since the 2008 systematic review calling for studies to rigorously evaluate the effectiveness of specialized palliative care (Bakitas et al., 2009; Temel et al., 2010; Zimmermann et al., 2014). These studies have shown that palliative care early in the illness trajectory improves patients' quality of life, mood, satisfaction with care, and symptom control. The inclusion criteria and main outcomes of these trials are shown in Table 3. The interventions are described in the section below.

In each RCT the effectiveness of early palliative care was measured by evaluating specific outcomes, all of which were in line with the primary goals of palliative care. Specifically, the effectiveness of early palliative care was measured via outcomes such as quality of life, satisfaction of care, symptom management, psychological factors, and healthcare utilization. Using self-report questionnaires, all three of the RCTs found significant improvements in patients' quality of life in the early palliative care intervention arm. This is clinically significant as improving quality of life is the primary goal of palliative care (WHO, 2014) and is also highly valued by patients diagnosed with a terminal illness (Steinhauser et al., 2001). Improvements in other clinical outcomes were also found, two of the three studies evaluated mood and found a reduction in depressive symptoms (Bakitas et al., 2009; Temel et al., 2010) and Zimmermann et al. (2014) found an improvement in satisfaction with care and symptom control.

The published RCTs not only evaluated clinical outcomes, two of the three also evaluated healthcare utilization (Bakitas et al., 2009; Temel et al., 2010). In the literature, aggressive end-of-life care has been cited to be 43% more costly than non-aggressive care (Cheung et al., 2015). While there is yet to be data published on the direct economic impact of early palliative care, indirect analyses have been done and the results are mixed. One of the early palliative care RCTs conducted in the United States, and their subsequent study, found no decrease in emergency, hospital, or ICU visits as a result of their early palliative intervention (Bakitas et al., 2015; Bakitas et al., 2009). In contrast, Temel et al. (2010) found that fewer patients in the early palliative care arm of the study received aggressive end-of-life care. These studies show that the economic implications of early palliative care are very complex. Further, it has yet to be studied if palliative care as it is currently structured in North America has an adequate amount of resources available to implement an early palliative care model.

Survival benefit was a post-hoc outcome measured in two of the three early palliative care RCTs; one of which found improved survival for patients with advanced cancer in their early palliative care intervention arm (Temel et al., 2010), while the other saw no significant difference (Bakitas et al., 2009). The implications of these results for the provision of palliative care is unclear, the WHO outlines in its definition of palliative care that palliative care "neither hastens nor postpones death" (WHO, 2014). In another study, conducted by Bakitas et al., (2015), they also reported an improvement in survival for advanced cancer patients who were enrolled in an early vs. a delayed (3 months) palliative integrated oncology care program. The mechanism responsible for improved survival is still unknown.

Study design must be carefully considered as it acts to support conclusions about the effectiveness of early palliative care. The three RCTs outlined were all thoughtfully designed, despite methodological and intervention differences, and therefore laid a substantial amount of groundwork supporting early palliative care in urban and rural populations. Data is still necessary to illustrate and elucidate the complete picture of the effectiveness of early palliative care, including cost analysis; implications and mechanism of improved survival; and more research on early palliative care for patients with a non-cancer diagnosis.

In conclusion, there is strong evidence to conclude that for patients with advanced cancers early palliative care is effective in improving patients' quality of life. While outcomes, such as reduction in depression, symptom control, satisfaction of care, and aggressiveness of care were evaluated, these early palliative care outcomes should be further studied to increase support and consistency of these findings and deepen our understanding. Furthermore, the more extensive the literature becomes supporting the effectiveness of early palliative care, the more developed and common early palliative care will become.

2.2.2 Models and timing of early palliative care

Patients who were recruited into the early palliative care arm of the RCTs had a prognosis of 6-24 months and/or an ECOG (Eastern Cooperative Oncology Group) score of 0-2 (0 = patient is asymptomatic, 1 = patient is symptomatic but fully ambulatory, 2 = patient is symptomatic and in bed <50% of the day saw improved quality of life, symptom control, satisfaction was care, and mood) (Bakitas et al., 2009; Temel et al., 2010; Zimmermann et al., 2014). Thus in an early palliative care model, patients who are referred early in their illness trajectory are often asymptomatic and ambulatory. Due to the often asymptomatic and ambulatory nature of patients at this point in their illness, the most obvious setting for early specialized palliative care is an outpatient clinic. Outpatient palliative care clinics are composed of multidisciplinary teams and are collaboratively integrated with the patient, family, referring team, and other care providers (Hannon et al., 2014).

Currently, palliative care is primarily provided in inpatient medical wards by general medical staff. Literature has shown that patient's outcomes were better in outpatient settings. Patients who were referred early to outpatient palliative care clinics had improved quality of care compared to inpatients (Hui et al., 2014). It has also been argued that the ideal setting for early primary palliative care is either the home or the office of the primary care physician (Quill & Abernethy, 2013). The justification for this argument is two-fold; first, that primary palliative care is suited to address the basic physical and psychosocial concerns of patients faced with a terminal-illness and second, to help with increased demand for beneficial palliative care services.

Several studies have evaluated and proposed models for integrating palliative care in the trajectory of cancer care (Abrahm, 2012; Bruera & Hui, 2010; Hui & Bruera, 2015; Hui et al., 2015; Hui, Elsayem, et al., 2010; Temel et al., 2007; Von Roenn, Voltz, & Serrie, 2013). A review by Hui and Bruera, (2015), identified various strategies to integrate oncology and palliative care, including putting oncology and palliative care clinics in close proximity of each other, routine patient symptom screening in oncology clinics; changing the name of palliative care to supportive care; enhancing communication, collaboration, and education; and increasing quality research in palliative care to increase awareness of issues and needs (Hui & Bruera, 2015). This framework was design specifically to integrate palliative care into cancer care. A European systematic review of the literature on the integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease (COPD) concluded that the while the literature supports a need for integrated palliative care for patients with a non-cancer diagnosis, the development of a standardized and well-supported framework for this population has yet to have been developed (Siouta et al., 2016).

Early palliative care interventions are also variable, each tailored to their environment and population of palliative patients served. One early palliative care RCT implemented a nurse led telephone based psychoeducational intervention in a rural cancer and medical center, in the U.S. state of New Hampshire (Bakitas et al., 2009). Advanced practice palliative care nurses performed patient distress assessments by phone and if threshold values were met, distressing concerns were discussed with the patient and a problem-solving educational module was employed. The nurses conducted four formal educational sessions with the patient. Following these sessions, monthly follow-up phone consultations were made. Nurses were available by phone and participants and caregivers were invited to monthly group/shared medical appointments with a palliative physician and a nurse practitioner. Nurses also assessed if there was need for outside referrals, such as hospice care, and expressed those needs to the clinical team when appropriate. Early palliative care delivered in this way was able to reach patients in rural environments.

The other two early palliative care studies were conducted in urban environments in the United States (Temel et al., 2010) and Canada (Zimmermann et al., 2014). Similar to the Bakitas et al., (2009) study the Temel et al., (2010) and the Zimmermann et al., (2014) studies also assessed patients' physical and psychological issues, however, it was provided by a palliative care team composed of physicians, nurses, and allied health care providers (e.g. social workers). Furthermore, Temel et al., (2010) and the Zimmermann et al., (2014) integrated early palliative care into standard oncological care and compared this integrated care to their control arm of standard oncological care alone. In addition, their early palliative care interventions took place in outpatient ambulatory clinics. Patients met monthly with the palliative care healthcare team until death, with additional visits as necessary.

In summary, in an early palliative care model, patients are referred to palliative care 6-24 months prior to the end of life. These patients are often ambulatory and asymptomatic. Although palliative care teams are large interdisciplinary units and provide expertise in many domains of care, there are consistent components of services that provide early palliative care in an outpatient setting. Generally these are clinics that are operated by a palliative care physician and nurse at a minimum, although some are more complex and involve many different specialties. Lastly, although models of early palliative care have been designed around the illness trajectory of cancer patients there is evidence to suggest that the management of patients with advanced non-cancer illnesses equally demands integrated care early in their illness (Goodlin, 2009).

Table 3 Early palliative care randomized control trials inclusion criteria and main outcomes.

Early Palliative Care Randomized Control Trials						
Publication	**Location**	**Participants**	**Cancer Diagnosis**	**Method**	**Assessment intervals**	**Outcomes**
Zimmermann et al., (2014)	Urban – Toronto, ON Canada	Stage IV cancer and stage III with poor clinical prognosis, prognosis 6-24 months, ECOG score of 0, 1, 2 N = 461	Breast or prostate (refractory to hormonal therapy), lung, GI, GU, gynecological	Cluster Randomized (24 clinics)	Baseline, monthly for four months or until death (**Primary end-point** 3 months, **Secondary end-point** 4 months)*	Quality of life,* Symptom intensity*, satisfaction of care*
Temel et al., (2010)	Urban – Boston, Massachusetts U.S.A	Newly diagnosed metastatic non-small cell lung cancer (within 8 weeks after diagnosis), ECOG score of 0, 1, 2 N = 151	Metastatic non-small cell lung cancer	Patient Randomized	Baseline and 12 weeks (or at an outpatient clinic visit within 3 weeks before or after that time point)	Quality of life*, Mood*, healthcare usage* **Post hoc:** survival*
Bakitas et al., (2009)	Rural – New Hampshire, U.S.A	Patients with life-limiting cancer – Prognosis 1 year, within 8-12 weeks of new diagnosis N = 322	GI, lung, GU, or breast cancer	Patient Randomized	Baseline, 1 month, every three months until study completion or death	Quality of life*, Mood*, symptom intensity, healthcare usage **Post hoc:** Survival*

ECOG (Eastern Cooperative Oncology Group): 0 = patient is asymptomatic, 1 = patient is symptomatic but fully ambulatory, 2 = patient is symptomatic and in bed <50% of the day; GI = gastrointestinal; GU = genitourinary

* Significantly improved patient outcomes

2.3 Barriers to early palliative care

Barriers to early palliative care are numerous. The ones described here are what we identified in the literature to be significant barriers to the provision of early palliative care; including, barriers at the level of referring physicians; lack of structures that promote early outpatient referral to palliative care; the limited availability of trained physicians and resources to provide early palliative care; and attitudes and knowledge of patients and the public towards palliative care.

2.3.1 Barriers at the level of referring physicians

Referring physicians' attitudes and referral practices

Timing of referral to specialized palliative care services is an obvious core barrier to early palliative care. However, this barrier may reflect many factors that may impede early referral. Only a few studies have specifically examined the barriers to receiving early specialized palliative care that are associated with the referral practices of oncologists or other physicians making referrals (Johnson, Girgis, Paul, & Currow, 2008; C. B. Smith et al., 2012; Wentlandt et al., 2012). Surveys in the United States and Canada have reported that referring physicians are also in favour of early referral to specialized palliative care (Ogle, Mavis, & Wyatt, 2002; Wentlandt et al., 2012). In one survey, 71% percent of referring physicians, including oncologists, hematologists, respirologists, and colorectal surgeons, agreed that patients should be referred early and 92% agreed that patients would benefit from specialized palliative care services while still receiving disease-modifying therapies (e.g. chemotherapy) (Johnson et al., 2008). The primary reason for referral to specialized palliative care was uncontrolled physical symptoms (Johnson et al., 2008; K Wentlandt et al., 2012). Psychosocial concerns were reported much less frequently as a cause for referral (Johnson, Girgis, Paul, & Currow, 2011).

Wentlandt et al. (2012) evaluated the referral practices to specialized palliative care of surgical, medical, and radiation oncologists in Canada. Of the 603 Canadian oncologists, 83% reported that they referred their patients at a prognosis of <6 months, which in that study was the cut-point for a late referral. In the same study, a *high frequency of referral* (physicians summed score for items scaled on a five point liker scale for various patient symptoms and prognoses from always refer to never refer) to specialized palliative care was associated with referring physicians' satisfaction with the availability of specialized palliative care; a greater number of available specialized palliative care services; palliative services acceptance of patients receiving chemotherapy; and physicians' comfort with referring patients before they are close to death. In another study conducted in Australia, factors associated with *high referral frequencies* (physician referred >60% of patients with advanced cancer referred to specialized palliative care) were female sex; having more than ten years in practice; having specialized palliative care services available; and agreeing that *all* people with advanced cancer should be referred and that referral is for integrated multidisciplinary management. In a study of 155 oncologists who specialized in lung cancer, *low referral rates* (physician referred <25% of patients for palliative care consult) were associated with physicians concern that referral to palliative care would alarm patients and families (C. B. Smith et al., 2012).

Factors associated with timing of referral to palliative care have also been evaluated. Factors associated with Canadian oncologists *referring at a prognosis of greater than 6 months* were female sex and access to specialized palliative care services that accept patients receiving chemotherapy (Wentlandt et al., 2012). Furthermore, 33% of Canadian oncologists stated that they would refer earlier to palliative care if it was renamed supportive care. The same study also reported that factors associated with an *oncologists' ideal referral timing* being at a prognosis of more than 6 months or at diagnosis of cancer/metastatic disease was having a radiation or surgical oncology specialty, younger age, female sex, and again specialized palliative care services which accepts patients on chemotherapy. Sex differences associated with earlier referrals reported by Johnson et al., (2008) and Wentlandt et al., (2012) may be due to female physicians being more engaged in collaborative behavior and information giving, including biomedical and psychosocial information (Roter, Lipkin, & Korsgaard, 1991).

Factors associated with referral to specialized palliative care have mainly been evaluated for cancer specialists (e.g. oncologists and hematologists). Limited research has examined the referral practices of general practitioners or family physicians. One study found, for general practitioners, *higher referral frequency* (physician referred >60% of patients with advanced cancer referred to specialized palliative care) was associated with the availability of palliative care physicians and consultation services; and agreeing that all patients with advanced cancer should be referred and that specialized palliative care better meets the needs of patients and their families. One limitation of this study, as with many palliative care studies, was that it only examined referrals to specialized palliative care for patients with cancer and did not include patients with non-cancer terminal illnesses. However, one study that examined all patients referred to specialized palliative care found that primary care physicians were 2.13 times more likely to refer a patient to outpatient palliative care if they themselves had personal experiences with palliative care (Ahluwalia & Fried, 2009).

Similar to the limited amount of research for patients without a cancer diagnosis regarding referral timing, less research has been done to better understand the referral practices of physicians making referrals to specialized palliative care for children with advanced illnesses. One study compared the referral practices of pediatric and adult oncologists and reported significant differences (Wentlandt et al., 2014). Firstly, pediatric oncologist palliative services accepted patients on chemotherapy more frequently than those of adult oncologists, 64% compared to only 37%. Only 13% of pediatric oncologists reported that they were less likely to refer only after chemotherapy, compared to 29% of adult oncologists. Furthermore, a majority of pediatric oncologists (73%) stated that ideal referral timing should occur at the diagnosis of cancer/incurable cancer, compared to a minority of adult oncologists (43%).

Canadian pediatric oncologists had limited access to an outpatient palliative care clinic (27%); however, almost 90% had access to a palliative care physician (Wentlandt et al., 2014). Lastly, 58% of pediatric oncologists agreed that they would refer sooner if palliative care were renamed supportive care (33% for adult oncologists) and 60% stated that their patients perceived palliative care negatively (43% for adult oncologists). While the study by Wentlandt et al., (2014) demonstrates that a larger proportion of pediatric oncologists prefer early referrals to specialized palliative care compared to their adult counterparts, these results may not be generalizable to all of pediatric palliative care. One study conducted in the United States evaluated pediatricians' perceptions of the preferred timing of palliative care referral. Their results demonstrated that for most illnesses that early referrals to palliative care were rarely the preference, less than 20% for most illnesses including cancer (Thompson, Knapp, Madden, & Shenkman, 2009).

The barriers to early palliative care cited here are those perceived by referring physicians; in contrast, the attitudes and barriers perceived by physicians providing palliative care have not been systematically assessed. To date, there are no studies that describe the attitudes and opinions of palliative care physicians towards early palliative care, in Canada or elsewhere, despite the fact that barriers reported by referring physicians were related predominantly to the availability and comprehensiveness of palliative care services. In order to improve the timely provision of palliative care in Canada, a comprehensive understanding of barriers, as perceived by physicians providing as well as referring to palliative care is needed.

Education of referring physicians in palliative care

Referring specialists are comfortable discussing end of life issues, but interestingly less comfortable providing palliative care (Johnson et al., 2008). Referring physicians discomfort with providing palliative care may stem from a lack of training. Less than half (48%) of Canadian oncologists believed they had the training required to care for advanced cancer patients' symptoms (Wentlandt et al., 2012).

Palliative care education in 32 accredited internal medicine residency programs in the United States showed that less than 30% provided education on symptoms other than pain (Mullan et al., 2002). Comprehensive education in palliative care, including both physical and psychosocial elements, is important for both palliative and referring physicians. In the paper by Johnson et al., (2008), 32% of referring specialists felt that specialized palliative care was not suited to address patient's psychosocial needs. These results highlight that there is still a considerable minority of referring physicians who may not understand the full scope of services that palliative care can provide. Standardized education in palliative care would benefit referring physicians by improving their understanding of the role of palliative care and what it provides for their patients. There is support in the literature that referring physicians with greater expertise in end-of-life care tend to refer more frequently to specialized palliative care (Johnson et al., 2008). Thus, a physician's understanding of the role of palliative care seems to be significantly influenced by their education, yet palliative care fellowships and mandatory rotations for oncology fellows are uncommon in major cancer centres (Hui, Elsayem, et al., 2010). A successfully integrated palliative care model, where palliative care and referring physicians work collaboratively, means that palliative care education will need to be formalized.

2.3.2 Lack of structures that promote early outpatient referral to palliative care

Several studies have identified structures which are lacking that are necessary to promote early referrals, including a lack of standardized referral criteria and symptom screening, limited access to outpatient palliative care clinics and integrated palliative care with standard care, such as oncological care.

Wentlandt et al., (2012) found that referral at a prognosis greater than six months was associated with oncologists reporting that palliative care services to which they had access accepted patients on chemotherapy. Seventy-eight percent of patients with metastatic cancer will eventually choose to undergo palliative chemotherapy (Koedoot et al., 2003). Patients tend to favor a model where palliative care and chemotherapy are offered concurrently, rather than having to choose between one or the other (Salz & Brewer, 2009).

Chemotherapy can be for palliative or curative in intent (Swetz & Smith, 2010). Patients may choose to receive chemotherapy for various reasons. There is evidence that palliative chemotherapy improves symptom intensity and improves quality of life, in addition to prolonging life (Helsing, Bergman, Thaning, & Hero, 1998). In a study of women with advanced ovarian cancer, 52% of women on palliative chemotherapy showed an improvement in quality of life. However, in the same study, 42% of the women thought that the chemotherapy had a moderate to high likelihood of curing their disease, which may suggest an unrealistic understanding of their prognosis and poor physicians communication of treatment intentions (Doyle, Crump, Pintilie, & Oza, 2014). Patients may incorrectly perceive the purpose of chemotherapy to be curative instead of palliative. In the study by Temel et al., (2010), only 9% of non-small cell lung cancer patients who were on intravenous chemotherapy within 60 days of death and randomized to the early palliative care arm had an accurate prognostic understanding of their illness, compared to 91% of those not on IV chemotherapy. These studies suggest that the topic of concurrent therapies during palliative care is not merely one of referral criteria, but also about physician-patient communication about goals of care and wishes for care at the end of life.

Patients early in their illness trajectory experience symptoms that are both physical and psychosocial in nature (Harrison et al., 2009; Whelan et al., 1997). Burdensome pain and symptoms are the most common reason why oncologists refer patients with a prognosis of greater than one year (Wentlandt et al., 2012). Similarly, in a study of Australian general practitioners, it was reported that physicians primarily refer for uncontrolled symptoms and symptom control and less so for psychosocial concerns (Johnson et al., 2011). Psychological symptoms are less likely than physical symptoms to be recognized or addressed. In one study, 96% of newly diagnosed cancer patients reported having symptoms related to fatigue, worried outlook, and pain (Whelan et al., 1997). Psychosocial concerns are rarely the reason for referral to palliative care (Johnson et al., 2008; Wentlandt et al., 2012); however patient distress as a result of psychosocial concerns is more common than distress due to physical symptoms (Glare, Semple, Stabler, & Saltz, 2011).

Due the lack of standardization, referral criteria to specialized palliative care is often very broad. At the Princess Margaret Cancer Centre, one the most comprehensive palliative care programs in North America, referral criteria to the outpatient palliative care clinics is available to any patient with advanced progressive cancer in the hospitals cancer program with no limitations on prognosis. While broad referral criteria increases access to early palliative care to all patients, symptom screening by referring physicians may help quickly identify patients who are most suited for and in need of specialized palliative care. Active and standardized symptom screening for patients' physical and psychosocial concerns early in their illness may help specialists to determine whether or not to make a referral to palliative care. Symptom screening can be performed for patients newly diagnosed with advanced stage illness by a trained nurse. One study, which evaluated a practical set of referral criteria for outpatient palliative care, suggested referral criteria triggers were changes in extent of illness, goals of care, performance status, and symptom burden (Glare et al., 2011).

Even when significant symptom burden is identified, referring physicians may feel that palliative care physicians do not have a strong enough oncology background to council patients about treatment decisions, ultimately resulting in delayed referrals (Abrahm, 2012). Conversely, reduction in quality of life as a result of complications or pain related to concurrent treatments were challenging for the palliative physicians to manage (Mitchell, 2002). An integrated model of palliative care is the gold standard for holistically addressing patients and families' needs and concerns. Unfortunately, an integrated model of palliative care is not exempt from barriers to it successful implementation. Firstly, integrated palliative care is provided early in outpatient palliative care clinics. However, only a minority of cancer centers have access to outpatient palliative care clinics, and these are even less prevalent for patients without cancer. In Ontario, more than 80% of hospitals reported not having outpatient palliative care (Towns et al., 2012). Lastly, an integrative palliative care model demands collaboration between referring, primary, and specialized palliative care. However, a European study found that very few oncological teams collaborated with specialized palliative care (Cherny & Catane, 2003).

2.3.3 Availability of trained physicians and resources to provide early palliative care

An integrated model of palliative care necessary for early palliative care includes a comprehensive multidisciplinary team composed of specialists and primary care physicians, nurses, social workers, psychiatrists, and physical therapists, to name a few (Hannon et al., 2015). In order for these individuals to provide high-quality palliative care to their patients, all professional parties need palliative care education and training (Hui & Bruera, 2015). While most research focuses on the formal training of oncologists in palliative medicine via fellowships and rotations, accreditation of palliative medicine for palliative care physicians is not uniform around the world. Palliative medicine is accredited in the United Kingdom and the United States, but in many other countries it is not. In Canada, due to the specialties relative infancy compared to other countries, palliative medicine is not yet an accredited specialty. The framework for a specialty is being developed and will be released in 2016 (Royal College of Physicians and Surgeons of Canada, 2014). For physicians who will provide palliative care, but will not be palliative care specialists, this training can be incorporated into existing residency programs with formal assessments of competencies (Mullan et al., 2002). These core competencies should at a minimum include pain assessment and treatment, non-pain symptoms such as psychosocial concerns, communication in skill in end-of-life discussions including preparations and transitions, as well as ethical concerns.

The limited availability of trained palliative care physicians is exacerbated by an unequal distribution of palliative care in urban and rural environments. Specialized palliative care and referring physicians are often concentrated in urban cancer centers (Robinson et al., 2009; Wentlandt et al., 2012). It is neither feasible nor desirable for patients in rural areas to travel potentially long distances for palliative care; therefore, it is obvious that palliative care must be available in urban and rural environments. Unfortunately, resources are a limiting factor to the development of rural palliative care. The more comprehensive the palliative care services available to Canadian oncologists, the more likely oncologists were to refer (Wentlandt et al., 2012).

Many of these studies took place at large cancer centers where research is feasible and access to resources is greater. As a result of most studies being concentrated in urban centers, access and resources as a barrier to early palliative care may be greatly understated. A qualitative study in Canada which conducted focus groups in seven provinces concluded that rural communities often function by doing with what they have with regards to resources (Kelley, 2006). Specifically, rural physicians providing palliative care were cited as feeling that that they provide palliative care with a very limited number of palliative care physicians, which they also struggled to retain, with a limited number of facilities to house the provision of this care. Compared to general practitioners in metropolitan areas, non-metropolitan general practitioners in an Australian study reported having significantly less access to palliative home nursing, palliative care physicians, and palliative care facilities (Johnson et al., 2011). While resources and access play a critical role in our understanding of the possible barriers to early palliative care, it is also challenging for referring physicians to refer patients when patients and their caregivers resist for various personal reasons.

Increasing limited resources, such as increasing the number of outpatient units, palliative care physicians, and educational programs for palliative care may not be feasible due to cost. More research is needed to better understand the feasibility of an early palliative care model on a large scale. Results describing the potential for early palliative care to reduce costly aggressive end-of-life care are variable. One RCT did show that early palliative care referrals were associated with reduction in costly aggressive end-of-life care (Temel et al., 2010), including utilization of hospital care, emergency room visits, and rates of hospitalization. In another early palliative care

RCT however, early palliative care was no different than standard with regards to hospital utilization (Bakitas et al., 2009). No studies have directly evaluated the cost of early palliative care. Research assessing resources and availability are also limited because many studies take place within single institutions or within specific countries where the health care model can be drastically different, limiting their generalizability. For example, many of the studies evaluating barriers to palliative care are conducted in the United States, and may not be completely generalizable to other countries such as Canada. In the United States, insurance must be considered as a factor which influences when referral to palliative care is most appropriate, whereas in Canada this is not the case (Casarett et al., 2009).

2.3.4 Attitudes/knowledge of patients and the public towards palliative care

A major barrier to palliative care is that patients often understand palliative care to only be applicable at the very end of life when all other medical interventions have been exhausted (Zimmermann et al., 2016). However, after patients have been referred to palliative services, 87% of families stated earlier integration of palliative care with oncologists would be of “great help”, “considerable help”, or “some help” (Morita et al., 2005). Forty-three percent of Canadian oncologists felt their patients had a negative perception of the term palliative care (Wentlandt et al., 2012). In addition, patients receiving palliative care have reported feeling stigmatized (Miyashita et al., 2008; Zimmermann et al., 2016). Some research has suggested that patients’ negative perceptions of palliative care are associated with its name. The name “supportive care” has been perceived most favorably compared to other names, such as comfort care, total care, and palliative care (Morstad Boldt et al., 2006). Several studies have been done to evaluate the name palliative care as a potential barrier to early palliative care referral (Dalal et al., 2011; Fadul et al., 2009; Maciasz et al., 2013; Morstad Boldt et al., 2006).

Other studies have found similar results. Pediatric oncologists’ have reported their patients had a very negative perception of palliative care; this was significantly greater than what has been observed with adult oncologists (Wentlandt et al., 2014). Additionally, one third of adult oncologists said they would refer sooner if palliative care was renamed to supportive care (Wentlandt et al., 2012), while 60% of pediatric oncologist felt a name change would increase their likelihood of referring to specialized palliative care (Wentlandt et al., 2014). The stark difference in the perceived impact of changing the name of palliative to supportive care between adult and pediatric oncologists illustrates how barriers may be greatly influenced by context.

In one study, changing the name from palliative to supportive care increased the percentage of cancer patients who were referred to outpatient palliative care services by 11% (Dalal et al., 2011). Furthermore, in the inpatient palliative care clinic, more referrals were made after the name was changed. In another study, the term supportive care was associated with improved understanding, favorable impressions, and higher future need than a program named palliative care (Maciasz et al., 2013). Most of these studies argue that the term supportive care is less distressing than the name palliative care. It is, however, not known if a name change to supportive care will remain less distressing in the long term. If patients feel less distressed after being referred to a program termed supportive care vs. palliative care it may indicate that they are misunderstanding the role of supportive care.

In fact, when parents were given the same non-threatening program description for a program named either palliative or supportive care, parents were just as likely to use either program (Morstad Boldt et al., 2006). However, in a more recent study that controlled for program description (patient-centered vs. traditional), supportive care was still associated with significantly more favorable impressions (Maciasz et al., 2013). A name change should be coupled with a mission to improve patient education on what palliative services provide and the benefits to them. Physician-patient communication plays a significant role in removing the stigma of palliative care. Fadul et al., (2009) found that 61% of patients associated supportive care with treating side effects related to chemotherapy. This misconception may be the result of referring physicians or patients believing that the role of supportive care is different or separate from palliative care. However, changing the name may provide palliative care with an opportunity to expand the scope of palliative care; for example, to explicitly outline that palliative care is integrated with disease-directed therapies and that patients can be referred to palliative care early in their disease trajectory while still undergoing chemotherapy. Rebranding palliative care may remove some of the stigma patients and their caregivers experience when referred to palliative care (Zimmermann et al., 2016); however, there is minimal evidence that a name change will significantly improve referral timing in a manner that is sustainable.

Beyond patients experiencing distress from the name palliative care, specialists feel that referral will cause patients to experience a loss of hope (C. B. Smith et al., 2012). As challenging as end-of-life conversations are, unrealistic expectations about prognosis can lead to complicated bereavement in caregivers (Wendler & Rid, 2014). Impact on the caregiver should not be overlooked; high quality palliative care is holistic and looks after both the patients' and their loved ones' needs (WHO, 2014). How patients perceive palliative care is an important factor influencing referral. A patient's perception of palliative care can be influenced by relationships. One study showed that having discussions about the end-of-life were challenging for referring physicians (Lamont & Christakis, 2002). However, despite how challenging these conversations may be, another study demonstrated that communicating and informing patients about palliative care was associated with higher referral rates (Johnson et al., 2008).

2.4 Conclusion

The field of palliative medicine has improved by leaps and bounds since its original development. In that time, the literature has demonstrated that palliative care that is integrated into standard care and provided early in a patient's illness trajectory improves patient's quality of life, symptom control, satisfaction with care, and mood (Bakitas et al., 2009; Temel et al., 2010; Zimmermann et al., 2014). However, as we have outlined, many significant barriers to the provision of early palliative care exist. Timing of referral to palliative care is the most obvious barrier to early palliative care, as referring physicians often refer patients late in their illness trajectory when little time remains for beneficial palliative care services to be implemented (Johnson et al., 2008; Wentlandt et al., 2012).

Palliative care is also not equitable for all groups of patients. Palliative care is needed for patients with cancer as well as patients with other life-threatening illnesses, such as heart failure or COPD. In addition, palliative care is also needed for pediatric patients. Since palliative care research is disproportionally designed around the needs of adult cancer patients, less is understood about early palliative care for patients of other groups. A significant barrier to early palliative care is limited access and knowledge about early palliative care for these more unique patient populations. Early palliative care is also limited in resource poor rural areas, where physicians, palliative settings, and the means to provide palliative care are scarce. High-quality palliative care should be integrated into patients' ongoing care regardless of demographics.

Several barriers to integrating referring, primary, and specialized palliative care also exist. First, few oncological teams collaborate with specialized palliative care (Johnson et al., 2008; Cherny & Catane, 2003). Secondly, a lack of standardized referral criteria and palliative care services that accept patients who are currently undergoing chemotherapy have also been demonstrated in the literature (Johnson et al., 2008; Wentlandt et al., 2012). Further, education in palliative care is also limited for physicians providing palliative care (Mullan et al., 2002). When physicians' understanding of palliative care is narrow, patients' knowledge and understanding also becomes a barrier to palliative care. Studies have shown that patients incorrectly understand palliative care to only be applicable at the very end of life, and that the name palliative care may be a significant barrier to referral (Zimmermann et al., 2016).

Many of the studies described here are from very specific vantage points, each shedding a unique light on the predominant barriers early palliative care faces. Realistically, none of the barriers to early palliative care stand independently; each barrier is interrelated with another. When multiple perceptions are pooled together, a complex picture emerges of the barriers to early palliative care. Although complex, the perceptions from both the receiving and the referring ends of palliative care are essential because early palliative care is integrative and collaborative. Despite this complexity, with each advancement in palliative care our understanding of the barriers to high-quality early palliative care becomes clearer and timely access to early palliative care improves. While all the barriers highlighted have been paramount to our understanding of the barriers to early palliative care, currently no studies have evaluated barriers to early palliative care as perceived by the physicians providing such care.

Chapter 3: Rationale

Patients who are diagnosed with a terminal illness experience wide range of physical, spiritual, psychological, and social concerns, often early in their diagnosis (Bruera, Neumann, Breneis, & Quan, 2000; Cheng et al., 2005; Whelan et al., 1997; Whitmer, Pruemer, Nahleh, & Jazieh, 2006). Specialized palliative care is holistic in philosophy, supports and coordinates care, and is directed at managing both the physical and psychosocial symptoms of patients (WHO, 2014). A number of organizations, including the World Health Organization (WHO) and the Canadian Hospice and Palliative Care Association (CHPCA), have recommended that palliative care be integrated early in the illness trajectory and in conjunction with other therapies (CHPCA, 2013; WHO, 2014). Furthermore, recent randomized control trials have demonstrated that early palliative care can improve the quality of life, satisfaction of care, mood, and symptom control of patients with advanced cancer (Bakitas et al., 2009; Temel et al., 2010; Zimmermann et al., 2014). However, referral to palliative care typically takes place late, in the last three month life or not at all (Cheng et al., 2005; Christakis & Escarce, 1996; Costantini et al., 1999; Earle et al., 2008; El Osta et al., 2008; Hui et al., 2014; Hui, Elsayem, et al., 2010; Hui, Parsons, et al., 2010).

The referral practices of Canadian oncologists to specialized palliative care have been evaluated in a previous study (Wentlandt et al., 2012). It was shown that significant predictors of early referral to palliative care by oncologists included the availability of specialized palliative care services and accepting patients receiving chemotherapy (Wentlandt et al., 2012). However, the attitudes of palliative care physicians regarding early palliative care have not been systematically assessed. As well, the characteristics of palliative care physicians who receive early referrals are not known. Thus there may be barriers to the provision of early palliative care on the part of providers that have not yet been identified. The principle aim of this study was to understand attitudes towards early palliative care among palliative care physicians. Another aim was to characterize factors on the part of palliative care physicians and their medical practice that might contribute to receiving earlier referrals for specialized palliative care.

Chapter 4: Objectives and Hypotheses

4.1 Objectives

The objectives of this study are:

1) Describe the practices, attitudes and opinions regarding early palliative care among physicians who provide palliative care in Canada;

2) Determine differences in these practices, attitudes and opinions among physicians who are practicing specialized palliative care versus those who are practicing primary palliative care;

3) Identify characteristics of specialized palliative care physicians who receive early versus late referrals.

4.2 Hypotheses

The hypotheses of the study are:

1) Canadian palliative care physicians will have a favorable attitude towards early palliative care;

2) Lack of resources will be identified as a major perceived barrier to the provision of early palliative care;

3) Palliative care physicians have a more favorable attitude towards the provision of early palliative care for patients with cancer than for those without cancer;

4) Specialized palliative care physicians who report receiving early referrals for palliative care will be those who are younger, have specialized training, work in palliative care teams, and have sufficient resources to provide early palliative care.

Chapter 5: Methods

5.1 Participants

We contacted the Canadian Society of Palliative Care Physicians (CSPCP) and solicited their assistance in identifying a cohort of physicians who provide palliative care in Canada. The CSPCP is a membership-based organization in Surrey, British Columbia, which promotes high-quality palliative care through advocacy, partnerships, research, and physician education (Canadian Society of Canadian Palliative Care Physicians, 2015). Members of the CSPCP are composed of active and retired physicians, residents, medical students, and researchers with a strong interest in the advancement of palliative care. Voting members are only active licensed Canadian physicians.

In November of 2014, the CSPCP distributed a survey to more than 60,000 active Canadian staff physicians who were members of the College of Family Physicians Canada and/or the Royal College of Physicians and Surgeons Canada (Human Resources Committee of the Canadian Society of Palliative Care Physicians, 2015). Their survey was titled the *National Palliative Medicine Survey.* The objective of this survey was to describe the palliative medicine workforce in Canada (Human Resources Committee of the Canadian Society of Palliative Care Physicians, 2015). In this survey, the CSPCP asked Canadian physicians if they practiced any palliative care.

The CSPCP had 2,116 physician respondents who responded yes to practicing any palliative care. At the completion of the survey, physicians who practiced any palliative care were asked if they would allow their contact information, mailing address and/or email, to be retained for participation in other surveys regarding palliative care. The 823 physicians who stated they practiced any palliative care and agreed to be contacted about future palliative care surveys made up the cohort of physicians who were contacted for our national *Early Palliative Care Survey.* Physicians who received our survey were first asked if they were “completely retired” or if they “do not practice any palliative care”; physicians who responded yes to either of these statements were excluded from our study.

5.2 Early palliative care survey instrument

No validated survey has been developed to assess the attitudes and opinions of palliative care physicians about early palliative care. Therefore we developed a survey and piloted it, as described below (see Section 5.3). The survey assessed physician demographics; characteristics of their palliative practice; nature and availability of palliative care resources in their practice area; and their attitudes and opinions about early palliative care (See Appendix A4).

Physician demographics included questions about the physicians' age, sex, membership in professional associations, palliative training, and medical specialty. Questions about physicians' *current palliative practice* included: type of practice (e.g. hospice, community, long-term care, etc.), type of patients (e.g. cancer vs. non-cancer, adults vs. pediatrics, etc.); average survival time of patients, proportion of patients with cancer, and referral criteria for particular workplace settings (e.g. palliative care clinic, palliative care unit, consultation service, and home palliative care).

The nature and availability of palliative care resources was determined by questions about professionals available within their palliative care practice (e.g. palliative nurses, social workers, etc.); satisfaction on a five point Likert scale (very dissatisfied to very satisfied) with their professional relationships with referring physicians, other palliative care physicians, and other palliative care team members; availability of services to their patients for referral (e.g. psychosocial support, home visits, etc.); and what types of patients their workplace settings accepted for referral (e.g. patients currently on chemotherapy, younger than 65, have not signed a DNR, etc.).

Attitudes and opinions about early palliative care for patients with cancer and those with a non-cancer diagnosis, respectively, were addressed by questions asking physicians to rank on a five-point Likert scale (strongly disagree to strongly agree) how much they agreed with statements regarding when palliative care should begin in relation to curative medicine; the responsibility of referring physicians to manage complications related to a shared patients treatment; and the perceived necessary outcomes for early palliative care to be considered effective, such as improved quality of life and survival.

Additional general opinion and attitudinal factors, not assessed for patients with cancer separately from patients without, were also assessed using a five-point Likert scale. Specifically, these statements addressed palliative care physicians' opinions and attitudes about whether or not patients should have stopped concurrent treatments, such as chemotherapy and hemodialysis, before palliative care referral; whether asymptomatic patients should be referred to palliative care; and whether patients and referring physicians would be more comfortable with early referral if palliative care were renamed supportive care.

Lastly, physicians who received referrals for palliative care from other physicians (i.e. not palliative care physicians providing primary palliative care only for their own patients) were asked to rank on a five-point Likert scale (strongly disagree to strongly agree) their level of comfort in caring for patients who had full resuscitation status and their perception of the scope of palliative care.

Upon completion of the survey, physicians were thanked and were invited to provide comments on any aspect of the survey. All comments were recorded and stored in an SPSS database.

5.3 Study design

5.3.1 Pilot study procedure

A pilot survey was developed by members of the thesis committee, including two palliative care physicians, a psychiatrist with expertise in palliative care, an oncologist, and myself. The pilot survey was approved by the Research Ethics Board (REB) of the University Health Network in Toronto, Ontario. Once REB approved, the pilot survey was tested by 10 English speaking physicians who were practicing palliative care in various healthcare settings in Toronto, Ontario, including in home palliative care, long-term care, and acute care. The pilot survey was completed using a paper format, which was either hand delivered or mailed to each of the participating palliative care physicians. Furthermore, physicians were instructed to make comments anywhere on the survey about specific survey questions and content. After physicians completed the pilot survey, they were also asked to complete a short questionnaire about their experience with the pilot survey, including their opinions of the length of the pilot; redundancy and appropriateness of the questions; and questions they felt should be added that address barriers to early palliative care. They were also invited to provide additional comments if they wished to do so. Pilot physicians were given a $5.00 Tim Horton’s gift card as an incentive and as a token of appreciation for their participation.

5.3.2 National study procedure

The physicians’ feedback from the pilot was incorporated into the final survey. Questions that were unclear or redundant were revised and/or removed. In order to reach a more representative Canadian sample, all study related materials were provided in French to physicians who indicated to CSPCP that this was their language of preference. Translation Experts Inc. in Toronto, Ontario, was contracted to provide a certified translation of the finalized English survey, introductory letter, and e-mail into French. The revised French and English surveys were submitted for REB review and final approval before sending them to our national study sample of physicians providing palliative care in Canada.

The final REB-approved *Early Palliative Care Survey* was sent by regular mail (with a $5.00 gift card for Tim Hortons as an incentive) and by e-mail. For participant convenience, an online version of the survey was created using FluidSurvey.com. Those physicians who had only provided the CSPCP with their e-mail address to receive palliative care surveys had the opportunity at the end of the online survey to provide a mailing address to which their $5.00 Tim Horton’s gift card incentive could be mailed. The online survey was accessible to study participants via a web address provided in the survey introductory letter and e-mail.

The first survey package mailing included the following items:

- Survey introductory letter 1
- Final version of REB-approved survey
- Gift card for Tim Hortons ($5 value)
- Stamped, addressed return-mailing envelope

We collected completed surveys by one of the following methods: mailed to us using the stamped, self-addressed envelope that was included in the study mailing package; faxed to the number provided on the cover page of survey; or completed online using a website link provided on the cover page of the survey, in the study introductory letter, and e-mail. The introductory letter, which was included in the survey mailing package and e-mail, outlined the study purpose, population surveyed, estimated amount of time required to complete the survey, and the web address required to complete the survey online.

Four weeks following the initial survey mailing, a reminder package was sent to all participants mailing to improve response rates. This included mailing both an additional hard copy of the survey and sending an e-mail to all potential participants.

The reminder package mailing included the following items:

- Survey introductory letter 2
- Final version of REB-approved survey
- Stamped, addressed return-mailing envelope

The second introductory letter thanked the study participants for completing the survey, if they had already done so, and reminded them to kindly complete the survey if they had not yet done so; they were also informed that this would be the final mailing.

5.3.3 Measures taken to improve the response rate

In order to limit non-response bias, we reviewed the literature to find ways to improve the response rate to the survey. Typically, surveys of health care professionals attain response rates of approximately 53% (Cho, Johnson, & Vangeest, 2013). Cho et al., (2013) have shown that health provider response rates have had a marked downward trend over the last half century. A systematic review by VanGeest, Johnson, & Welch, (2007) evaluated 66 studies that studied methodologies for improving response rates of physician surveys. In summary, they found that surveys had better response rates if they provided small monetary incentives, and if they were personalized, brief, endorsed by established legitimized institutions, and mixed-mode (i.e. physicians had an option to complete the survey online or by paper format). Another study found that a small $5.00 monetary incentive had the largest average effect size (OR >2.2) when compared to both smaller and larger incentives, ranging from 0, 1, 5, 10, and 20 dollar incentives

(VanGeest et al., 2007). Furthermore, incentives provided by pre-payment were more likely to improve response rates than those provided after the survey was completed.

Based on this literature, we implemented several measures to improve response rate. These included the use of a small monetary incentive of a $5.00 Tim Horton's gift card provided with the initial survey before completion; the survey was brief, well organized, and available in paper format or online; and was REB approved by the University Health Network in Toronto, Ontario. A previous survey of physicians using similar methods to improve participation achieved a response rate greater than 70% (Wentlandt et al., 2012, 2014).

5.4 Ethical considerations

This study employed an implied consent process; palliative care physicians who completed and returned the survey were considered to have provided consent for their survey data to used for analysis. Participants were informed that their participation was completely voluntary and that no identifying information would be on the returned surveys. All completed surveys were kept strictly confidential and anonymous. To reduce duplicate responses, the instructions included a request that physicians not complete the survey twice. The returned surveys were stored in a locked cabinet, which could only be accessed by study members. Survey data were coded in SPSS statistical software database and were stored in a secure password-protected Research Information Systems computer at the University Health Network, with the password known only to the research team study members. The Department of Supportive Care at the University Health Network will retain all records and documents pertaining to the study for at least 10 years from the completion of the study.

5.5 Data collection and statistics

All surveys that were returned by mail and online were given a unique identifying number. Next, all of these surveys were evaluated individually for completion, issues, and errors. Any concerns that were identified were noted in a excel spreadsheet, noting the unique survey number, the concern, the question of concern (if applicable). Using this spreadsheet, we could identify reoccurring concerns and the proportion of similar concerns per question. After each survey was evaluated for any concerns, the raw data were entered into a primary raw data database in SPSS

Statistical Software, exactly as the questions had been answered on the survey. All missing data were tabulated and the proportion of the total of respondents per survey item was recorded.

Once all the data were collected, these data were evaluated question by question. Rules were developed to guide interpretation of questions that were answered incorrectly or incompletely. Descriptive statistics were performed on the complete population of physicians providing palliative care in Canada and the valid percentage, not including missing data, was reported.

5.5.1 Categorization of early palliative care referral

Palliative care physicians were categorized as believing that cancer patients should ideally be referred "*early*" to palliative care if they answered question 27, "*In IDEAL circumstances, when is it appropriate for CANCER patients to be first referred to palliative care?*" as:

- At diagnosis of cancer regardless of prognosis *AND/OR*
- At diagnosis of incurable cancer *AND/OR*
- 6 months – 1 year prognosis *AND/OR*
- More than 1 year prognosis

In contrast, physicians were categorized as believing that cancer patients should ideally be referred "*late*" to palliative care when they answered question 27 as:

- Less than 1 week prognosis *AND/OR*
- 1 week – 1 month prognosis *AND/OR*
- 1-2 months prognosis *AND/OR*
- 3-6 months prognosis

Similarly, palliative care physicians were categorized as believing that non-cancer patients should ideally be referred "*early*" to palliative care if they answered question 28, "*In IDEAL circumstances, when is it appropriate for NON-CANCER patients to be first referred to palliative care?*" as:

- At diagnosis of life-limiting illness regardless of prognosis (e.g. CHF) *AND/OR*
- At diagnosis of incurable cancer *AND/OR*
- 6 months – 1 year prognosis *AND/OR*
- More than 1 year prognosis

Physicians who believed that non-cancer patients should ideally be referred *"late"* were categorized in the same way as for ideal referral timing of patients with cancer.

5.5.2 Categorization of physicians providing specialized palliative care physicians vs. those practicing primary palliative care

Physicians providing specialized palliative care were defined as those who did not answer Question 1 of the *Early Palliative Care Survey* as only "providing primary palliative care to my own patients". Thus, physicians practicing specialized palliative care would have indicated in Question 1 that they practiced palliative care by one or more of the following:

- Providing palliative care consultations and direct follow-up visits *AND/OR*
- Acting as a palliative care resource to other care providers *AND/OR*
- Providing indirect care as a part of a local/regional palliative care service *AND/OR*
- Or, Other

Additionally, physicians practicing specialized palliative care had to have indicated in Question 34 that they received referrals for palliative care from other physicians.

Physicians who indicated that they *only* provided primary palliative care to their own patients AND/*OR* indicated in Question 34 that they did *not* receive referrals for palliative care from other physicians were categorized as providing primary palliative care.

We compared the demographics and attitudinal factors of physicians practicing specialized vs. primary palliative care. Demographic characteristics between specialized palliative care and primary palliative care physicians were compared using 2 x *n* contingency tables and χ^2 tests, significant differences were determined, using an alpha=0.05 significance level. Significant differences between column proportions were determined using a z-test. The degree of association between survey items and providing specialized or primary palliative care was determined using Cramer's V.

Ordinal variables, such as the comprehensiveness of palliative care teams; number of referral services available to physicians providing palliative care; number of settings concurrently practicing palliative care in; and opinion and attitudinal factors, were compared between specialized and primary palliative care physicians using the Mann-Whitney U non-parametric test. A non-parametric test was used because responses for variables were not typically normally distributed. A statistical different between the reported Likert scale scores was determined using an alpha=0.05 level of significance.

5.5.3 Logistic regression analysis of factors associated with receipt of early vs. late referrals by specialized palliative care physicians

We performed a separate analysis on the sample of specialized palliative care physicians. Specialized palliative care physicians were categorized as receiving *"early"* referrals for their palliative care services if they answered Question 21, *"What is the approximate average survival time of the patients for whom you provide palliative care?"* as:

- 7 months – 12 months *OR*
- More than one year

Physicians were categorized as receiving *"late"* referrals for their palliative care services if they answered that the approximate average survival of their palliative patients in question 21 as:

- 2 weeks or less
- 3 weeks – 2 months
- 3 months – 6 months

Univariable analysis was performed using 2 x *n* contingency tables and χ^2 tests and the Mann-Whitney U test. χ^2 tests were used to determine statistical differences between demographic factors and the Mann-Whitney U test was used for attitudinal factors. Attitudinal factors were analyzed on a continuous scale using the Mann-Whitney U test because some attitudinal factors as categorical variables had cell counts that were too low for comparisons.

Using these statistical tests, we compared demographic and attitudinal factors that were associated with physicians practicing specialized palliative care receiving *"early"* vs. *"late"* referrals for their palliative care services. Items that were significant on a $p \leq 0.2$ level were selected for entry into the multivariable model. We performed a logistic regression analysis to determine factors associated with specialized palliative care physicians receiving "early" vs. "late" palliative care referrals. Backwards likelihood ratio was used to select covariates for the multivariate model. SPSS Statistical Software was used to perform all statistical analysis.

Chapter 6: Results

6.1 Physicians providing palliative care in Canada

6.1.1 Demographics

The total number of surveys mailed was 823; of this number, 67 physicians indicated that they were either retired or did not practice palliative care, and 10 surveys were returned to sender. The response rate for the *Early Palliative Care Survey* was 71% (531/746), with 489 English and 42 French participants. Fifty three percent of palliative care physicians (279/531) completed the survey by mail-in paper format, whereas 48% percent (252/531) completed the survey online.

As shown in Table 4, 53.7% (302/527) of the palliative care physicians were female and 42.7% (225/527) were male. The majority of physicians, 57.5% (304/529), were between 40 and 59 years of age. Furthermore, physicians were asked about their professional associations. Seventy-nine percent (418/521) were members of the College of Family Physicians of Canada; 20.0% (106/521) were Fellows of the Royal College of Physicians and Surgeons; and 9.0% (48/521) were members of the College des Médecins du Quebéc. Additionally, 54.8% (291/531) reported that they were a part of a palliative care association, such the Canadian Society of Palliative Care Physicians.

Physicians practiced palliative care across Canada: 15.7% (83/529) in British Columbia; 19.8% (105/529) in the Prairies (Alberta, Saskatchewan, and Manitoba); 43.1% (229/529) in Ontario; 9.6% (51/529) in Quebéc; and 11.5% (61/529) in Atlantic Canada (Nova Scotia, New Brunswick, Prince Edward Island, and Newfoundland and Labrador), the Northwest Territories, and Nunavut. Few physicians, 15.3% (63/413), worked in rural workplace settings.

Table 4 Canadian palliative care physicians' general demographic characteristics.

Item	**N=531**
	n (%)
Sex	
Male	225 (42.7)
Female	302 (57.3)
Age	
20-39 years	110 (20.8)
40-59 years	304 (57.5)
60+	115 (21.7)
Professional associations memberships	
College of Family Physicians of Canada	418 (78.7)
Royal College of Physicians and Surgeons	106 (20.0)
College des Médecins du Quebéc	48 (9.0)
Palliative care associations or societies memberships	
NO	291 (54.8)
YES	240 (42.2)
Province/territory	
British Columbia	83 (15.7)
Alberta, Saskatchewan, Manitoba	105 (19.8)
Ontario	229 (43.1)
Quebec	51 (9.6)
Nova Scotia, New Brunswick, Prince Edward Island, Newfoundland and Labrador, Northern Territories, and Nunavut	61 (11.5)
Urban or rural workplace setting	
Urban	350 (84.7)
Rural	63 (15.3)

Note: Numbers may not add up to total 531 due to missing responses for individual items. Physicians' responses to professional associations were not exclusive all other items were.

Of the physicians, 26.8% (130/485) had completed a Master's and/or a PhD and the majority did not practice medicine in an academic centre, (63.4% [332/524]) (Table 5). Although some physicians reported that they were certified in specialties and subspecialties such as oncology, internal medicine, pediatrics, psychiatry, and anesthesiology, most physicians indicated they were certified in family medicine (68.5% [364/486]). Very few physicians reported that they were certified in a palliative medicine specialty (12.6% [67/486]). Only 13.0% (69/531) of physicians reported they completed accredited postgraduate training or a year of added competence (YAC) in palliative medicine. While 42.5% (220/517) of physicians had completed other training in palliative care, 28.6% of those with other training reported that this other training lasted three months or less. Furthermore, this other training largely did not involve an exam (89.5% [197/220]). A minority of physicians received their most recent palliative training outside of Canada (9.2% [41/446]).

Table 5 Canadian palliative care physicians' demographic characteristics: training and certifications.

Item	**N=531**
	n (%)
Postgraduate education	
NO	355 (73.2)
YES (Masters and/or PhD)	130 (26.8)
Practice palliative care in an academic centre	
NO	332 (63.4)
YES	192 (36.6)
Certified specialties/subspecialties	
Family Medicine	364 (68.5)
Oncology	16 (3.0)
Internal Medicine	32 (6.0)
Pediatrics	20 (3.8)
Psychiatry	10 (1.9)
Palliative Medicine	67 (12.6)
Anesthesiology	12 (2.3)
Other	79 (14.9)
Primary practice	
Family Medicine with a focused practice in palliative care	104 (19.7)
Family Medicine with a focused other than palliative care	65 (12.3)
Family Medicine without a focused practice	214 (40.5)
Specialist/Subspecialist	137 (25.9)
Other	9 (1.7)
Accredited training/ year of added competence in palliative medicine	
NO	462 (87.0)
YES	69 (13.0)
Other training in palliative care	
NO	297 (57.4)
YES – 3 months or less	148 (28.6)
YES – 4 months or more	72 (13.9)
Exams in other training	
NO	197 (89.5)
YES	23 (10.5)
Recent palliative care training	
In Canada	405 (90.8)
Outside Canada	41 (9.2)

Note: Numbers may not add up to total 531 due to missing responses for individual items. Physicians' responses to certified specialties and subspecialties were not exclusive all other items were. Only physicians who responded "yes" to having other training in palliative care were asked if their other training had exams.

Most palliative care physicians stated that they worked full-time (83.3% [439/527]) (Table 6). However, approximately half reported that they spent 10% or less of their clinical time in a work week practicing palliative care, while approximately one quarter reported that they spent greater than 50% of their clinical time practicing palliative care. The number of years a physician had been practicing palliative care was variable, and ranged from 5 years or less (24.1% [127/528]) to more than 20 years (34.1% [180/528]).

Table 6 Canadian palliative care physicians' demographic characteristics: amount and length of time practicing medicine and palliative care.

Item	**N=531**
	n (%)
Full or part-time physician	
Full-time physician	439 (83.3)
Part-time physician	88 (16.7)
Proportion of clinical time spent practicing palliative care per work week	
10% or less	278 (52.6)
11-50%	122 (23.1)
51% +	129 (24.4)
Years practicing palliative care	
5 years or less	127 (24.1)
6 – 10 years	88 (16.7)
11-20 years	133 (25.2)
More than 20 years	180 (34.1)

Note: Numbers may not add up to total 531 due to missing responses for individual items.

Of the 531 participants, palliative care physicians worked in various settings including hospices (23.4%), private offices (44.4%), long-term care facility/nursing homes (33.5%), palliative care units (33.7%), inpatient palliative care consultations in hospitals (36.2%), outpatient ambulatory palliative care clinics (18.1%), palliative home care (54.6%), and other places such as emergency rooms and critical care units (22.8%) (Table 7). On average, they worked in approximately three (SD 1.45) different facilities practicing palliative care.

Palliative care physicians worked in numerous workplace settings (Table 8). The majority of physicians (>87.0% in all cases) who worked in palliative care clinics/consultation services, reported that patients who were younger than 65 years old; had not signed a do-not-resuscitate (DNR) order; were non-cancer patients; had a prognosis greater than 1 year or between 6 – 12 months; and were receiving oral chemo/hormone therapy, IV chemotherapy, or blood transfusions were eligible for referral. Although physicians who provided home palliative care also accepted patients in most of these categories, only 64.9% of physicians reported that their home palliative care service accepted patients with a prognosis greater than one year. Finally, less than half of palliative care units accepted patients who had not signed a DNR; patients with a prognosis greater than one year; or those receiving IV chemotherapy. Additionally, only 62.4% of physicians reported that their palliative care unit accepted patients with a prognosis between 6 – 12 months.

Table 7 Canadian palliative care physicians' palliative workplace setting.

Item	**N=531**
	n (%)
Workplace setting	
Hospice	124 (23.4)
Private Office	236 (44.4)
Long-term care facility/nursing home	178 (33.5)
Palliative care unit	179 (33.7)
Inpatient palliative consultation in a hospital	192 (36.2)
Outpatient ambulatory palliative care clinic	96 (18.1)
Inpatient and/or Outpatient	208 (39.2)
Palliative home care	290 (54.6)
Other	121 (22.8)
Number of settings practicing palliative care in…	
	Mean (SD)
Minimum 1 setting – Maximum 8 setting	2.66 (1.45)

Note: Numbers may not add up to total 531 due to missing responses for individual items. Physicians' responses to workplace setting were not exclusive.

Table 8 Proportion of patients accepted for referral/admission in different practice settings.

Palliative services patient criteria	***n (%)***		
	N=170	N=276	N=168
My service accepts patients who…	**Palliative Care Unit**	**Home Palliative Care**	**Palliative Clinic/ Consultation**
Are younger than 65 years old	170 (100.0)	266 (96.4)	164 (97.6)
Have NOT signed a DNR	77 (45.3)	231 (83.7)	156 (92.9)
Are Non-Cancer patients	158 (92.9)	263 (95.3)	154 (91.7)
Have a prognosis greater than 1 year	70 (41.2)	179 (64.9)	146 (86.9)
Have a prognosis between 6-12 months	106 (62.4)	248 (89.9)	157 (93.5)
Are receiving oral chemo/hormone therapy	125 (73.4)	247 (89.5)	164 (97.6)
Are receiving blood transfusions	126 (74.1)	238 (86.2)	162 (96.4)
Are receiving IV chemotherapy	79 (46.5)	218 (79.0)	158 (94.0)

Note: "n" is the number of physicians providing palliative care who responded that their service - palliative care unit, home palliative care, and/or palliative clinic/consultation - accepts patients who are of the listed type. The denominator for each setting (N), listed at the top of the table in blue, was determined by the number of physicians working in that setting as listed in Table 4 minus the number of missing responses.

Although 55.0% (290/527) of physicians strongly agreed or agreed that they had "sufficient resources to provide high-quality palliative care 6 – 24 months prior to the end of life", 31.5% (166/527) felt they did not (Table 9). Palliative care physicians had the capacity to refer their patients to numerous services (Table 10). The average number of services available for referral was approximately 5 referral services (SD 2.08). Furthermore, the majority of physicians provided 24-hour on-call services for their palliative patients, 76.5% (400/523).

Table 9 Canadian palliative care physicians' opinion on the sufficiency of resources to provide early palliative care.

SCALE				
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I have sufficient resources in my palliative care practice to provide high-quality palliative care 6 – 24 prior to the end of life ***n (%)***				
40 (7.6)	126 (23.9)	71 (13.5)	203 (38.5)	87 (16.5)

Table 10 Canadian palliative care physicians' availability of palliative services for patients.

Item	**N=531**
	n (%)
Palliative services available for referral by physician providing palliative care	
Hospice	339 (63.8)
Palliative care unit in a hospital	351 (66.1)
Outpatient ambulatory palliative care clinic	236 (44.4)
Pain clinic	270 (50.8)
Palliative care home visits	396 (74.6)
Palliative consultation service in a hospital	363 (68.4)
Bereavement support	296 (55.7)
Psychosocial support	330 (62.1)
Other	37 (7.0)
Number of referral services available to physicians providing palliative care	
	Mean (SD)
Minimum 0 – Maximum 9	4.98 (2.08)
Team provides a 24-hour on-call services for palliative patients	
	n (%)
NO	123 (23.5)
YES	400 (76.5)

Note: Numbers may not add up to total 531 due to missing responses for individual items. Physicians' responses to available referral services were not exclusive.

Just over half of physicians stated that they worked in palliative care teams (Table 11). The average number of people in each palliative care team was approximately three (SD 3.16). Disciplines working within palliative care teams included: registered nurses, other palliative care physicians, psychiatrists, social workers, counselors, physical therapists, pharmacists, and volunteers. Of the 328 palliative care physicians who reported that they worked in a palliative care team who received referrals for palliative care, 70.9% (227/320), indicated they were satisfied or very satisfied with their professional relationships with referring physicians. However, 90.8% (294/324) and 92.0% (299/325) of physicians reported being very satisfied with their professional relationships with other palliative care physicians and other palliative team members respectively (Fig 2).

Table 11 Canadian palliative care physicians' demographics regarding collaborations.

Item	**N=531**
	n (%)
Part of a palliative care team	
NO	272 (51.4)
YES	257 (48.6)
Comprehensiveness of palliative care team	
	Mean (SD)
Minimum 0 team members – Maximum 9 team members	2.68 (3.16)

Note: Numbers may not add up to total 531 due to missing responses for individual items.

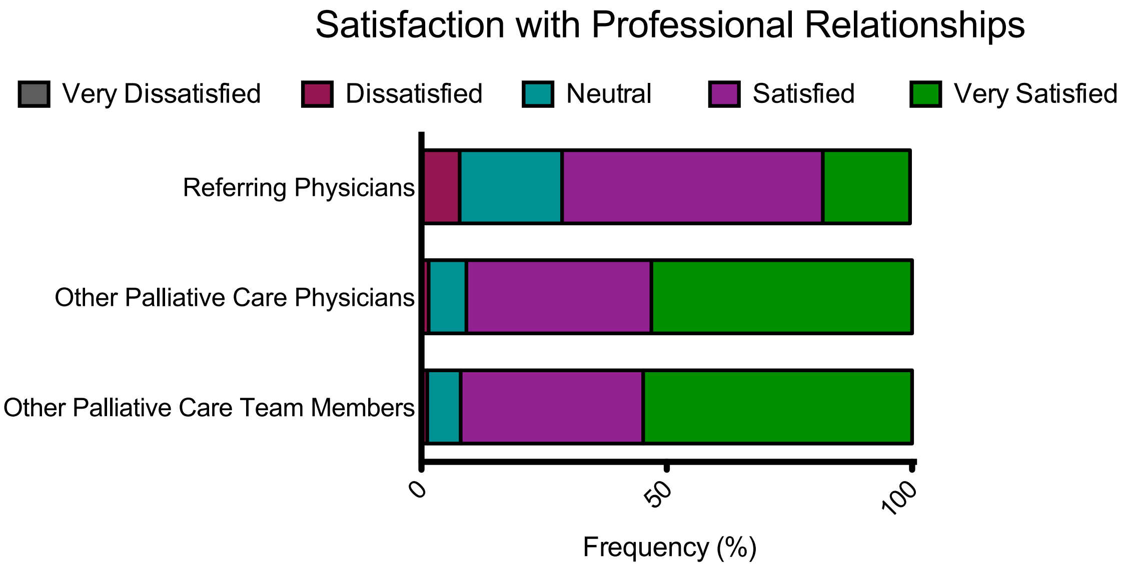


Figure 2 Satisfaction with professional relationships of 328 palliative care physicians who work in a palliative care team and receive palliative care referrals. Of those physicians, 70.9%, 90.8%, and 92.0% were satisfied or very satisfied with their professional relationship with referring physicians, other palliative care physicians, and other palliative care team members respectively.

Palliative care physicians were asked the average number of unique palliative patients they saw per month, including new and follow-up patients: 47.5% (251/528) reported seeing only 1-5 patients per month. Patients receiving palliative care were largely adults 18 years of age or older, (94.9% [503/530]). Physicians saw patients with a cancer and non-cancer diagnoses for palliative care; however, 74.4% (393/528) of physicians reported that 51% or more of the palliative care they provide was for patients with cancer (Table 12).

Table 12 Type and number of palliative patients seen by Canadian palliative care physicians.

Item	**N=531**
	n (%)
Average number of unique patients seen per MONTH (new and follow-up) for palliative care	
1-5 pts	251 (47.5)
6-20 pts	149 (28.2)
21-50 pts	128 (24.2)
Type of patients palliative services are provided for	
Adults greater than (=) 18 years old	503 (94.9)
Children less then18 years old	27 (5.1)
Proportion of the palliative care provided for patients with cancer	
50% or less	135 (25.6)
51-100%	393 (74.4)

Note: Numbers may not add up to total 531 due to missing responses for individual items.

6.1.2 Opinions on the scope and benefits of palliative care for patients with and without cancer

For a subset of statements regarding the scope and benefits of palliative care, physicians were asked to rate separately their opinions for patients with cancer and those without cancer (Table 13). Responses for patient with and without cancer did not differ substantially. The large majority of palliative care physicians agreed that for both groups, the involvement of palliative care teams 6-24 months prior to the end of life improved patients' quality of life with a larger number of neutral responders to the statement that it "has a survival benefit". For both groups, less than 10% agreed with the statement "Palliative care teams should only be involved in the last few weeks of life". Approximately a third of physicians agreed, were neutral, or disagreed that "It is the responsibility of the referring physicians to manage complications related to the treatment of a shared patient's primary disease". Similarly there were variable responses to the question of whether the specialty of palliative care should be renamed "supportive care", with approximately 40% opposed, 30% neutral, and 30% in favour.

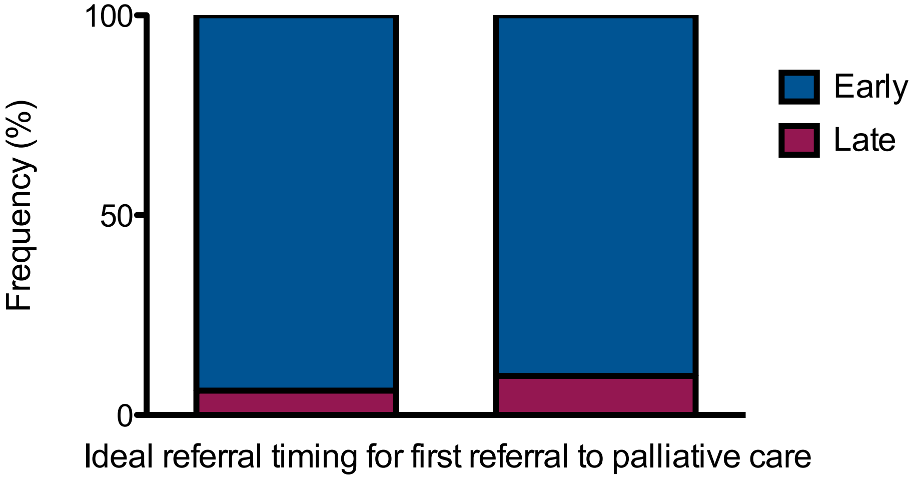
Table 13 Canadian palliative care physicians' attitudes and opinions regarding early palliative care for patients with a cancer or a non-cancer diagnosis independently.

SCALE					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
n (%)					
Involvement of palliative care teams 6-24 months prior to the end of life improves patients' quality of life					
Cancer	3 (0.6)	3 (0.6)	27 (5.3)	135 (26.3)	345 (67.3)
Non-cancer	4 (0.8)	5 (1.0)	43 (8.2)	149 (28.5)	321 (61.5)
Involvement of palliative care teams 6-24 months prior to the end of life has a survival benefit					
Cancer	8 (1.6)	24 (4.7)	155 (30.3)	159 (31.1)	165 (32.3)
Non-cancer	9 (1.7)	27 (5.2)	205 (39.7)	157 (30.4)	119 (23.0)
Palliative care teams should only be involved in the last few weeks of life					
Cancer	341 (66.2)	129 (25.0)	14 (2.7)	8 (1.6)	23 (4.5)
Non-cancer	298 (57.5)	137 (26.4)	43 (8.3)	17 (3.3)	23 (4.4)
It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient's primary disease					
Cancer	58 (11.3)	124 (24.2)	150 (29.2)	133 (25.9)	48 (9.4)
Non-cancer	59 (11.2)	110 (21.2)	150 (28.9)	145 (27.9)	56 (10.8)
The specialty of palliative care should be renamed supportive care					
Cancer	116 (22.6)	89 (17.3)	162 (31.5)	85 (16.5)	62 (12.1)
Non-cancer	119 (22.8)	85 (16.3)	164 (31.5)	90 (17.3)	63 (12.1)

Note: Numbers may not add up to total 531 due to missing responses for individual items.

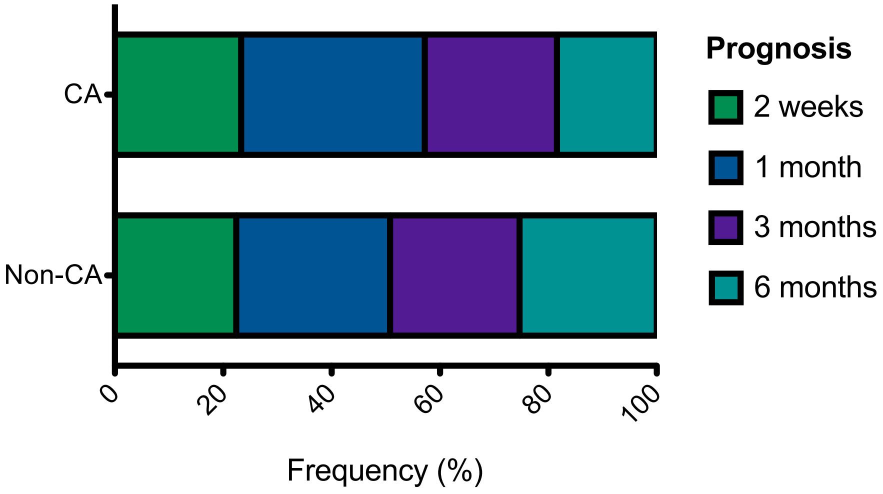
6.1.3 Timing of referral to palliative care for patients with and without cancer

Palliative care physicians were also asked, for patients with and without cancer, respectively, “In IDEAL circumstances, when is it appropriate for CANCER/NON-CANCER patients to be first referred to palliative care”. Physicians overwhelmingly felt that for patients with cancer [92.5%; (468/506)] and those without cancer [85.6%; (434/507)] palliative referral should ideally be provided early (at prognosis >6 months, upon diagnosis of cancer/life-limiting illness, or upon diagnosis of incurable cancer) (Fig. 3). However, when physicians were asked, “What do you consider to be a late referral for palliative care?” there was greater variability in the responses, both for patients with cancer and for those without cancer (Fig. 4).



CA = For CANCER pts   Non-CA = For Non-CANCER pts

Figure 3 Canadian palliative care physicians’ opinions on the ideal timing of referral to palliative care for cancer and non-cancer patients. For cancer and non-cancer patients respectively, 92.5% and 85.6% of physicians providing palliative care reported that ideally patients should be referred early to palliative care. “Early” was categorized as ideal first referral to palliative care: at prognosis >6 months, upon diagnosis of cancer/life-limiting illness, or upon diagnosis of incurable cancer. “Late” was categorized as ideal first referral at a prognosis of: less than 1 week, 1 week – 1 month, 1-2 months, or 3-6 months.



CA = For CANCER pts

Non-CA = For Non-CANCER pts

Figure 4 Canadian palliative care physicians' opinion on what they considered to be a late referral to palliative care for cancer and non-cancer patients, respectively. Reported responses for prognosis 2 weeks, 1 month, 3 months, and 6 months were: for cancer patient, 23.3, 33.9, 24.4, 18.4% respectively and for non-cancer patients, 22.4, 28.4, 23.9, 25.3% respectively.

6.1.4 General attitudes and opinions about early palliative care

We also assessed the general attitudes and opinions of physicians providing palliative care regarding early palliative care. First, they were asked about their opinions relating to palliative care referral criteria (Table 14A). More than 85% disagreed or strongly disagreed with the statement, "Patients should have stopped all chemotherapy before referral to palliative care", and with the statement "Hematology patients should have stopped all blood transfusions before referral to palliative care". Similarly, more than 80% of physicians providing palliative care disagreed or strongly disagreed that "Patients without symptoms do not need palliative care before the last few weeks of life".

Second, physicians were asked what, in their view, were the perceptions of referring physicians and patients to the name palliative care (Table 14B). More than half of the physicians reported that they agreed or strongly agreed that “Patients have a negative perception of the term palliative care”. Further, a substantial minority agreed or strongly agreed that patients (41.6% [220/528]) and referring physicians (37.5% [198/531]) would feel more comfortable with referral to palliative care 6 – 24 months prior to the end of life if it were renamed supportive care.

6.1.5 Missing data

The percentage of missing data for each item was calculated (See Appendix A1). No survey item had a percentage missing greater than 22%. Furthermore, only a few items had a percent missing greater than 10%. The following survey items had a percentage missing greater than 10%:

- Location of completion of the most recent palliative care training, 16.0% (85/531)
- Urban vs. Rural palliative workplace setting, 22.2% (118/531)
- Types of patients accepted in palliative care clinics/consultation service, 19.2% (40/208)

For one specific survey item, where we asked physicians if they were a member of any palliative care associations, the percentage missing was unknown. Physicians who were not a member of any palliative care association left the question blank; thus an answer of “no” was indistinguishable from a missing answer.

Table 14 Canadian palliative care physicians' attitudes and opinions regarding early palliative care. **A.** Attitudes and opinions about referral criteria. **B.** Attitudes and opinions about changing the name palliative care to supportive care.

SCALE				
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
A.		***n (%)***		
		Patients should have stopped all chemotherapy before referral to palliative care		
226 (42.8)	236 (44.7)	44 (8.3)	13 (2.5)	9 (1.7)
		Hematology patients should have stopped all transfusions before referral to palliative care		
238 (45.1)	227 (43.0)	40 (7.6)	16 (3.0)	7 (1.3)
		Patients without symptoms do not need palliative care before the last few weeks of life		
160 (30.3)	275 (52.1)	58 (11.0)	34 (6.4)	1 (0.2)
B.		***n (%)***		
		Patients would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care		
36 (6.8)	70 (13.3)	202 (38.3)	157 (29.7)	63 (11.9)
		Referring physicians would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care		
35 (6.6)	109 (20.6)	186 (35.2)	147 (27.8)	51 (9.7)
		Patients have a negative perception of the term palliative care		
6 (1.1)	77 (14.6)	143 (27.1)	243 (46.1)	58 (11.0)

Note: Numbers may not add up to total 531 due to missing responses for individual items.

6.2 Characteristics of physicians providing specialized and primary palliative care

Physicians who provide palliative care may do so in different capacities (Table 15). Physicians were asked about how they practiced palliative care by choosing among the following categories: providing palliative care consultations and direct follow-up visits; acting as a palliative care resource to other care providers; providing indirect care as a part of a local/regional palliative care service; providing palliative care to my own patients; and/or other (e.g. critical care unit or emergency room).

Table 15 Percentage of physicians who practice various type of palliative care.

Item	**N=531**
	n (%)
Type of palliative care practice	
Providing palliative care consultations & direct follow up visits	234 (44.1)
Acting as a palliative care resource to other care providers	241 (45.1)
Providing indirect care as a part of a local/regional palliative care service	132 (24.9)
Providing primary palliative care to my own patients	388 (73.1)
Other	24 (4.5)

Note: Numbers may not add up to total 531 due to missing responses for individual items. Physicians' responses to the type of palliative care practiced were not exclusive.

Physicians were categorized as providing either specialized palliative care or primary palliative care. Specifically, physicians providing specialized palliative care were those who received referrals for palliative services and who did not *only* provide primary palliative care to their own patients. Physicians were categorized as specialized or primary palliative care physicians as outlined in Fig. 5. Of the 531 physicians, 48.4% were categorized as practicing specialized palliative care (257/531), while 51.6% (274/531) were categorized as practicing primary palliative care.

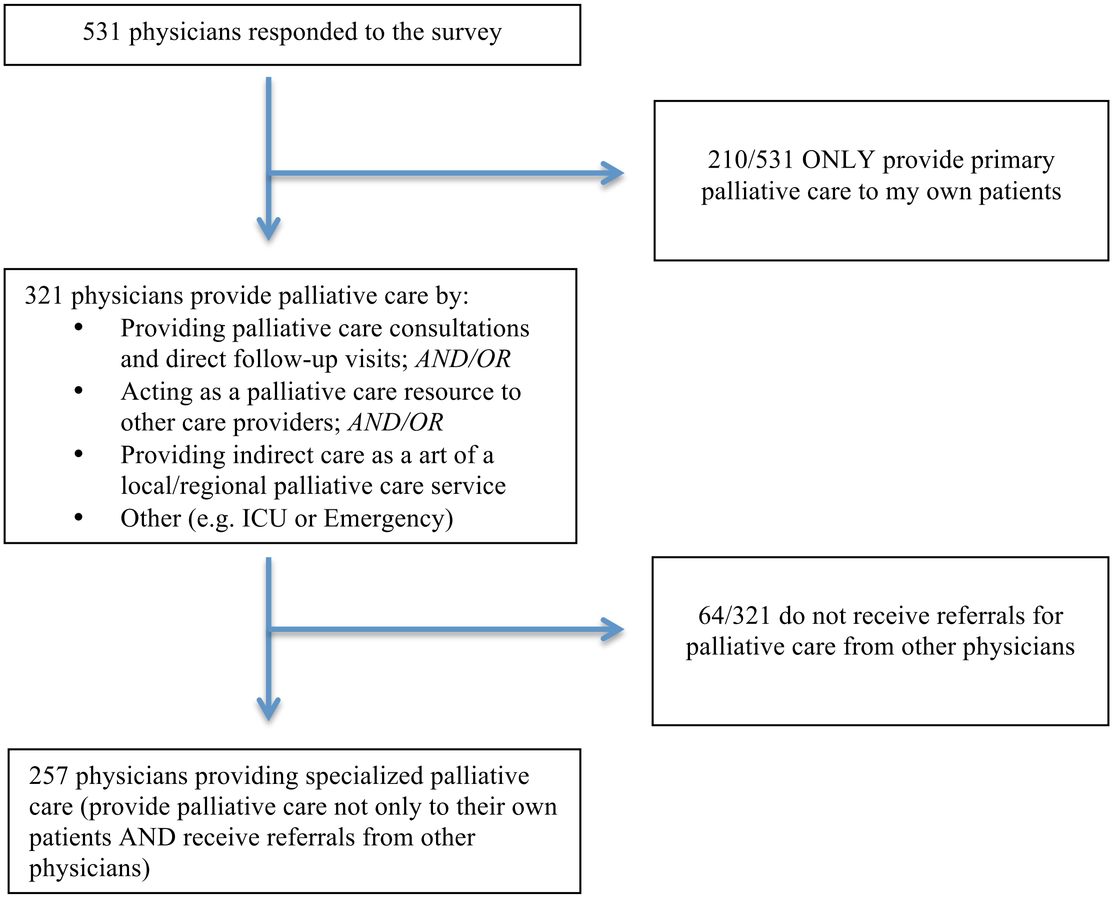


Figure 5 Process of categorization of physicians as specialized or primary palliative care physicians.

Contingency tables and χ^2 tests were used to determine the associations between demographic items and the type of palliative care provided (specialized or primary palliative care). Significant differences across column proportions were also reported. Type of palliative care provided was statistically associated with several demographic variables (Table 16). Type of palliative care provided was weakly associated with sex (χ^2 (1, n=527) = 9.729, p=0.002, V =0.136). Of the physicians practicing primary palliative care, 63.8% were female, compared to 50.4% of those practicing specialized palliative care.

Providing specialized palliative care was significantly associated with being a member of a palliative care association/society (χ^2 (1, n=531) = 140. 117, p=0.001, V =0.514). The majority of physicians practicing specialized palliative care (71.6%), were a part of palliative care association/society while the majority of those practicing primary palliative care physicians, (79.6%), were not.

No significant associations were found between providing specialized vs. primary palliative care and the province in which physicians practiced; however, there was a significant association with working in a urban or rural workplace setting (χ^2 (1, n=413) = 27.389, p<0.0001, V =0.258). Physicians practicing specialized palliative care worked primarily in urban settings (94.1%), whereas this was the case for 75% of those practicing primary palliative care.

Table 16 Specialized and primary palliative care physicians' general demographic characteristics.

Item	**Specialized n=257**	**Primary n=274**	**p-value**
	n (%)	***n (%)***	
Sex			
Male	127 (49.6) [a]	98 (36.2) [b]	0.002
Female	129 (50.4) [a]	173 (63.8) [b]	
Age			
20-39 years	52 (20.3)	58 (21.2)	0.996
40-59 years	148 (58.7)	156 (57.1)	
60+	56 (21.9)	59 (21.6)	
Palliative care associations or societies memberships			
NO	73 (28.4) [a]	218 (79.6) [b]	<0.0001
YES	184 (71.6) [a]	56 (20.4) [b]	
Province/territory			
British Columbia	45 (17.6)	38 (13.9)	0.127
Alberta, Saskatchewan, Manitoba	40 (15.7)	65 (23.7)	
Ontario	115 (45.1)	114 (41.6)	
Quebec	28 (11.0)	23 (8.4)	
Nova Scotia, New Brunswick, Prince Edward Island, Newfoundland and Labrador, Northern Territories, and Nunavut	27 (10.6)	34 (12.4)	
Urban or rural workplace setting			
Urban	192 (94.1) [a]	158 (75.6) [b]	<0.0001
Rural	12 (5.9) [a]	51 (24.2) [b]	

Note: Superscripts *a* and *b* denote a significant difference across the column proportions for physicians providing specialized and primary palliative care using a z-test. We used 2 x n contingency tables and $\chi 2$ tests to assess significant association between providing specialized or primary palliative care. Numbers may not add up to totals due to missing responses for individual items. All expected cell counts were greater than five unless stated.

There was no association between the types of palliative care provided and having completed a Masters or a PhD (Table 17). However, there was a significant association between practicing specialized palliative care and working in an academic centre (χ^2 (1, n=524) = 26.849, p<0.0001, V =0.226). Approximately 48% of physicians practicing specialized palliative care reported that they worked in an academic centre, compared to 26% of those practicing primary palliative care. Furthermore, there was a significant association between the type of palliative care provided and having completed postgraduate training or a year of added competence (YAC) in palliative medicine (χ^2 (1, n=531) = 66.620, p<0.0001, V =0.354), as well as with having had other training in palliative medicine (χ^2 (2, n=517) = 44.460 p<0.0001, V =0.300). Approximately 25% of physicians practicing specialized palliative care had completed postgraduate training/YAC and 25% had completed other training in palliative care that was four months or more in length. Of those practicing primary palliative care, only 1.5% had completed postgraduate training/YAC and 65.6% had not completed any other training in palliative medicine. No significant associations were found between type of palliative care provided and the location of most recent palliative care training.

Table 17 Specialized or primary palliative care with physicians' training and educational demographics.

Item	Specialized n=257	Primary n=274	p-value
	n (%)	*n (%)*	
Graduate education			
NO	168 (71.2)	188 (75.5)	0.282
YES (Masters and/or PhD)	68 (28.8)	61 (24.5)	
Practice palliative care in an academic centre			
NO	133 (52.2) ^{a}	199 (74.0) ^{b}	<0.0001
YES	122 (47.8) ^{a}	70 (26.0) ^{b}	
Accredited training/ year of added competence in palliative medicine			
NO	192 (74.7) ^{a}	270 (98.5) ^{b}	<0.0001
YES	65 (25.3) ^{a}	4 (1.5) ^{b}	
Other training in palliative care			
NO	120 (47.4) ^{a}	177 (65.6) ^{b}	<0.0001
YES – 3 months or less	66 (26.7)	82 (30.4)	
YES – 4 months or more	61 (24.7) ^{a}	11 (4.1) ^{b}	
Recent palliative care training			
In Canada	211 (89.0)	194 (92.8)	0.166
Outside Canada	26 (11.0)	15 (7.2)	

Note: Superscripts *a* and *b* denote a significant difference across the column proportions for physicians providing specialized and primary palliative care using a z-test. We used 2 x n contingency tables and $\chi 2$ tests to assess significant association between providing specialized or primary palliative care. Numbers may not add up to totals due to missing responses for individual items. All expected cell counts were greater than five unless stated.

Working full or part-time as a physician was significantly, albeit weakly, associated with providing specialized or primary palliative care (χ^2 (1, n=527) = 6.115, p=0.013, V =0.108) (Table 18). A larger proportion of physicians providing specialized palliative care tended to work full-time (88% vs. 79%). Similarly, physicians who practiced specialized palliative care spent a significantly larger proportion of their clinical time practicing palliative care compared to those practicing primary palliative care (χ^2 (2, n=529) = 213.371, p<0.0001, V =0.635). More than 80% of physicians providing primary palliative care reported that in a workweek 10% or less of their clinical time is comprised of practicing palliative care, whereas this was the case for only 21% of those practicing specialized palliative care. There was a weak association between number of years practicing palliative care and the type of palliative care provided (χ^2 (3, n=528) = 10.263, p=0.016, V =0.139), with those practicing specialized palliative care more likely to have been doing so for 6 – 10 years (20% vs. 13%) and those practicing primary palliative care more likely to have been doing so for more than 20 years (40% vs. 28%)

Table 18 Amount and length of time practicing medicine and palliative care for physicians providing specialized and primary palliative care.

Item	Specialized n=257	Primary n=274	p-value
	n (%)	*n (%)*	
Full or part-time physician			
Full-time physician	223 (87.5) [a]	216 (79.4) [b]	0.013
Part-time physician	32 (12.5) [a]	56 (20.6) [b]	
Proportion of clinical time spent practicing palliative care per workweek			
10% or less	55 (21.4) [a]	223 (82.0) [b]	<0.0001
11-50%	81 (31.5) [a]	41 (15.2) [b]	
51% +	121 (47.1) [a]	8 (2.9) [b]	
Years practicing palliative care			
5 years or less	60 (23.3)	67 (24.7)	0.016
6 – 10 years	52 (20.2) [a]	36 (13.3) [b]	
11-20 years	72 (28.0)	61 (22.5)	
More than 20 years	73 (28.4) [a]	107 (39.5) [b]	

Note: Superscripts *a* and *b* denote a significant difference across the column proportions for physicians providing specialized and primary palliative care using a z-test. We used 2 x n contingency tables and χ2 tests to assess significant association between providing specialized or primary palliative care. Numbers may not add up to totals due to missing responses for individual items. All expected cell counts were greater than five unless stated.

Physicians practicing specialized palliative care were more likely to provide care in specialized palliative care settings (Table 17). Specifically, those providing specialized palliative care were more likely to work in hospices (34% vs. 14%; χ^2 (1, n=531) = 28.446, p<0.0001, V =0.231), palliative care units (54% vs. 15%; χ^2 (1, n=531) = 89.032, p<0.0001, V =0.409), provide inpatient palliative care consultations in hospitals (64% vs. 10%; χ^2 (1, n=531) = 165.011, p<0.0001, V =0.557), work in outpatient ambulatory palliative care clinics (33% vs. 12%; χ^2 (1, n=531) = 71.738, p<0.0001, V =0.368), and provide palliative home care (65% vs. 45%; χ^2 (1, n=531) = 20.003, p<0.0001, V =0.194). Conversely, those providing primary palliative care were more likely to practice in private offices (57% vs. 31%; χ^2 (1, n=531) = 37.8888, p<0.0001, V =0.267) or other places (33% vs. 12%; χ^2 (1, n=531) = 34.966, p<0.0001, V =0.257).

Approximately equal proportions practiced in long-term care facilities or nursing homes (roughly a third of respondents in each group).

The number of settings in which specialized and primary palliative care physicians practiced was significantly different (U = 20,685.00, z = -8.429, p <0.0001). Specifically, those practicing specialized palliative care practiced in a larger number of settings than primary palliative care physicians (Mean Rank 322.51 vs. 212.99) (Table 19).

Table 19 Association between practicing specialized or primary palliative care with palliative workplace setting.

Item	**Specialized n=257**	**Primary n=274**	**p-value**
	n (%)	***n (%)***	
Workplace setting			
Hospice	86 (33.5) [a]	38 (13.9) [b]	<0.0001
Private Office	79 (30.7) [a]	157 (57.3) [b]	<0.0001
Long-term care facility/nursing home	83 (32.3)	95 (34.7)	0.562
Palliative care unit	138 (53.7) [a]	41 (15.0) [b]	<0.0001
Inpatient palliative consultation in a hospital	164 (63.8) [a]	28 (10.2) [b]	<0.0001
Outpatient ambulatory palliative care clinic	84 (32.7) [a]	12 (4.4) [b]	<0.0001
Inpatient and/or Outpatient	173 (67.3) [a]	34 (12.4) [b]	<0.0001
Palliative home care	166 (64.6) [a]	124 (45.3) [b]	<0.0001
Other	30 (11.7) [a]	91 (33.2) [b]	<0.0001
Number of palliative care settings practiced in…			
	Mean Rank	***Mean Rank***	p <0.0001
	322.51	212.99	

Note: Superscripts *a* and *b* denote a significant difference across the column proportions for physicians providing specialized and primary palliative care using a z-test. We used 2 x n contingency tables and χ2 tests to assess significant association between providing specialized or primary palliative care. We used a Mann-Whitney U test to asses the difference between the number of palliative care settings in which physicians practice. Numbers may not add up to totals due to missing responses for individual items. All expected cell counts were greater than five unless stated.

There was no significant difference between the responses of physicians who did or did not provide specialized palliative care, in terms of their opinions about whether they had sufficient resources to provide high quality palliative care 6-24 months before the end of life (U=33058.50, z=-0.971, p=0.331). However, there was a significant difference in the number of services available for specialized and primary palliative care physicians' patients, such as bereavement support and pain clinics (U = 22,504.00, z = -6.871, p <0.0001). The number of services available to physicians providing specialized palliative care (6.00) was higher than that for those practicing primary palliative care (4.50). There was a significant association between providing specialized palliative care and providing 24-hour on-call services for patients requiring palliative care (χ^2 (1, n=523) = 24.448, p<0.0001, V =0.216). Specifically, 85% of physicians practicing specialized palliative care provided 24-hour on-call services for their patients requiring palliative care, whereas 65% of physicians providing primary palliative care did so (Table 20).

Table 20 Resources of specialized and primary palliative care physicians.

Item	**Specialized n=257**	**Primary n=274**	**p-value**
	n (%)	***n (%)***	
Team provides a 24-hour on-call services for palliative patients			
NO	36 (14.1) [a]	87 (32.5) [b]	<0.0001
YES	219 (85.9) [a]	181 (67.5) [b]	<0.0001
Number of palliative services available to patients			
	Median	***Median***	p <0.0001
	6.00	4.50	
I have sufficient resources in my palliative care practice to provide high-quality palliative care 6 – 24 prior to the end of life**			
	Mean Rank	***Mean Rank***	0.331
	270.37	257.99	

Note: Superscripts *a* and *b* denote a significant difference across the column proportions for physicians providing specialized and primary palliative care using a z-test. We used 2 x n contingency tables and χ2 tests to assess significant association between providing specialized or primary palliative care. We used a Mann-Whitney U test to asses the difference between the number of palliative care services to physicians' patients and sufficiency of resources to provide early palliative care. The distributions of the number of services available to physicians' patients were of similar shape between specialized and primary palliative care, thus medians could be compared. Numbers may not add up to totals due to missing responses for individual items. All expected cell counts were greater than five unless stated.

There was a significant association between practice of specialized palliative care and working in a palliative care team (χ^2 (1, n=529) = 227.402, p<0.0001, V =0.656); average number of unique palliative care patients seen per month (χ^2 (2, n=528) = 189.526, p<0.0001, V =0.599); and the proportion of palliative care provided for patients with cancer (χ^2 (1, n=528) = 25.816, p<0.0001, V =0.221) (Table 21). Specifically, 83% of physicians practicing specialized palliative care worked on a palliative care team, whereas 83% of primary palliative care physicians did not. Furthermore, compared to those practicing primary palliative care, physicians practicing specialized palliative care provided palliative care to a larger number of unique patients per month and a greater proportion stated that more than half of the palliative care they provided was for patients with cancer (84 vs. 65%).

Table 21 Specialized and primary palliative care physicians' practice.

Item	**Specialized n=257**	**Primary n=274**	**p-value**
	n (%)	***n (%)***	
Part of a palliative care team			
NO	45 (17.6) ^{a}	227 (83.2) ^{b}	<0.0001
YES	211 (82.4) ^{a}	46 (16.8) ^{b}	
Average number of unique patients seen per MONTH (new and follow-up) for palliative services			
1-5 pts	47 (18.5) ^{a}	204 (74.5) ^{b}	<0.0001
6-20 pts	91 (35.8) ^{a}	58 (21.2) ^{b}	
21-50 pts	116 (45.7) ^{a}	12 (4.4) ^{b}	
Type of patients palliative services are provided for			
Adults greater than (=) 18 years old	243 (94.9)	260 (94.9)	0.987
Children less then18 years old	13 (5.1)	14 (5.1)	
Proportion of palliative care provided for CANCER patients			
50% or less	40 (15.6) ^{a}	95 (34.9) ^{b}	<0.0001
51-100%	216 (84.4) ^{a}	177 (65.1) ^{b}	

Note: Superscripts *a* and *b* denote a significant difference across the column proportions for physicians providing specialized and primary palliative care using a z-test. We used 2 x n contingency tables and χ2 tests to assess significant association between providing specialized or primary palliative care. Numbers may not add up to totals due to missing responses for individual items. All expected cell counts were greater than five unless stated.

6.2.1 Specialized vs. primary palliative care physicians opinions and attitudes about early palliative care

There was no association between practicing primary or specialized palliative care and opinions about the ideal timing of referral to palliative care for patients with cancer, nor was there a difference in the opinion about what was considered a late referral for patients with or without cancer (Table 22). However, there was a significant association between type of practice and ideal referral timing for patients without cancer (χ^2 (1, n=508) = 8.252, p=0.004, V =0.157). Specifically, a larger proportion of physicians providing specialized palliative care reported that the first referral to palliative care for patients without cancer should be "early" (90 vs. 83%).

Table 22 Specialized or primary palliative care physicians' reported opinions on referral timing.

Item	**Specialized**	**Primary**	
	n=257	**n=274**	**p-value**
	n (%)	***n (%)***	
Ideal referral timing for cancer patients			
Early	229 (93.9)	239 (91.2)	0.262
Late	15 (6.1)	23 (8.8)	
Ideal referral timing for non-cancer patients			
Early	222 (90.2) [a]	213 (81.3) [b]	0.004
Late	24 (9.8) [a]	49 (18.7) [b]	
Late referral timing for cancer patients			
At 2 weeks prognosis	64 (25.3)	56 (21.3)	0.621
At 1 month prognosis	84 (33.2)	91 (34.6)	
At 3 months prognosis	57 (22.5)	69 (26.3)	
At 6 months prognosis	48 (19.0)	47 (17.9)	
Late referral timing for non-cancer patients			
At 2 weeks prognosis	58 (23.0)	57 (21.8)	0.794
At 1 month prognosis	75 (29.8)	71 (27.1)	
At 3 months prognosis	56 (22.2)	67 (25.6)	
At 6 months prognosis	63 (25.0)	67 (25.6)	

Note: Superscripts *a* and *b* denote a significant difference across the column proportions for physicians providing specialized and primary palliative care using a z-test. We used 2 x n contingency tables and $\chi 2$ tests to assess significant association between providing specialized or primary palliative care. "Early" was categorized as ideal first referral to palliative care: at prognosis >6 months, upon diagnosis of cancer/life-limiting illness, or upon diagnosis of incurable cancer. "Late" was categorized as ideal first referral at a prognosis of: less than 1 week, 1 week – 1 month, 1-2 months, or 3-6 months. Numbers may not add up to totals due to missing responses for individual items. All expected cell counts were greater than five unless stated.

Differences between specialized and primary palliative care physicians' opinions and attitudes were analyzed using the Mann-Whitney U test (See Appendix A2). Most opinion and attitudinal factors had significantly different distributions between specialized and primary palliative care physicians ($p<0.05$). Physicians scored their attitudes on a five point Likert scale, strongly disagree to strongly agree. Physicians providing specialized palliative care scored significantly higher when responding to statements: "Involvement of palliative care teams 6-24 months prior to the end of life improves patients' quality of life"; "Involvement of palliative care teams 6-24 months prior to the end of life has a survival benefit"; and "It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient's primary disease". In contrast, physicians providing primary palliative care scored significantly higher than specialized palliative care physicians when responding to the statements: "Palliative care teams should only be involved in the last few weeks of life"; "Patients should have stopped all chemotherapy before referral to palliative care"; "Hematology patients should have stopped all transfusions before referral to palliative care"; "Patients without symptoms do not need palliative care before the last few weeks of life"; "The specialty of palliative care should be renamed supportive care"; and "Patients would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care". Physicians who provide specialized vs. primary palliative care did not differ in their attitudes regarding the statements: "Patients have a negative perception of the term palliative care" and "Referring physicians would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care".

6.3 Specialized palliative care physicians opinions about early palliative care

While 55.7% (143/256) of physicians practicing specialized palliative care agreed or strongly agreed that they had sufficient resources to provide high-quality palliative care 6-24 months prior to the end of life, 33.8% (87/256) strongly disagreed or disagreed (Table 23).

Table 23 Specialized palliative care physicians' opinions of the sufficiency of resources to provide early palliative care.

SCALE				
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
n (%)				
I have sufficient resources in my palliative care practice to provide high-quality palliative care 6 – 24 months prior to the end of life				
25 (9.7)	62 (24.1)	26 (10.1)	84 (32.7)	59 (23.0)

Note: Numbers may not add up to total 531 due to missing responses for individual items.

For a subset of statements regarding the scope and benefits of palliative care, specialized physicians were asked to rate separately their opinions for patients with cancer and those without cancer (Table 24). Responses for patients with cancer vs. those without did not differ substantially. The large majority of palliative care physicians agreed that for both groups, the involvement of palliative care teams 6-24 months prior to the end of life improved patients' quality of life with a larger number of neutral responders to the statement that it "has a survival benefit". For both groups, less than 10% agreed with the statement, "Palliative care teams should only be involved in the last few weeks of life". Specialized palliative care physicians were divided regarding the statement "It is the responsibility of the referring physicians to manage complications related to the treatment of a shared patient's primary disease". Similarly there were variable responses to the question of whether the specialty of palliative care should be renamed "supportive care", with approximately 50% opposed, 30% neutral, and 20% in favour.

Table 24 Specialized palliative care physicians' opinions of the scope and benefits of early palliative care.

	SCALE				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
n (%)					
Involvement of palliative care teams 6-24 months prior to the end of life improves patients' quality of life					
Cancer	2 (0.8)	1 (0.4)	8 (3.2)	48 (19.2)	191 (76.4)
Non-Cancer	2 (0.8)	2 (0.8)	15 (5.9)	58 (22.7)	178 (69.8)
Involvement of palliative care teams 6-24 months prior to the end of life has a survival benefit					
Cancer	4 (1.6)	8 (3.2)	53 (21.2)	82 (32.8)	103 (41.2)
Non-Cancer	5 (2.0)	8 (3.2)	90 (35.7)	79 (31.3)	70 (27.8)
Palliative care teams should only be involved in the last few weeks of life					
Cancer	182 (72.8)	50 (20.0)	4 (1.6)	2 (0.8)	12 (4.8)
Non-Cancer	159 (62.8)	59 (23.3)	18 (7.1)	6 (2.4)	11 (4.3)
It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient's primary disease					
Cancer	26 (10.4)	53 (21.3)	61 (24.5)	79 (31.7)	30 (12.0)
Non-Cancer	25 (9.9)	51 (20.2)	61 (24.1)	82 (32.4)	34 (13.4)
The specialty of palliative care should be renamed supportive care					
Cancer	82 (32.8)	50 (20.0)	67 (26.8)	32 (12.8)	19 (7.6)
Non-Cancer	84 (32.9)	46 (18.0)	68 (26.7)	37 (14.5)	20 (7.8)

Note: Numbers may not add up to total 531 due to missing responses for individual items.

We also assessed the general attitudes and opinions of physicians providing palliative care regarding early palliative care. First, they were asked about their opinions relating to palliative care referral criteria (Table 25A). The majority of specialized palliative care physicians disagreed or strongly disagreed with the statements, "Patients should have stopped all chemotherapy before referral to palliative care"; "Hematology patients should have stopped all blood transfusions before referral to palliative care"; and "Patients without symptoms do not need palliative care before the last few weeks of life".

Second, physicians were asked what, in their view, were the perceptions of referring physicians and patients to the name palliative care (Table 25B). More than half of the physicians reported that they agreed or strongly agreed that “Patients have a negative perception of the term palliative care”. Further, a little more than a third agreed or strongly agreed that patients (35.5% [91/256]) and referring physicians (38.6% [99/256]) would feel more comfortable with referral to palliative care 6 – 24 months prior to the end of life if it were renamed supportive care.

Lastly, specialized physicians were asked their opinions regarding statements that were of specific importance to specialized palliative care physicians; thus, these statements were not asked to primary palliative care physicians (Table 25C). Specially, specialized palliative care physicians were asked if they were comfortable caring for patients who are full resuscitation, 65.8% (167/254) agreed or strongly agreed that they were. Regarding the nature of their relationship with referring physicians, 47.6% (120/252) of specialized palliative care physicians agreed or strongly agreed that “Referring physicians tend to refer late to my palliative practice”; however, 63.8% (162/254) reported that once they are following a patient for palliative care that the referring physician does not stop seeing that patient. Finally, 61.5% (155/ 252) of physicians providing specialized palliative care did not prefer a model of care in which they completely take over palliative care from the referring physician.

Table 25 Attitudes and opinions of 257 physicians providing specialized palliative care regarding the scope and benefits of early palliative care.

SCALE				
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
A.		***n (%)***		
Patients should have stopped all chemotherapy before referral to palliative care				
128 (50.0)	103 (40.2)	15 (5.9)	5 (2.0)	5 (2.0)
Hematology patients should have stopped all transfusions before referral to palliative care				
133 (52.0)	92 (35.9)	16 (6.3)	9 (3.5)	6 (2.3)
Patients without symptoms do not need palliative care before the last few weeks of life				
99 (38.7)	119 (46.5)	21 (8.2)	16 (6.3)	1 (0.4)
B.		***n (%)***		
Patients would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care				
29 (11.3)	43 (16.8)	93 (36.3)	70 (27.3)	21 (8.2)
Referring physicians would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care				
21 (8.2)	46 (18.0)	90 (35.2)	82 (32.0)	17 (6.6)
Patients have a negative perception of the term palliative care				
3 (1.2)	38 (14.8)	63 (24.6)	125 (48.8)	27 (10.5)
C.		***n (%)***		
I am comfortable caring for patients who are full resuscitation				
11 (4.3)	36 (14.2)	40 (15.7)	85 (33.5)	82 (32.3)
Once I am following a patients for palliative care, the referring physician stops seeing the patient				
48 (18.9)	114 (44.9)	39 (15.4)	39 (15.4)	14 (5.5)
Referring physicians tend to refer late to my palliative practice				
1 (0.4)	46 (18.3)	85 (33.7)	95 (37.7)	25 (9.9)
I prefer a model of care in which I completely take over palliative care from the referring physician				
69 (27.4)	86 (34.1)	53 (21.0)	30 (11.9)	14 (5.6)

Note: Numbers may not add up to total 531 due to missing responses for individual items.

6.3 Factors associated with receiving “early” referrals for palliative care among physicians practicing specialized palliative care

Palliative care physicians who provided specialized palliative care were asked, “What is the approximate average survival time of the patients for whom you provide palliative care?” Specialized palliative care physicians’ responses were categorized as receiving “early” vs. “late” referrals for palliative care. Physicians who responded “7 months – 12 months” or “more than 1 year” were categorized as receiving “early” referrals for their palliative services. Conversely, physicians who responded “2 weeks or less”, “3 weeks to 2 months”, or “3 months to 6 months” were categorized as receiving “late” referrals. Only 20.5% (52/254) of specialized palliative care physicians reported receiving “early” referrals for their palliative services (Fig. 6).

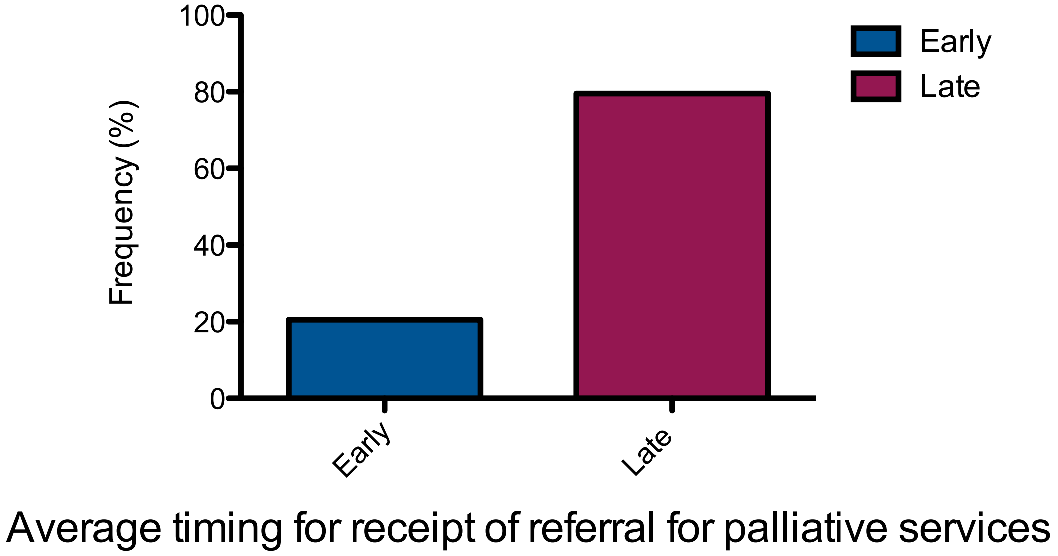


Figure 6 Average timing of receipt of referral for palliative services, as determined by approximate average survival time of patients referred to specialized palliative care physicians palliative practice.

Univariable analysis was performed using 2 x *n* contingency tables and χ^2 tests to compare demographic characteristics of physicians practicing specialized palliative care who received early vs. late referrals for palliative care (See Appendix A3). Similarly, attitudinal factors were analyzed using the non-parametric Mann-Whitney U test. Based on univaraible analysis (entry $p \leq 0.2$) and our understanding of the research aims, demographic and attitudinal items were selected for entry into the multivariate model.

Demographic items (Table 26) entered into the model were: having a Masters or a PhD; location of most recent palliative training; sex; age; pediatric or adult palliative care provided; provided 24-hour-on-call service; proportion of palliative care provided for cancer or non-cancer patients; providing palliative care in a long-term care/nursing home, palliative care unit, outpatient ambulatory palliative care clinic, or other (e.g. emergency room). Attitudinal items (Table 27) entered into the model were: “Patients should have stopped all [chemotherapy/ transfusions] before referral to palliative care”; Patients without symptoms do not need palliative care before the last few weeks of life”; “I am comfortable caring for patients who are full resuscitation”; “Once I am following a patient for palliative care, the referring physician stops seeing the patient”; for patients with a cancer and non-cancer diagnosis, “Palliative care teams should only be involved in the last few weeks of life”, for only patients with a non-cancer diagnosis; “It is the responsibility of referring physicians to manage complications related to the treatment of a shared patient’s primary disease”; and “Involvement of palliative care teams 6-24 months prior to the end of life improves patients’ quality of life”. Backwards likelihood ratio was used to select covariates for the multivariate model.

Table 26 Demographic items of specialized palliative care physicians entered into the multivariable model.

N=257	Late n=202 (79.5)	Early n=52 (20.5)	p-value
	***n* (%)**		
Completed a Masters or a PhD			
NO	140 (74.9)	26 (55.3)	0.008
YES	47 (25.1)	21 (44.7)	
Most recent palliative care training			
In Canada	171 (91.9)	37 (77.1)	0.004
Outside Canada	15 (8.1)	11 (22.9)	
Sex			
Male	104 (51.7)	21 (40.4)	0.114
Female	97 (48.3)	31 (59.6)	
Age			
20-39 years	43 (21.4)	9 (17.3)	0.688
40-59 years	117 (58.2)	30 (57.7)	
60+	41 (20.4)	13 (25.0)	
Type of patients palliative services are provided for			
Adults greater than (=) 18 years old	198 (98.5)	42 (80.8)	<0.001†
Children less then18 years old	3 (1.5)	10 (19.2)	
Provide a 24-hour on-call service for your patients receiving palliative services			
NO	23 (11.5)	12 (23.1)	0.032
YES	177 (88.5)	40 (76.9)	
Proportion of the palliative care provided for CANCER patients			
50% or less	23 (11.4)	17 (33.3)	<0.001
51-100%	179 (88.6)	34 (66.7)	
Workplace setting			
Long-term care facility/nursing home	70 (34.7)	12 (23.1)	0.111
Palliative care unit	115 (56.9)	21 (40.4)	0.033
Outpatient ambulatory palliative care clinic	62 (30.7)	21 (40.4)	0.184
Other	21 (10.4)	9 (17.3)	0.168

Note: We used 2 x n contingency tables and χ2 tests to assess significant association between specialized palliative care physicians receiving early vs. late referrals. "Early" was categorized as ideal first referral to palliative care: at prognosis >6 months, upon diagnosis of cancer/life-limiting illness, or upon diagnosis of incurable cancer. "Late" was: less than 1 week, 1 week – 1 month, 1-2 months, or 3-6 months. † Expected cell count less than five Exact Test preformed.

Table 27 Opinion and attitudinal items of specialized palliative care physicians entered into the multivariable model.

N=257	Late n=202 (79.5)	Early n=52 (20.5)	p-value
	Mean Rank (Mann-Whitney Test)		
Palliative care teams should only be involved in the last few weeks of life			
For Cancer	126.63	114.15	0.152
For Non-cancer	128.07	115.72	0.202
It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient’s primary disease			
For Non-cancer	128.20	114.98	0.230
Involvement of palliative care teams 6-24 months prior to the end of life improves patients’ quality of life			
For Non-cancer	124.23	135.23	0.228
Patients should have stopped all chemotherapy before referral to palliative care			
	135.45	94.33	<0.001
Hematology patients should have stopped all transfusions before referral to palliative care			
	133.13	103.32	0.004
Patients without symptoms do not need palliative care			
	129.54	117.18	0.237
I am comfortable caring for patients who are full resuscitation			
	120.94	145.36	0.025
Once I am following a patient for palliative care, the referring physician stops seeing the patient			
	129.65	112.05	0.100

Note: We used the Mann-Whitney U test to assess significant differences between specialized palliative care physicians receiving early vs. late referrals. “Early” was categorized as ideal first referral to palliative care: at prognosis >6 months, upon diagnosis of cancer/life-limiting illness, or upon diagnosis of incurable cancer. “Late” was categorized as: less than 1 week, 1 week – 1 month, 1-2 months, or 3-6 months. Physicians rated attitudinal items on a five point Likert scale from strongly disagree to strongly agree.

Logistic regression was performed on the sample of 257 specialized palliative care physicians who responded to the question asking what the average survival time of their patients referred to them for palliative services was. The logistic regression model was statically significant, χ^2 (5) = 40.218 and p<0.0001. The model correctly classified 82.6% of cases. Using the Hosmer and Lemeshow goodness of fit test it could be determined that the model was a good fit (p = 0.659). Factors included in the final multivariable model were: having a graduate degree such as a Masters or a PhD; sex; primarily seeing adult palliative patients; proportion of palliative care provided for cancer patients; and physicians' opinions regarding whether patients should have stopped all chemotherapy before referral to palliative care

Of the five factors, four reached statistical significance in the multivariable model (Table 28). Having a postgraduate degree (OR 2.5, 95% CI 1.1-5.5); providing care mainly for patients without cancer (OR 4.0, 95% CI 1.3-12.3); and female sex (OR 2.7, 95% CI 1.2-6.2) were associated with receiving early referrals for palliative care. Those agreeing that patients should have stopped all chemotherapy before palliative care referral were less likely to receive early referrals for palliative care (OR 0.34, 95% CI 0.16-0.73).

Table 28 Logistic regression: factors associated with physicians receiving early referrals for their palliative services.

	B	***SE***	***Wald***	***df***	**p-value**	***Odds ratio***	**95% Confidence Interval**	
Characteristic							***Lower***	***Upper***
Postgraduate degree ***No postgraduate degree (reference group)*** ***Master's and or PhD***	*0.907*	*0.411*	4.871	1	0.027	2.478	1.107	5.547
Sex ***Male (reference group)*** ***Female***	*1.020*	*0.420*	5.906	1	0.015	2.774	1.218	6.317
Adult vs. pediatric palliative care ***Adult (reference group)*** ***Pediatric***	*1.596*	*0.863*	3.420	1	0.064	4.935	0.909	26.794
Proportion of palliative care provided to cancer patients ***51% + (reference group)*** ***50% or less***	*1.395*	*0.568*	6.023	1	0.014	4.035	1.324	12.293
Patients should have stopped all chemotherapy before referral to palliative care	*1.066*	*0.386*	7.613	1	0.006	0.344	0.161	0.734

Chapter 7: Discussion

There were three aims of this study. First, we aimed to describe the practices, attitudes and opinions regarding early palliative care among physicians who provided palliative care in Canada. Secondly, we aimed to determine differences in these practices, attitudes and opinions among physicians who were practicing specialized palliative care vs. those who were practicing primary palliative care. Third, we aimed to identify characteristics of specialized palliative care physicians who received early vs. late referrals. We hypothesized that physicians who provided palliative care in Canada would have favorable attitudes about early palliative care; that a lack of resources would be identified as a major barrier to the provision of early palliative care; that physicians would have a more favorable attitude towards the provision of early palliative care for patients with cancer than those without; and that specialized palliative care physicians who reported receiving early referrals for palliative care would be those who were younger, have had specialized training, worked in palliative care teams, and had sufficient resources to provide early palliative care.

7.1 Physicians practicing palliative care in Canada: primary versus specialized palliative care

To our knowledge, there have been no other studies that have described physicians who provide palliative care in Canada, with the exception of the *National Palliative Medicine Survey* conducted by the Canadian Society of Palliative Physicians (CSPCP), which was not published in the medical literature (Human Resources Committee of the Canadian Society of Palliative Care Physicians, 2015). We were able to distinguish two succinct groups of physicians who provided palliative care in Canada: those who received referrals from others for specialized palliative care (48.4%) and those who provided primary palliative care as part of their practice (51.6%). Similar results were found in the CSPCP survey: just over 50% of physicians in that survey were specialized or focused in palliative medicine. In our study, most physicians who provided palliative care in Canada were certified in family medicine, but physicians were also certified in other fields, including oncology, internal medicine, and anesthesiology. Our results highlight that palliative care in Canada is provided by a diverse group of physicians, who provide palliative care in different capacities, as either specialized or primary palliative care physicians.

7.1.1 Characteristics and practices of physicians providing primary versus specialized palliative care

The early integration of specialized palliative care with primary and secondary care, such as family doctors and oncologists, has been shown to improve patients' quality of life, symptom control, satisfaction with care, and mood (Bakitas et al., 2009; Temel et al., 2010; Zimmermann et al., 2014). Our study demonstrated that these two groups practice palliative care in different ways. A larger proportion of specialized palliative care physicians were male (50 vs. 36%); worked in urban areas (94 vs. 76%) and academic centres (48 vs. 26%); worked as full-time physicians (88 vs. 79%). As well, they were more likely to spend more than 50% of their clinical time practicing palliative care (47 vs. 2%); to see > 20 unique palliative care patients per month (45.7 vs. 4.4%); to provide a 24-hour on call service for their palliative care patients (86 vs. 68%); and to work as part of a palliative care team (82 vs. 17%). Furthermore, our results showed that a larger proportion of specialized palliative care physicians provided palliative care in hospices (34 vs. 14%), palliative care units (54 vs. 15%), inpatients and outpatient palliative clinics (67 vs. 12%), and in home care (65 vs. 45%). In contrast, primary palliative care physicians commonly provided palliative care in private offices (57 vs. 31% for specialized palliative care) and other settings such as emergency rooms (33 vs. 12%). Physicians practicing specialized palliative care also tended to provide a greater proportion of care for patients with cancer (84 vs. 65%), while only 5% of physicians in both groups stated that they provided palliative care for pediatric patients. Specialized palliative care physicians did not differ from primary palliative care physicians in their age; graduate education (Master's degree or PhD); or where they trained in palliative care (inside or outside Canada); or which province they practiced palliative care in.

These results are consistent with previous reports that specialized palliative care is provided mainly for adults with cancer (Human Resources Committee of the Canadian Society of Palliative Care Physicians, 2015), with most services concentrated in urban areas (Robinson et al., 2009). It is important that specialized palliative care expand beyond the cancer population and also provide support for physicians providing primary palliative care in rural environments ((Johnson et al., 2011; Mitchell, 2002). In the latter group, more use could be made of consultations over the telephone (Bakitas et al., 2009) or by web portal. Our results also highlighted that physicians providing primary palliative care tend not to provide 24-hour on call services and are less likely to work as part of a larger team. In a UK study, the larger the collaborative network primary palliative care physicians were a part of the greater they felt palliative care was an important part of their role as care providers (Burt, Shipman, White, & Addington-Hall, 2006). Further, a study in the Holland showed that patients of primary care physicians who provided after-hour call services had fewer unnecessary hospital admissions (De Korte-Verhoef et al., 2012). Neither group was likely to provide care for pediatric patients, which remain an underserved group for palliative care (Rapoport, 2009).

In order for early palliative care to be possible, several conditions of practice are necessary. These include palliative care specialists seeing patients in outpatient settings, rather than only in inpatient, hospice, and home settings and collaboration between primary care physicians and specialized palliative care physicians. In our study, only 33% of specialized palliative care physicians practiced in outpatient palliative care clinics, and less than half of the overall group surveyed had access to such a clinic. These clinics tend to be more developed in oncology settings (Hannon et al., 2015), while few have been developed for patients outside oncology (Rabow, Smith, Braun, & Weissman, 2010). Further development of palliative care clinics, including in non-oncology and pediatric settings, will be necessary to support the expansion of early palliative care into territory outside the traditional realm of adult cancer care.

Due the high volume of patients seen by specialized palliative care physicians and the limited amount of time available, specialized palliative care physicians are best aligned to care for patients with complex and unmanaged palliative care concerns (Ferris et al., 2009). It is therefore paramount that specialized and primary palliative care physicians work collaboratively (Cancer Care Ontario, 2009). A model of palliative care that integrates primary palliative care with specialized palliative care is encouraged in Canada by the CHPCA, and also by the WHO and the American Society of Clinical Oncology (ASCO); however the degree of integration is variable (CHPCA, 2013; Rubin et al., 2015; T. J. C. B. Smith et al., 2012; World Wide Palliative Care Alliance, 2014). Our results suggest that primary palliative care physicians were not well integrated into a multidisciplinary palliative care team but instead provided palliative care in silos. A clinical framework, such as the one outlined and discussed by Hui & Bruera, should be used to better integrate palliative care by optimizing clinical infrastructure, processes, education, and research (Hui & Bruera, 2015). Hallmarks of successful integration include routine symptom screening and standardized referral criteria; combined palliative and oncology rounds and embedded clinics; renaming palliative care to supportive care; mandatory palliative care education for cancer specialists and combined training activities for palliative care physicians and oncologists. Further, the framework details a clinical structure that encourages early patient referrals to outpatient clinics composed of a comprehensive multidisciplinary team. It is important to note that this framework was specifically designed around integrating palliative care into standard cancer care. A European systematic review of the literature on the integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease (COPD) concluded that while the literature supports a needs for integrated palliative care for patients with a non-cancer diagnosis, the development of a standardized framework for this population has yet to have been developed (Siouta et al., 2016).

Limited resources may also play a significant role in building well-integrated teams. About a third of all physicians providing palliative care, specialized and primary palliative care physicians, in our study felt that they did not have sufficient resources to provide early palliative care. One area where limited resources have had a significant impact on the feasibility of an integrated palliative care model is in rural communities. A qualitative study in Canada, which conducted focus groups in seven provinces, concluded that rural communities often function by doing with what they have with regards to resources (Kelley, 2006). Specifically, rural physicians providing palliative care were cited as feeling that that they provided palliative care with a very limited number of of other palliative care physicians, which they also struggled to retain, with a limited number of facilities in which to provide palliative care. Similarly, in a comprehensive review of rural palliative care, a lack of resources was cited as a significant barrier to high-quality rural palliative care (Robinson et al., 2009).

7.1.2 Relationships among specialized palliative care physicians and referring physicians

Although not all physicians who provide palliative care work in palliative care teams, in our study those who did were generally satisfied with their relationships with each other and with referring physicians. Specifically, of the physicians who worked in a palliative care team and received palliative care referrals, 71% were satisfied or very satisfied with their professional relationships with referring physicians, 91% with their relationships with other palliative care physicians, and 92% with other palliative care team members. Other studies have shown that referring physicians also feel positively about their relationship with palliative care colleagues once they are involved. In one study, 83% of referring physicians agreed that specialized palliative care supported them in providing care for their patients (Johnson et al., 2008). Although in our study the level of satisfaction was high overall, a larger proportion of physicians providing palliative care were satisfied with their relationships with other palliative care physicians and team members than they were with their relationships with referring physicians.

Despite the positive sentiments on both sides about collaborative care, studies of American, Australian, and European oncologists have suggested that less than one third of oncological teams collaborate with specialized palliative care (Johnson et al., 2008; Cherny & Catane, 2003). In our study, palliative care physicians reported greater collaboration than that reported in the literature. Approximately, 64% of specialized palliative care physicians reported that once they were following the patient, the referring physician did not stop seeing the patient. Furthermore, specialized palliative care physicians in our study preferred a collaborative palliative care model with referring physicians. More than 60% of specialized palliative care physicians preferred a model of care where they did not completely take over palliative care from the referring physician.

While our results show that there is still work to be done to foster better relationships between physicians providing palliative care and referring physicians, overall specialized palliative care physicians appear to have a favorable opinion of their interactions with referring physicians, which is essential to an early palliative care model. Both referring physicians and specialized palliative care physicians play an important role in providing palliative care to patients. In a qualitative study in the United States, oncologists reported that they felt that palliative care was an important part of their role as physicians; thus, a thoughtful and well-designed early palliative care program that encourages and facilitates collaborations is needed (Schenker et al., 2014). As well, in the early palliative care model described by Zimmermann et al., (2014), increased proximity through shared clinics spaces with oncologist and palliative care physicians facilitated collaboration.

7.1.3 Education in palliative care and provision of early palliative care

Palliative care education has been cited in the literature as an important means to promote early palliative care. In one study, only 48% of referring physicians believed they were well trained to care for the symptoms of patients with advanced cancer (Johnson et al., 2008). In another, oncologists who had completed a rotation in palliative care as part of their training were more likely to refer early to specialized palliative care (Wentlandt et al., 2012). Lack of education in palliative care has also been cited as a barrier to the provision of primary palliative care (Rubin et al., 2015). Primary palliative care physicians tend to lack confidence in their skills to provide palliative care (Mitchell, 2002), and would benefit from more formal palliative education (Rubin et al., 2015), as well as mentorship from specialized palliative care physicians. However, our study has highlighted that in Canada, improved education in palliative care is also necessary for physicians practicing specialized palliative care. Only 25% of physicians providing specialized palliative care reported having completed accredited postgraduate training or a year of added competence in palliative medicine.

In Canada, the lack of formal palliative care education among physicians practicing palliative care is in large part due to the late development of specialized training programs in this area. It was only in 2000 that a one-year conjoint program in palliative care began, which was jointly accredited by the Royal College and the CFPC (Monette, 2012). This program is stated after completing postgraduate training in family medicine or internal medicine. Since 76% of physicians providing palliative care in our study had been practicing palliative medicine for 6 or more years, most would not have had the opportunity to receive specialized training in palliative care, unless they acquired it outside of Canada. With the palliative medicine subspecialty program starting in July 2017, a new cohort of specialized palliative care physicians will be trained in Canada (Royal College of Physicians and Surgeons of Canada, 2014). This should offer greater access to palliative care across Canada, including for patients at earlier stages of their disease. Education in palliative medicine should also be more deeply incorporated into existing medical education and across specialties. Increased and improved education in palliative medicine at all levels of care will not only increase skill competencies in providing palliative care; it will also help increase understanding of the role of palliative care and of the benefits it provides to patients.

7.1.4 Early palliative care and perceptions of the name palliative care

In our study, 57% of physicians who provided palliative care reported that they felt that patients had a negative perception of the term palliative care. This is greater than the 43% of Canadian oncologists who stated that their patients perceived the term palliative care negatively in another study (Wentlandt et al., 2012). The literature suggests that patients often incorrectly understand palliative care to only be applicable at the very end of life when no other options are available to them (Miyashita et al., 2008; Zimmermann et al., 2016). Improved patient understanding of the role and benefits of palliative care may reduce the degree to which patients receiving palliative care feel stigmatized (Zimmermann et al., 2016).

Research has also suggested that changing the name palliative care to something less stigmatizing such as “supportive care” may be one possible solution (Dalal et al., 2011; Fadul et al., 2009; Morstad Boldt et al., 2006; Zimmermann et al., 2016). Patients with advanced cancer perceived the name supportive care more favorably, perceived a greater need for such services, and had a better understanding of palliative care when it was instead called supportive care (Maciasz et al., 2013). Almost 40% of physicians providing palliative care in our study stated that they felt referring physicians and patients would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care. Furthermore, a large minority, approximately a third, of physicians who provided palliative care in our study reported that they felt that the specialty of palliative care should be renamed supportive care. These results, as well as those in other literature, demonstrate that changing the name of palliative care may improve early referral to palliative care (Dalal et al., 2011; Fadul et al., 2009; Maciasz et al., 2013; Zimmermann et al., 2016).

7.3 Attitudes about early palliative care among physicians providing specialized versus primary palliative care

Our results demonstrated that both physicians who provided primary palliative care, as well as specialized palliative care physicians, overwhelmingly believed that patients with or without cancer should be referred early to palliative care (at prognosis >6 months, upon diagnosis of cancer/life-limiting illness, or upon diagnosis of incurable cancer). However, compared to specialized palliative care physicians, a larger proportion of primary palliative care physicians reported that late referral timing was most ideal for patients without cancer (19 vs. 10% of specialized palliative care physicians). There was no difference in the reported ideal referral timing between specialized and primary palliative care physicians for patients with cancer.

Surveys in the United States and Canada have reported that referring physicians are also in favour of early referral to specialized palliative care (Ogle et al., 2002; Wentlandt et al., 2012). In one survey, 71% percent of referring physicians, including oncologists, hematologists, respirologists, and colorectal surgeons, agreed that patients should be referred early and 92% agreed that patients would benefit from specialized palliative care services while still receiving disease-modifying therapies (e.g. chemotherapy) (Johnson et al., 2008).

Despite the preference for early referrals among specialized palliative care physicians in our survey, the majority still reported receiving late referrals. Only 21% of specialized palliative care physicians stated that they received early referrals for palliative care (at prognosis >6 months, upon diagnosis of cancer/life-limiting illness, or upon diagnosis of incurable cancer) and almost 50% agreed or strongly agreed that referring physicians tended to refer late to their palliative practice. Our results are consistent with the reported referral practices of Canadian oncologists; in a previous survey, 83% reported that they typically referred patients at a prognosis of <6 months (Wentlandt et al., 2012).

We also asked about opinions regarding the rationale for early palliative care. The majority of physicians providing palliative care agreed or strongly agreed that for both patients with (94%) and without cancer (90%), the involvement of palliative care teams 6-24 months prior to the end of life improved patients' quality of life. Similarly, for both patients with and without cancer the majority disagreed or strongly disagreed that palliative care teams should only be involved in the last few weeks of life (91% and 84%, respectively). Physicians also tended to disagree or strongly disagree that patients without symptoms do not need palliative care before the last few weeks of life. Our results support our hypothesis that physicians who provide palliative care in Canada are heavily in support of an early palliative care model. Furthermore, our results show that physicians providing palliative care are in alignment with the WHO definition of palliative care, that palliative care should begin early and aim to improve the quality of life of patients with a life-threatening illness.

Three RCTs that evaluated patient benefits from early palliative care for quality of life, symptom control, and mood, reported an association between early palliative care and improved patient survival (Bakitas et al., 2015; Temel et al., 2010), and one saw no difference (Bakitas et al., 2009). Physicians in our study were less sure of the survival benefit of early palliative care for patients with cancer, with approximately one third being neutral, agreeing, or strongly agreeing with this statement. Furthermore, almost 10% more physicians were neutral regarding a survival benefit for patients without cancer (7% disagreed and 53% agreed). The WHO operationalized palliative care as neither hastening nor postponing death (WHO, 2014). Moreover, there is little understanding about the possible mechanisms for the association of a survival benefit with early palliative care (Pirl et al., 2012), and there is as yet no research in this area in patients without cancer, further research is indicated before firm conclusions can be drawn.

Other attitudes and opinions about the provision of early palliative care did significantly differ amongst specialized and primary palliative care physicians. While primary palliative care physicians also agreed, physicians providing specialized palliative care agreed significantly more when responding to the statements, “Involvement of palliative care teams 6-24 months prior to the end of life improves patients’ quality of life”; “Involvement of palliative care teams 6-24 months prior to the end of life has a survival benefit”; and “It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient’s primary disease”. In contrast, physicians providing primary palliative care agreed significantly more than specialized palliative care physicians when responding to the statements, “Palliative care teams should only be involved in the last few weeks of life”; “Patients should have stopped all chemotherapy before referral to palliative care”; “Hematology patients should have stopped all transfusions before referral to palliative care”; “Patients without symptoms do not need palliative care before the last few weeks of life”; “The specialty of palliative care should be renamed supportive care”; and “Patients would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care”. The formal role of tertiary specialized palliative care physicians is to be palliative care leaders that participate and engage in palliative care infrastructure, organization, research, and advocacy (Cancer Care Ontario, 2009). The differences in attitudes and opinions of specialized and primary palliative care physicians may be due to these characteristics of specialized palliative care physician resulting in their stronger subscription to an early palliative care philosophy.

Lastly, we hypothesized that early palliative care would be perceived more favorably for patients with cancer than those without. The majority of palliative care physicians in our study reported that most of the palliative care they provide was for patients with cancer. Furthermore, most palliative care studies have been designed around the needs of patients with cancer (Addicott, 2012). However, physicians overall supported an early palliative care model, whether it be for patients with or without cancer.

7.4 Factors associated with specialized palliative care physicians receiving early referrals

Our results showed that there were four factors that were significantly and independently associated with specialized palliative care physicians receiving early referrals for palliative care: having a graduate degree, female sex, providing a larger proportion of palliative care for patient without cancer, and disagreeing with the statement that patients should have stopped all chemotherapy before referral to palliative care. Although previous studies have evaluated factors associated with referring physicians providing early referrals to palliative care (C E Johnson et al., 2008; Wentlandt et al., 2012), this is the first study to evaluate factors associated with receiving early referrals for specialized palliative care.

Specialized palliative care physicians with a Master's degree and/or a PhD were 2.5 times more likely to receive early referrals for palliative care. As discussed above, limited postgraduate medical education in palliative medicine is known to be a substantial barrier to the provision of specialized and primary palliative care (Hui, Elsayem, et al., 2010; Johnson et al., 2008; Mullan et al., 2002). However, no research has been done regarding the impact of graduate education in the provision of palliative care. A considerable minority of specialized palliative care physician in our study (almost one third), reported having completed a Master's degree or a PhD. Cancer Care Ontario's Regional Model of Hospice Palliative Care has outlined the roles of primary, secondary, and tertiary palliative care; the specific role of tertiary specialized palliative care physicians was described to include research as well as advocacy for improved palliative care strategies (Cancer Care Ontario, 2009). Individuals with graduate education may be more likely not only to conduct research but also to advocate for and practice in a manner that is supported by evidence from clinical trials, including allowing and perhaps soliciting referrals for early palliative care.

There is also limited understanding of how a physician's sex may influence receiving early referrals for palliative care. Female specialized palliative care physicians in our study were 2.8 times more likely to report receiving early referrals for palliative care. Other studies have found similar results among referring physicians: in previous studies, female oncologists were more likely to refer to specialized palliative care (Johnson et al., 2008) and were more likely to refer at a prognosis greater than 6 months (Wentlandt et al., 2012). Additionally, female oncologists were more likely to state that ideally patients should be referred early to palliative care (Wentlandt et al., 2012). No studies have evaluated a mechanism for an individual's sex to be associated with receiving or providing earlier referrals to palliative care. However, it is possible that characteristics of female specialized palliative care physicians may play a significant role in their receiving early referrals. One study in the United States showed that female physicians engaged in more collaborative behavior and information giving, including biomedical and psychosocial information, than males (Roter et al., 1991). These characteristics, which closely align with the philosophy of early palliative care, may also contribute to our findings.

The proportion of palliative care provided for patients without cancer was also significantly associated with specialized palliative care physicians receiving early referrals. Specialized palliative care physicians who reported they provided more palliative care for patients without cancer were 4 times more likely to state that they received early referrals. Patients with heart failure or chronic obstructive pulmonary disease (COPD) may have periodic episodes of exacerbated symptoms interspersed with period of relatively good health, in contrast to the gradual continuous decline that is common in patients with cancer (Gadoud & Johnson, 2015). Thus prognosis may be variable and these patients may live longer while receiving symptom-related treatment for exacerbations related to their disease. Furthermore, specialized palliative care physicians may be more integrated with the primary and secondary care of patient without cancer because the management of their symptoms often relates closely to the management of the disease itself. The management of end-stage non-cancer patients demands integrated care, from early on often all the way to the very time of death, in order to manage complex symptoms, medications, and devices, such as pace makers, specific to their disease (Goodlin, 2009).

Relatedly, unlike in cancer, there is no "curative" treatment for many non-cancer diseases such as heart failure and COPD. Thus the divide between "curative" and "palliative" treatment and the (often factitious) "transition" from curative to palliative care does not exist for most advanced non-cancer illnesses.

Another factor that was associated with receiving early referrals was whether or not the physician agreed that patients should have stopped all chemotherapy before referral to palliative care. Most specialized palliative care physicians disagreed that patients should have stopped all chemotherapy and transfusions before referral to palliative care. However, the more a specialized palliative care physician agreed that patients should have stopped all chemotherapy before referral to palliative care the less likely they were to receive early referrals. These results are in keeping with those of a survey of Canadian oncologists (Wentlandt et al., 2012). In that survey, one of the factors associated with oncologists referring at a prognosis of greater than 6 months was their reported access to specialized palliative care services that accepted patients receiving chemotherapy.

Our results also indicate possible reasons that some physicians may be reluctant to accept referrals for patients who are still receiving chemotherapy. Specialized palliative care physicians in our study reported somewhat mixed responses to the statement "It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient's primary disease". While approximately 50% disagreed or strongly disagreed, 20% were neutral, and 20% agreed or strongly agreed. Some specialized palliative care physicians may find it challenging to manage complications of chemotherapy such as neutropenia, nausea or bleeding. However, collaborative practice, with clear communication between treating physicians about who is responsible for what role, should allow the successful management of disease and treatment related symptoms in these patients.

Lastly, providing palliative care primarily for pediatric patients remained a factor in the final model associated with receiving early referrals, although it was not statistically significant. The lack of significance is likely in part due to the fact that only 5% of specialized palliative care physicians provided palliative care for pediatric patients. However, with a larger sample size it is possible there might have been a statistically significant association for this variable. The limited research that has been done to better understand the referral practices of pediatricians and pediatric oncologists to palliative care is consistent with the results of our survey. One study compared the referral practices of pediatric and adult oncologists and reported significant differences (Wentlandt et al., 2014). Pediatric oncologists were more likely than adult oncologists to report that their palliative services accepted patients on chemotherapy (64% compared to only 37%). As well, only 13% of pediatric oncologists reported that they tended to refer only after having stopped chemotherapy, compared to 29% of adult oncologists. Further, a majority of pediatric oncologists (73%) stated that ideally referral to palliative care should occur at the diagnosis of cancer/incurable cancer, compared to a minority of adult oncologists (43%). One study conducted in the United States evaluated pediatricians' perceptions of the preferred timing of palliative care referral. Their results demonstrated that for most illnesses including cancer that early referrals to palliative care were rarely the preference, less than 20% for most illnesses including cancer (Thompson et al., 2009). In the context of cancer specialists, both those making and those receiving referrals preferred early referral for pediatric patients. However, primary pediatric physicians very rarely preferred early referrals to palliative care, it is possible that cancer specialist in the Canadian study saw higher preferences for early palliative care due to increased access to palliative services; more than 80% of the pediatric oncologist worked in academic hospitals and cancer centers. While only 27% of Canadian pediatric oncologists had access to an outpatient palliative care clinic, almost 90% had access to a palliative care physician (Wentlandt et al., 2014).

We hypothesized that specialized palliative care physicians who reported receiving early referrals for palliative care would be those who were younger, have had specialized training, worked in palliative care teams, and had sufficient resources to provide early palliative care. While our study demonstrated that these characteristics play an important role in the successful integration of primary and specialized palliative care, which is paramount to the efficacy of early palliative care, they were not specifically the factors associated with specialized palliative care physicians receiving early referrals as hypothesized.

7.5 Implications

This study was the first to evaluate practices, attitudes and opinions regarding early palliative care among physicians providing palliative care. Although the large majority of physicians practicing palliative care in Canada were in strong support of a model providing early palliative care, most did not receive early referrals for their palliative services and close to one third stated they had insufficient resources to provide early palliative care. These results are consistent with those of previous surveys of referring physicians, and highlight the gap between policy and practice in this area. It is clear that important barriers still stand in the way of early referrals.

We were able to identify two distinct groups of physicians – those providing primary palliative care and those practicing specialized palliative care; both of these groups have an important role in the provision of early palliative care. Special attention should be made when implementing models for early palliative care across Canada to ensure that there are clear lines of communication between these two groups of physicians, as well as with other groups providing care for patients with advanced illness. Better efforts will need to be made to connect patients and their loved ones to collaborative early palliative care across Canada, closing the gap between rural and urban palliative care, and providing care for pediatric patients, as well as those without cancer. As well, developing programs in education for specialized palliative care physicians must be complemented by increased training for those providing primary palliative care. From a research perspective, investigators should be conscientious to keep patients without a cancer diagnosis in mind when developing studies in this area. Our results also suggest that from the point of view of physicians providing palliative care, the name palliative care is perceived as a barrier to early referrals. These results, which are supported by research with referring physicians and patients, suggest that education and advocacy may help inform the public and referring physicians about the benefits of early palliative care. At present it is unclear whether changing the name of palliative care to supportive care is necessary to improve patient access, or whether redefining palliative care and retaining its name could achieve the same result. Clearly, however, barriers such as lack of acceptance or lack of referral of patients who are still undergoing concurrent disease-related treatment must be removed in order for early palliative care to occur. As early palliative care becomes more viable across Canada, flexible referral criteria should be considered to improve patient access and increase early referrals.

7.6 Strengths and limitations

Like all studies, ours had strengths and limitations. Our survey was sent to 823 physicians practicing palliative care who agreed to be contacted for surveys when the CSPCP conducted their initial survey of palliative care physicians. Given that we did not have consent to send out our survey to the total list of 2,116 physicians who reported providing palliative care in the CSPCP study, our study may not be representative of the larger group of physicians who report providing palliative care in Canada. Furthermore, in order to be included in the CSPCP study, physicians had to be a member of the College of Family Physicians Canada and/or the Royal College of Physicians and Surgeons Canada. Membership in these organizations are not mandatory and thus those physicians who provide palliative care and who are not members would not have been included in their study or in ours, particularly if they were from Quebec, which has its own certification process. Therefore, the generalizability of our findings may be hindered. Lastly, the CSPCP's survey depended on self-report as to the question "Do you provide any palliative care"; physicians who did not perceive that the care that they provided was defined as palliative care would not have been included. Thus, non-response bias is an important limitation of this study.

There has been no validated survey developed to evaluate attitudes and opinions on the topic of early palliative care among physicians providing palliative care. Therefore the survey we designed was not prevalidated and might have missed questions that may also be important factors associated with specialized palliative care physicians receiving early referrals to palliative care. One strength of our survey was that we piloted it with 10 palliative care physicians from various palliative care settings, including home palliative care, long-term care, and acute care. Furthermore, the committee that contributed to the creation of the survey included an oncologist, a psychiatrist, and palliative care physicians with backgrounds in internal medicine and family medicine, who all provided questions and input from their diverse perspectives. An extensive literature review, of both qualitative and quantitative research, was performed to ensure an adequate comprehension of current relevant issues in early palliative care and palliative care in general. However, piloting the survey with more physicians from more diverse practices and environments, such as in rural settings in other provinces of Canada, would have helped to further ensure that no important questions were missing.

Physicians who completed our survey did so completely anonymously and thus we had no way to verify directly that surveys were not completed in duplicate. Despite our best efforts to ensure that physicians did not complete duplicate surveys, including clearly stating on the survey itself and in the introductory letters to not complete the survey more than once as well as checking data for matching physician profiles, it is possible that that physicians did so in rare instances.

Another limitation of our study is that, like in most surveys, physicians' responses were self-reported and therefore our study may be limited by response bias. As the early palliative care model has become increasingly supported in the literature, physicians might have responded with best practices rather than by reporting what they actually experienced or thought. Furthermore, the physicians who responded to our survey were categorized as providing specialized or primary palliative care. These categorizations were defined by the research team and based on literature; however, our categorizations may not completely represent or be generalizable to all physicians practicing specialized or primary palliative care. However, detailed statistical analysis allowed us to conclude confidently that these two groups were significantly different in ways that one would expect of physicians practicing specialized and primary palliative care.

While our study had limitations it also had many notable strengths. The most significant strength of our study was the 71% response rate, with a very limited amount of missing data. No survey item had a percentage missing greater than 22% and only three items had a percent missing greater than 10%. While the primary limitations of any survey are response bias and non-response bias, our good response rate helped to mitigate their effects on our results. Our response rate could be attributed to our successful study design: based on the literature, we included a small monetary incentive to encourage survey completion; the survey was brief, well organized, and available in paper format or online; and the study was approved by REB at the University Health Network, giving the survey credibility. Another strength of our study was that extensive statistical analysis was performed in order to verify our results, such as evaluating differences between specialized and primary palliative care physicians, and comparing multiple multivariate models. Lastly, our study was a national survey conducted across Canada, in both urban and rural environments, and in French and English. Many palliative care studies take place in only a single site, or in a particular city, or province. The national nature of our study provides greater generalizability to our findings.

Chapter 8: Conclusions

This study is the first to assess the barriers to early palliative care as perceived by physicians providing palliative care. We have described two distinct groups of physicians that provide palliative care in Canada: those who provided specialized palliative care and those who provided primary palliative care. Specialized palliative care physicians received referrals from others for their palliative services; were largely concentrated in urban academic centers; worked in settings specifically dedicated to caring for palliative patients such as palliative care units and outpatient clinics; saw a large number of palliative patients per month, and provided palliative care in palliative care teams. Physicians who provided primary palliative care did not receive referrals for their palliative services; were concentrated in rural environments; and primarily worked in private offices or other settings not specific to palliative care such as an intensive care unit or an emergency room.

Specialized and primary palliative care physicians both play a vital and unique role in providing integrated palliative care, which is fundamental to an early palliative care model. Our results demonstrated that specialized palliative care physicians were less likely to work in rural environments, provide care to patients with non-cancer diagnosis, or provide care to children. Furthermore, primary palliative care physicians did not have access to essential resources important to an early palliative care model, such as 24-hour on-call services or palliative care teams, and only a minority of those providing specialized palliative care had access to outpatient palliative care clinics. In order for more patients to have equitable access to palliative care earlier in their illness trajectory, the integration of specialized and primary palliative care must be supported for all patients with life-limiting illnesses.

Our results also demonstrate that palliative medicine education needs to continue to improve for primary and specialized palliative care physicians in Canada, as most of the physicians in our study had not completed accredited postgraduate training in palliative medicine. Increased education will increase awareness and advocacy for palliative care, as well as increasing the feasibility of applying an early palliative care model.

As hypothesized, the physicians who completed the survey had favorable attitudes and opinions about early palliative care. The large majority of physicians providing specialized and primary palliative care stated that patients with and without cancer should be referred early to palliative care (at prognosis >6 months, upon diagnosis of cancer/life-limiting illness, or upon diagnosis of incurable cancer). The attitudes and opinions of specialized and primary palliative care physicians differed, with specialized palliative care physicians subscribing more strongly to an early palliative care philosophy. Despite this preference for early referral, only a small minority of specialized palliative care physicians received early referrals, which is consistent with previous literature.

Four factors were significantly and independently associated with specialized palliative care physicians receiving early referrals for palliative care: having a graduate degree; female sex; providing a larger proportion of palliative care for patients without cancer; and disagreeing with the statement that patients should have stopped all chemotherapy before referral to palliative care. These factors can inform policy and practice to improve patients' access to beneficial early palliative care before the end of life. Specific methods by which this may occur include: increased research and advocacy for early palliative care; increased collaboration among physicians providing primary palliative care, specialized palliative care physicians, and referring physicians; improved understanding of the unique palliative care needs of patient with a non-cancer diagnosis; and more flexible referral criteria so patients who are currently undergoing chemotherapies will not be excluded from the potential benefits of simultaneous early palliative care. Although insufficient resources were not a significant predictor of receiving early referrals, fully 34% of physicians stated that they had insufficient resources to provide early palliative care. Thus resources are another important barrier to providing this care.

Although it is a contentious topic, evidence from this survey also suggests that a substantial proportion of physicians providing palliative care may be in favour of changing the name "palliative care" to "supportive care". A majority of physicians were of the opinion that patients and referring physicians would feel more comfortable with early referral if the name were changed, and a substantial minority believed that the specialty of palliative care should be renamed supportive care. The latter opinion was particularly held among physicians providing primary palliative care. These results underline the importance of education of patients and referring physicians about the relevance of palliative care early in the disease course. Renaming the specialty should not be the first option, but is one that can also be considered.

In conclusion, physicians providing palliative care are overwhelmingly in support of an early palliative care model. However, this model is not currently being enacted. We have identified potential barriers that can be addressed at the level of those providing palliative care. These include greater integration among groups providing palliative care; increased training in palliative care for palliative care specialists and primary providers; broadening of referral criteria; education of patients and referring physicians about early palliative care; increased resources; and rebranding and/or renaming the specialty.

Chapter 9: Future Directions

Future investigations need to be conducted in order to deepen our understanding of the barriers and facilitators to early palliative care referrals. Our study outlined potential barriers to integrating primary and specialized palliative care. Future research should further investigate and confirm these individual findings in order to improve integration between primary and specialized palliative care and increase early palliative care referrals.

Our results showed that specialized palliative care is practiced mainly for adults with cancer in urban centres. Moreover, primary palliative care physicians generally practiced alone in office-based clinics, rather than as part of a larger team. Further research is required to investigate how early palliative care can be facilitated in diverse settings, including for pediatric patients, those with non-cancer diagnoses, and in rural areas. As well, the associations found in our logistic regression analyses should be further explored in future research.

The integration of primary and specialized palliative care may not be identical for patients who were diagnosed with cancer and those who were diagnosed with a non-cancer life-threatening illness. Our results demonstrated that physicians were in favour of early palliative care for patients with and without a cancer diagnosis. Although referrals to specialized care were less common for non-cancer patients, specialized palliative care physicians reported that these patients were usually referred earlier in the course of illness. Since palliative care has been primarily studied in populations of patients with cancer, future research should investigate the specific differences in palliative care when it is provided for patients with cancer vs. those with a non-cancer diagnoses. For example, what are triggers for referrals in patients with cancer vs. those without? Furthermore, research should specifically evaluate how patients without a cancer vs. a non-cancer diagnosis utilized palliative care and their personal understanding of the role of palliative care at the time of their diagnosis and at the end of life.

Future research should also take into consideration the disparities in the provision of early palliative care for children vs. adult populations. Children faced with life-limiting illnesses also need palliative services. A retrospective national study in the United States, spanning over 19 years, estimated that each year 15,000 children die of complex chronic diseases (Feudtner et al., 2001). Children who are dying are a particularly vulnerable group and conducting research in this group is challenging. Thus, there is a limited amount of research in this population (Rapoport, 2009). Unlike in adult populations, pediatric patients with non-cancer diagnoses make up a considerable proportion of individuals using palliative services (Feudtner et al., 2001). Our study found that specialized palliative care physicians who saw pediatric patients for their palliative care services were more likely to receive early referrals; however this result was most likely insignificant in statistical analysis because so few specialized palliative care physicians in our study saw pediatric patients. A similar study to the one we conducted here could be designed; however the cohort of physicians would need to come from a source that is geared specifically towards pediatric palliative care physicians in order to improve the sample size. One study found that the referral practices of pediatric oncologist in Canada were different from those of oncologists who primarily see adult patients (Wentlandt et al., 2014). Given our results and the literature, it may be reasonable then to hypothesize that there may be factors associated with receiving early referrals for specialized pediatric palliative physicians that still need to be discovered and understood.

Our study demonstrated that only 33% of specialized palliative care physicians practiced in outpatient palliative care clinics, and less than half of the overall group surveyed had access to such a clinic. These clinics tend to be more developed in oncology settings (Hannon et al., 2015), while few have been developed for patients outside oncology (Rabow et al., 2010). In order to better understand how early palliative care will handle increased demand, in addition to increased outpatient clinics, it may be interesting to evaluate early palliative care models outside of the typical outpatient clinics, such as in private offices and long-term care homes. With the geriatric population growing significantly globally and in Canada (Statistics Canada, 2014), early palliative care may have a significant and positive impact on the quality of life for a great number of people in the coming future. Older adults frequently suffer from dementia and other life altering comorbidities, patient with limited mobility who cannot go to outpatient clinics would benefit from early palliative care just the same (Canadian Institute for Health Information, 2010). Barriers to early palliative care may be unique in long term care, where older adults may live for a long time.

Further research is required to explain our findings that specialized palliative care physicians who were female or had graduate education, such as a Master's degree or a PhD, were more than twice as likely to receive early referrals for palliative care. Since no mechanisms have been proposed for females being more likely to support or engage in an early palliative care model, a small qualitative study interviewing male and female palliative care physicians may uncover potential undetected mechanisms for this finding in our study and in others (Wentlandt et al., 2012). There is also no previous research to point at reasons that those with a graduate degree are more likely to receive early referrals. It is possible that these factors are related to characteristics of these individuals, such as their willingness and desire to advocate for early palliative care or engage in collaborative relationships. A quantitative study looking at the timing of receiving referrals for palliative care and how much and in what ways physicians advocate for early palliative care may prove be useful in designing and promoting early palliative care programs. At the very least, future research should include factors related to advocacy when designing studies which evaluate referral practices.

As early palliative care becomes increasingly adopted, it is clear that diversity of patients seeking and utilizing palliative care will increase. Therefore, future studies evaluating palliative care referral criteria are needed. In our study, the more a specialized palliative care physician agreed that patients should have stopped all chemotherapy before referral to palliative care, the less likely the physician was to receive early referrals. Similarly, for Canadian oncologists, one of the factors associated with both ideal referral timing and actual referrals at a prognosis of greater than 6 months was their reported access to specialized palliative care services that accepted patients receiving chemotherapy (Wentlandt et al., 2012). A survey study of palliative care physicians, inquiring about their referral criteria, the basis of those criteria, and tools they use to screen patients may be valuable.

Referral criteria as a barrier to early palliative care referral may also be an indication of there being an unclear line between who holds what responsibility in providing palliative care. Specialized palliative care physicians in our study reported somewhat mixed responses for patients with and without cancer independently, to the statement “It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient’s primary disease”. While approximately 50% disagreed or strongly disagreed, 20% were neutral, and 20% agreed or strongly agreed. Some specialized palliative care physicians may feel challenged managing treatment related concerns of patients who are referred to them early who are still undergoing treatments such as chemotherapy. Future research, via a survey of primary, secondary, and tertiary palliative care physicians' perceived responsibilities in caring for a shared patient may help determine physicians comfort level and how they see themselves and their colleagues collaborating to provide palliative care. A study of this kind may also uncover areas of care where there is a blind spot. For example, if two physicians caring for a shared patient each believe the other is providing symptom management, then neither is providing this service and therefore the shared patient is potentially receiving substandard care.

Even if both referring and palliative care physicians believe palliative care to be of benefit, patients may be apprehensive about early referral to palliative care. Patients often incorrectly understand palliative care to only be applicable at the very end of life when no other options are left available to them (Miyashita et al., 2008; Zimmermann et al., 2016). Furthermore, improved patient understanding of the role and benefits of palliative care may reduce the degree to which patients receiving palliative care feel stigmatized (Zimmermann et al., 2016). Research has suggested that patients' negative perceptions of palliative care was associated with its name, and that changing the name to something less stigmatizing such as "supportive care" may be one possible solution (Dalal et al., 2011; Fadul et al., 2009; Maciasz et al., 2013; Morstad Boldt et al., 2006; Zimmermann et al., 2016). In our study, 40% of physicians disagreed, 31.5% were neutral, and 28.5% agreed that the specialty of palliative care should be renamed supportive care. A future study may involve assessing the factors associated with the degree to which physicians agree with changing the name. Associated factors may aid in determining for whom the name is easily adopted and where barriers may exist resulting in the perpetuation of patients feeling stigmatize and later referrals. This quantitative study could be complemented with a qualitative study of physicians' opinions and feelings on changing the name to supportive care.

In conclusion, interesting and important questions remain regarding the provision of early palliative care. Future studies should include both quantitative and qualitative methods from the perspective of multiple stakeholders including but not limited to patients and their caregivers, referring and palliative care physicians, and other allied healthcare professionals. In this way, the collective knowledge of early palliative care will increase, resulting in improved access for a greater number of patients.

References

Abrahm, J. L. (2012). Integrating palliative care into comprehensive cancer care. *Journal of the National Comprehensive Cancer Network*, *10*(10), 1192–1198.

Addicott, R. (2012). Delivering better end-of-life care in England: Barriers to access for patients with a non-cancer diagnosis. *Health Economics, Policy, and Law*, *7*(4), 441–54. doi:10.1017/S1744133112000230

Ahluwalia, S. C., & Fried, T. R. (2009). Physician factors associated with outpatient palliative care referral. *Palliative Medicine*, *23*(7), 608–615. doi:10.1177/0269216309106315

Bakitas, M. A., Tosteson, T. D., Li, Z., Lyons, K. D., Hull, J. G., Li, Z., … Ahles, T. A. (2015). Early versus delayed initiation of concurrent palliative oncology care: Patient outcomes in the ENABLE III randomized controlled trial. *Journal of Clinical Oncology*, *33*(13), 1438–1445. doi:10.1200/JCO.2014.58.6362

Bakitas, M., Lyons, K. D., Hegel, M. T., Balan, S., Brokaw, F. C., Seville, J., … Ahles, T. A. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The project enable II randomized controlled trial. *JAMA*, *302*(7), 741–749. Retrieved from http://dx.doi.org/10.1001/jama.2009.1198

Bruera, E., & Hui, D. (2010). Integrating supportive and palliative care in the trajectory of cancer: Establishing goals and models of care. *Journal of Clinical Oncology*, *28*(25), 4013–4017. doi:10.1200/JCO.2010.29.5618

Bruera, E., Neumann, C., Breneis, C., & Quan, H. (2000). Frequency of symptom distress and poor prognostic indicators in palliative cancer patients admitted to a tertiary paliative care unit, hospices, and acute care hospitals. *Journal of Palliative Care*, *16*(3), 16–21.

Burt, J., Shipman, C., White, P., & Addington-Hall, J. (2006). Roles, service knowledge and priorities in the provision of palliative care: A postal survey of London GPs. *Palliative Medicine*, *20*(5), 487–492. doi:10.1191/0269216306pm1159oa

Canadian Cancer Research Alliance. (2011). *Investment in research on survivorship and palliative end-of-life Care, 2005-2008: A special report from the Canadian Cancer research alliance's survey of government voluntary sector investment in cancer research*. Toronto: CCRA.

Canadian Hospice Palliative Care Association. (2013). *A model to guide hospice palliative care* (Rivised an). Ottawa, Ontario: Canadian Hospice Palliative Care Association.

Canadian Hospice Palliative Care Association. (2016). The Canadian Hospice Palliative Care Association... A History. Retrieved from http://www.chpca.net/about-us/history.aspx

Canadian Institute for Health Information. (2010). *Caring for seniors with alzheimer's disease and other forms of dementia*. Ottawa: CIHI.

Canadian Medical Association. (2015). *Palliative Care: Canadian Medical Association's national call to action 2014-2015*. Ottawa: CMA.

Canadian Society of Canadian Palliative Care Physicians. (2015). Vison, Mission, and Goals. Retrieved from http://www.cspcp.ca/about/vision-mission-goals/

Cancer Care Ontario. (2009). *Regional models of care for palliative cancer care: Recommendations for the organization and delivery of palliative cancer care in Ontario provincial palliative care program, December 2009*. Toronto: CCO.

Casarett, D. J., Fishman, J. M., Lu, H. L., O'Dwyer, P. J., Barg, F. K., Naylor, M. D., & Asch, D. a. (2009). The terrible choice: re-evaluating hospice eligibility criteria for cancer. *Journal of Clinical Oncologyy*, *27*(6), 953–9. doi:10.1200/JCO.2008.17.8079

Cheng, W., Willey, J., Palmer, J. L., Zhang, T., & Bruera, E. (2005). Interval between palliative care referral and death among patients treated at a comprehensive cancer center. *Journal of Palliative Care*, *8*(5), 1025–1032.

Cherny, N. I., & Catane, R. (2003). Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer. *Cancer*, *98*(11), 2502–2510. doi:10.1002/cncr.11815

Cheung, M. C., Earle, C. C., Rangrej, J., Ho, T. H., Liu, N., Barbera, L., … Mittmann, N. (2015). Impact of aggressive management and palliative care on cancer costs in the final month of life. *Cancer*, *121*(18), 3307–3315. doi:10.1002/cncr.29485

Cho, Y. I., Johnson, T. P., & Vangeest, J. B. (2013). Enhancing surveys of health care professionals: A meta-analysis of techniques to improve response. *Evaluation & the Health Professions*, *36*(3), 382–407. doi:10.1177/0163278713496425

Christakis, N. A., & Escarce, J. J. (1996). Survival of medicare patients after enrollment in hospice programs. *New England Journal of Medicine*, *335*(3), 172–178.

Costantini, M., Toscani, F., Gallucci, M., Brunelli, C., Miccinesi, G., Tamburini, M., … Addington-Hall, J. (1999). Terminal cancer patients and timing of referral to palliative care: A multicenter prospective cohort study. *Journal of Pain and Symptom Management*, *18*(4), 243–252.

Dalal, S., Palla, S., Hui, D., Nguyen, L., Chacko, R., Li, Z., … Bruera, E. (2011). Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *The Oncologist*, *16*(1), 105–111. doi:10.1634/theoncologist.2010-0161

De Korte-Verhoef, M. C., Pasman, H. R. W., Schweitzer, B. P., Francke, A. L., Onwuteaka-Philipsen, B. D., & Deliens, L. (2012). End-of-life hospital referrals by out-of-hours general practitioners: A retrospective chart study. *BMC Family Practice*, *13*(1), 89. doi:10.1186/1471-2296-13-89

Doyle, C., Crump, M., Pintilie, M., & Oza, A. M. (2014). Does palliative chemotherapy palliate? Evaluation of expectations, outcomes, and costs in women receiving chemotherapy for advanced ovarian cancer. *Journal of Clinical Oncology*, *19*(5), 1266–1274.

Earle, C. C., Landrum, M. B., Souza, J. M., Neville, B. a, Weeks, J. C., & Ayanian, J. Z. (2008). Aggressiveness of cancer care near the end of life: Is it a quality-of-care issue? *Journal of Clinical Oncology*, *26*(23), 3860–3866. doi:10.1200/JCO.2007.15.8253

El Osta, B., Palmer, J. L., Paraskevopoulos, T., Pei, B.-L., Roberts, L. E., Poulter, V. A., … Bruera, E. (2008). Interval between first palliative care consult and death in patients diagnosed with advanced cancer at a comprehensive cancer center. *Journal of Palliative Medicine*, *11*(1), 51–57. doi:10.1089/jpm.2007.0103

Fadul, N., Elsayem, A., Palmer, J. L., Del Fabbro, E., Swint, K., Li, Z., … Bruera, E. (2009). Supportive versus palliative care: What's in a name? *Cancer*, *115*(9), 2013–2021. doi:10.1002/cncr.24206

Ferris, F. D., Bruera, E., Cherny, N., Cummings, C., Currow, D., Dudgeon, D., … Von Roenn, J. H. (2009). Palliative cancer care a decade later: Accomplishments, the need, next steps - From the American Society of Clinical Oncology. *Journal of Clinical Oncology*, *27*(18), 3052–3058. doi:10.1200/JCO.2008.20.1558

Feudtner, C., Hays, R. M., Haynes, G., Geyer, J. R., Neff, J. M., & Koepsell, T. D. (2001). Dealths attributed to pediatric complex chronic conditions: National trends and implications for supportive care services. *Pediatrics*, *107*(6).

Gadoud, A. C., & Johnson, M. J. (2015). Palliative care in non-malignant disease. *Medicine*, *43*(12), 726–729. doi:10.1016/j.mpmed.2015.09.009

Glare, P. A., Semple, D., Stabler, S. M., & Saltz, L. B. (2011). Palliative care in the outpatient oncology setting: Evaluation of a practical set of referral criteria. *Journal of Oncology Practice*, *7*(6), 366–370. doi:10.1200/JOP.2011.000367

Goodlin, S. J. (2009). Palliative Care in Congestive Heart Failure. *Journal of the American College of Cardiology*, *54*(5), 386–396. doi:10.1016/j.jacc.2009.02.078

Hannon, B., Swami, N., Pope, A., Rodin, G., Dougherty, E., Mak, E., … Zimmermann, C. (2014). The oncology palliative care clinic at the Princess Margaret Cancer Centre: an early intervention model for patients with advanced cancer. *Supportive Care in Cancer*. doi:10.1007/s00520-014-2460-4

Hannon, B., Swami, N., Pope, A., Rodin, G., Dougherty, E., Mak, E., … Zimmermann, C. (2015). The oncology palliative care clinic at the Princess Margaret Cancer Centre: an early intervention model for patients with advanced cancer. *Supportive Care in Cancer*, *23*(4), 1073–1080. doi:10.1007/s00520-014-2460-4

Harrison, J. D., Young, J. M., Price, M. A., Butow, P. N., & Solomon, M. J. (2009). What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care* *in Cancer*, *17*(8), 1117–1128. doi:10.1007/s00520-009-0615-5

Helsing, M., Bergman, B., Thaning, L., & Hero, U. (1998). Quality of life and survivial in patients with advanced non-small cell lung cancer receiving supportive care plus chemotherapy with carboplatin and etoposide or supportive care only. A multicentre randomized phase III trial. *European Journal of Cancer*, *34*(7), 1036–1044.

Hui, D., & Bruera, E. (2015). Integrating palliative care into the trajectory of cancer care. *Nature Reviews Clinical Oncology*, *13*(3), 159–171. doi:10.1038/nrclinonc.2015.201

Hui, D., Elsayem, A., De La Cruz, M., Berger, A., Zhukovsky, D. S., Palla, S., … Bruera, E. (2010). Availability and integration of palliative care at US cancer centers. *JAMA*, *303*(11), 1054–1061.

Hui, D., Kim, S. H., Roquemore, J., Dev, R., Chisholm, G., & Bruera, E. (2014). Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer*, *120*(11), 1743–1749. doi:10.1002/cncr.28628

Hui, D., Kim, Y. J., Park, J. C., Zhang, Y., Strasser, F., Cherny, N., … Davis, M. P. (2015). Integration of oncology and palliative care: A systematic review. *The Oncologist*, *20*, 77–83. doi:10.1634/theoncologist.2014-0312.

Hui, D., Parsons, H., Nguyen, L., Palla, S. L., Yennurajalingam, S., Kurzrock, R., & Bruera, E. (2010). Timing of palliative care referral and symptom burden in phase 1 cancer patients: A retrospective cohort study. *Cancer*, *116*(18), 4402–4409. doi:10.1002/cncr.25389

Human Resources Committee of the Canadian Society of Palliative Care Physicians. (2015). *Highlights from the National Palliative Medicine Survey*. Surrey: Canadian Society of Palliative Care Physicians.

Johnson, C. E., Girgis, A., Paul, C. L., & Currow, D. C. (2008). Cancer specialists' palliative care referral practices and perceptions: Results of a national survey. *Palliative Medicine*, *22*, 51–57.

Johnson, C. E., Girgis, A., Paul, C. L., & Currow, D. C. (2011). Palliative care referral practices and perceptions: The divide between metropolitan and non-metropolitan general practitioners. *Palliative & Supportive Care*, *9*(2), 181–9. doi:10.1017/S1478951511000058

Kelley, M. Lou. (2006). Developing rural communities' capacity for palliative care: A conceptual model. *Journal of Palliative Care*, *23*(3), 143–153.

Koedoot, C. G., de Haan, R. J., Stiggelbout, a M., Stalmeier, P. F. M., de Graeff, a, Bakker, P. J. M., & de Haes, J. C. J. M. (2003). Palliative chemotherapy or best supportive care? A prospective study explaining patients' treatment preference and choice. *British Journal of Cancer*, *89*(12), 2219–26. doi:10.1038/sj.bjc.6601445

Lamont, E. B., & Christakis, N. A. (2002). Physician factors in the timing of cancer patient referral to hospice palliative care. *Cancer*, *94*(10), 2733–2737. doi:10.1002/cncr.10530

Maciasz, R. M., Arnold, R., Chu, E., Park, S. Y., White, D. B., Borgenheimer, L., & Schenker, Y. (2013). Does it matter what you call it? A randomized trail of language used to describe palliative care services. *Supportive Cancer Care*, *21*(12), 1–16. doi:10.1007/s00520-013-1919-z.

Mitchell, G. K. (2002). How well do general practitioners deliver palliative care? A systematic review. *Palliative Medicine*, *16*(6), 457–464. doi:http://dx.doi.org/10.1191/0269216302pm573oa

Miyashita, M., Hirai, K., Morita, T., Sanjo, M., & Uchitomi, Y. (2008). Barriers to referral to inpatient palliative care units in Japan: A qualitative survey with content analysis. *Supportive Care in Cancer*, *16*(3), 217–222. doi:10.1007/s00520-007-0215-1

Monette, M. (2012). Palliative care subspecialty in the offing. *CMAJ*, *184*(13), 1456–1457. doi:10.1503/cmaj

Morita, T., Akechi, T., Ikenaga, M., Kizawa, Y., Kohara, H., Mukaiyama, T., … Uchitomi, Y. (2005). Late referrals to specialized palliative care service in Japan. *Journal of Clinical Oncology*, *23*(12), 2637–2644. doi:10.1200/JCO.2005.12.107

Morstad Boldt, A., Yusuf, F., & Himelstein, B. P. (2006). Perceptions of the term palliative care. *Journal of Palliative Medicine*, *9*(5), 1128–1136. doi:10.1089/jpm.2006.9.1128

Mount, B. M. (1976). The problem of caring for the dying in a general hospital; the palliative care unit as a possible solution. *CMAJ*, *115*(2), 119–121.

Mullan, P. B., Weissman, D. E., Ambuel, B., & Von Gunten, C. (2002). End-of-Life care education in internal medicine residency programs: An interinstitutional study. *Journal of Palliative Medicine*, *5*(4), 487–496.

Murray, S. A., & Sheikh, A. (2008). Care for all at the end of life. *BMJ*, *336*(7650), 958–959. doi:10.1136/bmj.39535.491238.94

Ogle, K. S., Mavis, B., & Wyatt, G. K. (2002). Physicians and hospice care: attitudes, knowledge, and referrals. *Journal of Palliative Medicine*, *5*(1), 85–92. doi:10.1089/10966210252785042

Pirl, W. F., Greer, J. A., Traeger, L., Jackson, V., Lennes, I. T., Gallagher, E. R., … Temel, J. S. (2012). Depression and survival in metastatic non-small-cell lung cancer: Effects of early palliative care. *Journal of Clinical Oncology*, *30*(12), 1310–1315. doi:10.1200/JCO.2011.38.3166

Quill, T. E., & Abernethy, A. P. (2013). Generalist plus specialist palliative care - Creating a more sustainable model. *New England Journal of Medicine*, *368*(13), 1173–1175. doi:10.1056/NEJMp1302513

Rabow, M. W., Smith, A. K., Braun, J. L., & Weissman, D. E. (2010). Outpatient palliative care practices. *Archives of Internal Medicine*, *170*(70), 654–655.

doi:10.1001/archinternmed.2010.56

Rapoport, A. (2009). Addressing ethical concerns regarding pediatric palliative care research. *Archives of Pediatrics & Adolescent Medicine*, *163*(8), 688–691. doi:10.1001/archpedi.163.8.688

Robinson, C. A., Pesut, B., Bottorff, J., Mowry, A., Broughton, S., & Fyles, G. (2009). Rural palliative care: A comprehensive review. *Journal of Palliative Medicine*, *12*(3), 253–258.

Roter, D., Lipkin, M., & Korsgaard, A. (1991). Sex differences in patients' and physicians' communication during primary care medical visits. *Medical Care*, *29*(11), 1083–1093.

Royal College of Physicians and Surgeons of Canada. (2014). Palliative medicine: Program directors. Retrieved from http://www.royalcollege.ca/portal/page/portal/rc/credentials/accreditation/arps/specialty/palliative

Rubin, G., Berendsen, A., Crawford, S. M., Dommett, R., Earle, C., Emery, J., … Zimmermann, C. (2015). The expanding role of primary care in cancer control. *The Lancet Oncology*, *16*(12), 1231–1272. doi:10.1016/S1470-2045(15)00205-3

Salz, T., & Brewer, N. T. (2009). Offering chemotherapy and hospice jointly: One solution to hospice underuse. *Medical Decision Making*, *29*(4), 521–31. doi:10.1177/0272989X09333123

Schenker, Y., Crowley-Matoka, M., Dohan, D., Rabow, M. W., Smith, C. B., White, D. B., … Arnold, R. M. (2014). Oncologist factors that influence referrals to subspecialty palliative care clinics. *Journal of Oncology Practice*, *10*(2), e37–e44. doi:10.1200/JOP.2013.001130

Sepúlveda, C., Marlin, A., Yoshida, T., & Ullrich, A. (2002). Palliative care: The world health organization's global perspective. *Journal of Pain and Symptom Management*, *24*(2), 91–96. Retrieved from http://www.scopus.com/inward/record.url?eid=2-s2.0-0036701604&partnerID=40&md5=79c376d1f30377e12460b41cc8626d6c

Siouta, N., van Beek, K., Preston, N., Hasselaar, J., Hughes, S., Payne, S., … Menten, J. (2016). Towards integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease: A systematic literature review of European guidelines and pathways. *BMC Palliative Care*, *15*(1), 18. doi:10.1186/s12904-016-0089-4

Sleeman, K. E., Gomes, B., & Higginson, I. J. (2012). Research into end-of-life cancer care - Investment is needed. *The Lancet*, *379*(9815), 519. doi:10.1016/S0140-6736(12)60230-X

Smith, C. B., Nelson, J. E., Berman, a R., Powell, C. a, Fleischman, J., Salazar-Schicchi, J., & Wisnivesky, J. P. (2012a). Lung cancer physicians' referral practices for palliative care consultation. *Annals of Oncology : Official Journal of the European Society for Medical Oncology / ESMO*, *23*(2), 382–7. doi:10.1093/annonc/mdr345

Smith, C. B., Nelson, J. E., Berman, A. R., Powell, C. A., Fleischman, J., Salazar-Schicchi, J., &

Wisnivesky, J. P. (2012b). Lung cancer physicians' referral practices for palliative care consultation. *Annals of Oncology*, *23*(2), 382–387. doi:10.1093/annonc/mdr345

Smith, T. J., Temin, S., Alesi, E. R., Abernethy, A. P., Balboni, T. a, Basch, E. M., … Von Roenn, J. H. (2012). American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *Journal of Clinical Oncology*, *30*(8), 880–7. doi:10.1200/JCO.2011.38.5161

Statistics Canada. (2012). Leading causes of death, by sex (both sexes). Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/hlth36a-eng.htm

Statistics Canada. (2014). Population projections : Canada, the provinces and territories, 2013 to 2063. Retrieved from http://www.statcan.gc.ca/daily-quotidien/140917/dq140917a-eng.htm

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., Grambow, S., Parker, J., & Tulsky, J. A. (2001). Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *Journal of Pain and Symptom Management*, *22*(3), 727–737.

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., Mcintyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*, *284*(19), 2476–2482.

Swetz, K. M., & Smith, T. J. (2010). Palliative chemotherapy: When is it worth it and when is it not? *The Cancer Journal*, *16*(5), 467–473.

Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., … Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, *363*(8), 733–742. doi:10.1056/NEJMoa1000678

Temel, J. S., Jackson, V. A., Billings, J. A., Dahlin, C., Block, S. D., Buss, M. K., … Lynch, T. J. (2007). Phase II study: Integrated palliative care in newly diagnosed advanced non-small-cell lung cancer patients. *Journal of Clinical Oncology*, *25*(17), 2377–2382. doi:10.1200/JCO.2006.09.2627

The Economist Intelligence Unit. (2015). *The 2015 quality of death index: Ranking palliative care across the world*. Retrieved from http://www.eiuperspectives.economist.com/healthcare/2015-quality-death-index

Thompson, L. A., Knapp, C., Madden, V., & Shenkman, E. (2009). Pediatricians' perceptions of and preferred timing for pediatric palliative care. *Pediatrics*, *123*(5), e777–782. doi:10.1542/peds.2008-2721

Towns, K., Dougherty, E., Kevork, N., Wiljer, D., Seccareccia, D., Rodin, G., … Zimmermann, C. (2012). Availability of services in Ontario hospices and hospitals providing inpatient palliative care. *Journal of Palliative Medicine*, *15*(5), 527–534. doi:10.1089/jpm.2011.0453

VanGeest, J., Johnson, T. P., & Welch, V. L. (2007). Methodologies for improving response rates in surveys of physicians. *Evaluation & the Health Professions*, *30*(4), 303 – 321. Retrieved from http://resolver.scholarsportal.info/resolve/01632787/v30i0004/303_mfirrisop.xml

Von Roenn, J. H., Voltz, R., & Serrie, A. (2013). Barriers and approaches to the successful integration of palliative care and oncology practice. *Journal of the National Comprehensive Cancer Network*, *11*(1), S12–S16.

Wendler, D., & Rid, A. (2014). The effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine*, *154*(5), 336–346.

Wentlandt, K., Krzyzanowska, M. K., Swami, N., Rodin, G., Le, L. W., Sung, L., & Zimmermann, C. (2014). Referral practices of pediatric oncologists to specialized palliative care. *Supportive Care in Cancer*, *22*(9), 2315–2322. doi:10.1007/s00520-014-2203-6

Wentlandt, K., Krzyzanowska, M. K., Swami, N., Rodin, G. M., Le, L. W., & Zimmermann, C. (2012). Referral practices of oncologists to specialized palliative care. *Journal of Clinical Oncology*, *30*(35), 4380–4386. doi:10.1200/JCO.2012.440248

Whelan, T. J., Mohide, E. A., Willan, A. R., Arnold, A., Tew, M., Sellick, S., … Levine, M. N. (1997). The supportive care needs of newly diagnosed cancer patients attending a regional cancer center. *Cancer*, *80*(8), 1518–1524.

Whitmer, K. M., Pruemer, J. M., Nahleh, Z. A., & Jazieh, A. R. (2006). Symptom management needs of oncology outpatients. *Journal of Palliative Medicine*, *9*(3), 628–630.

World Health Organization. (2014). WHO definition of palliative care. Retrieved from http://www.who.int/cancer/palliative/definition/en/

World Wide Palliative Care Alliance. (2014). *Global atlas of palliative care at the end of life*. London: WPCA.

Zimmermann, C., Riechelmann, R., Krzyzanowska, M., Rodin, G., & Tannock, I. (2008). Effectiveness of specialized palliative care: A systematic review. *JAMA*, *299*(14), 1698–1709.

Zimmermann, C., Swami, N., Krzyanowska, M., Natasha, L., Rydall, A., Rodin, G., … Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ*. doi:10.1503/cmaj.160206

Zimmermann, C., Swami, N., Krzyzanowska, M., Hannon, B., Leighl, N., Oza, A., … Lo, C. (2014). Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *The Lancet*, *6736*(13), 1–10. doi:10.1016/S0140-6736(13)62416-2

Appendices

A1: Missing data tables

Table A1.1 Missing data for all survey items and multivariate model.

Item	N=531
	n (%)
Q1. Type of Palliative care practice	0 (0)
Q2. For which professional association are you a current member?	10 (1.9)
Q3. Are you a part of a palliative care association or society?	Unknown
Q4. Have you completed any postgraduate education?	46 (8.7)
Q5ab. What best describes your primary practice?	2 (0.4)
Q5c. What specialties/subspecialties are you certified in?	45 (8.5)
Q6. How many years have you been practicing palliative care?	3 (0.6)
Q7. Have you completed an accredited postgraduate training/YAC in Palliative Medicine?	0 (0)
Q8a-b. Did you complete other training in palliative care?	14 (2.6)
Q8c. Did you have any exams in this other training?	14 (2.6)
Q9. Where did you receive your most recent palliative care training?	85 (16.0)
Q10. In which province/territory do you currently practice?	2 (0.4)
Q11. Urban vs. Rural	118 (22.2)
Q12. You are a full-time or a part-time physician?	4 (0.8)
Q13. What is your sex?	4 (0.8)
Q14. What is your age?	2 (0.4)
Q15. In work week, proportion of clinical time spent practicing palliative care?	2 (0.4)
Q16. Do you practice palliative care in an academic centre?	7 (1.3)
Q17. On avg. how many unique palliative patients do you see per MONTH (including new and follow-up)?	3 (0.6)
Q18. What type of palliative patients do you see?	1 (0.2)
Q19. Does your team provide a 24-hour on-call services for your palliative patients?	8 (1.5)
Q20. What proportion of the palliative care you provide is for CANCER patients?	3 (0.6)
Q21. What is the approx. avg. survival time of the patients for whom you provide palliative care?	7 (1.3)
Q22a. What type of facilities do you practice palliative care in?	0 (0)
Q22b. Types of patients accepted in – Palliative Care Unit (n = 170)	9 (5.0)
Q22b. Types of patients accepted in – Home Palliative Care (n = 276)	14 (4.8)
Q22b. Types of patients accepted in – Palliative Care Clinic/Consultation (n = 168)	40 (19.2)
Q23. Which of the following services are available for you to refer your patients to?	5 (0.9)
Q24a. Are you a part of a palliative care team?	1 (0.4)
Q25. In your community or area, palliative care is typically provided by:	4 (0.8)
Q27. In IDEAL circumstances, when is it appropriate for CANCER patients to be first referred to palliative care?	11 (2.1)
Q28. In IDEAL circumstances, when is it appropriate for NON-CANCER patients to be first referred to palliative care?	24 (4.5)
Q29. For CANCER patients, what do you consider to be a late referral to palliative care?	15 (2.8)
Q30. For NON-CANCER patients, what do you consider to be a late referral to palliative care?	17 (3.2)
Q31. Not a part of a team who receives referrals for palliative care	14 (2.6)
Satisfaction with your relationship with referring physicians (n=342)	23 (6.7)
Satisfaction with your relationship with other palliative care physicians (n=342)	18 (5.2)
Satisfaction with your relationship with other palliative team members (n=342)	17 (5.0)
Q26. I have sufficient resources in my palliative care practice to provide high-quality palliative care 6 – 24 months prior to the end of life	4 (0.8)

Item	N=531
Q32. Palliative care teams should only be involved in the last few weeks of life - CANCER	16 (3.0)
Q32. Palliative care teams should only be involved in the last few weeks of life – NON-CANCER	13 (2.4)
Q32. It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient's primary disease – CANCER	18 (3.4)
Q32. It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient's primary disease – NON-CANCER	12 (2.3)
Q32. Involvement of palliative care teams 6-24 months prior to the end of life has a survival benefit - CANCER	20 (3.8)
Q32. Involvement of palliative care teams 6-24 months prior to the end of life has a survival benefit – NON-CANCER	14 (2.6)
Q32. Involvement of palliative care teams 6-24 months prior to the end of life improves patients' quality of life - CANCER	18 (3.4)
Q32. Involvement of palliative care teams 6-24 months prior to the end of life improves patients' quality of life – NON-CANCER	9 (1.7)
Q32. The specialty of palliative care should be renamed supportive care - CANCER	17 (3.2)
Q32. The specialty of palliative care should be renamed supportive care – NON-CANCER	10 (1.9)
Q33. Patients should have stopped all chemotherapy before referral to palliative care	3 (0.6)
Q33. Hematology patients should have stopped all transfusions before referral to palliative care	3 (0.6)
Q33. Patients without symptoms do not need palliative care before the last few weeks of life	3 (0.6)
Q33. Patients would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care	3 (0.6)
Q33. Referring physicians would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care	3 (0.6)
Q33. Patients have a negative perception of the term palliative care	4 (0.8)
Q34. I am comfortable caring for patients who are full resuscitation (n=257)	13 (5.0)
Q34. Once I am following a patients for palliative care, the referring physician stops seeing the patient (n=257)	14 (5.4)
Q34. Referring physicians tend to refer late to my palliative practice (n=257)	19 (7.4)
Q34. I prefer a model of care in which I completely take over palliative care from the referring physician (n=257)	16 (6.2)
MULTIVARIATE MODEL	56 (21.8)

Note: For question 3 (Q3), the number of missing is unknown because physicians who did not answer the question were indistinguishable from physicians who did not answer because they were not a part of a palliative care association or society. For question 22b (Q22b), missing data is calculated out of those physicians who responded to question 22a (Q22a) for the palliative care setting references in Q22b. For question 27 (Q27), 14 (2.6%) physicians responded in such as way what made their answer invalid and could not be used in analysis. For question 31 (Q31), 189 physicians responded that they were not a part of team who receives referrals for palliative care; therefore the "n" for subsequent questions for physician who were a part of a team who receives referrals for palliative care is 342. For Question 32 (Q32), physicians responded to the statement independently for patients with cancer and for patients without. For questions 26 and 32-34 physicians answered by responding to the statement on a five point Likert scale from strongly disagree to strongly agree. For question 34 (Q34), only 257 physicians who were categorized as specialized palliative care physicians responded to these statements; therefore the "n" for the subsequent statements was 257.

A2: Mann-Whitney U test comparing opinion and attitudinal factors of physicians providing specialized and primary palliative care

Table A2.1 Specialized and primary palliative care physicians' opinions and attitudes for cancer and non-cancer patients regarding scope of early palliative care.

		Specialized n=257	Primary n=274	p-value	U
		Mean Rank	*Mean Rank*		
Palliative care teams should only be involved in the last few weeks of life	*Cancer*	242.04	273.06	0.004	29135.00
	Non-Cancer	246.31	272.09	0.027	31185.50
It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient's primary disease	*Cancer*	278.27	236.94	0.001	27573.00
	Non-Cancer	278.17	242.72	0.006	29053.00
Involvement of palliative care teams 6-24 months prior to the end of life has a survival benefit	*Cancer*	288.52	224.85	<0.0001	24495.00
	Non-Cancer	278.23	240.71	0.003	28543.50
Involvement of palliative care teams 6-24 months prior to the end of life improves patients' quality of life	*Cancer*	280.62	234.55	<0.0001	26971.00
	Non-Cancer	283.52	240.47	<0.0001	28428.50
The specialty of palliative care should be renamed supportive care	*Cancer*	218.23	295.52	<0.0001	23183.00
	Non-Cancer	224.65	296.69	<0.0001	24646.50

Table A2.2 Specialized vs. and primary palliative care physicians' opinions and attitudes about early palliative care.

	Specialized n=257	Primary n=274	p-value	U
	Mean Rank	*Mean Rank*		
Patients should have stopped all chemotherapy before referral to palliative care	244.00	283.79	0.001	29568.00
Hematology patients should have stopped all transfusions before referral to palliative care	249.29	278.82	0.015	30921.00
Patients without symptoms do not need palliative care before the last few weeks of life	241.73	285.93	<0.0001	28986.00
Patients would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care	236.08	291.25	<0.0001	27539.50
Referring physicians would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care	263.95	265.01	0.934	34676.00
Patients have a negative perception of the term palliative care	241.73	285.93	0.599	33827.00

A3: Complete univariable analysis of specialized palliative care physicians survey items

Table A3.1 Comparison of survey variables between specialized palliative care physicians who receive early vs. late referrals for their palliative care.

N=257	Late n=202 (79.5)	Early n=52 (20.5)	p-value
	n (%)		
Are you a part of a palliative care association or society?			
NO	59 (29.2)	14 (26.9)	0.745
YES	143 (70.8)	38 (73.1)	
Have you completed a Masters or a PhD?			
NO	140 (74.9)	26 (55.3)	**0.008**
YES	47 (25.1)	21 (44.7)	
What specialties/subspecialties are you certified in?			
Family Medicine	146 (76.4)	29 (58.0)	0.009
Oncology	3 (1.6)	2 (4.0)	0.277[†]
Internal Medicine	12 (6.3)	4 (8.0)	0.749[†]
Pediatrics	3 (1.6)	4 (8.0)	0.036[†]
Psychiatry	4 (2.1)	2 (4.0)	0.607[†]
Palliative Medicine	52 (27.2)	11 (22.0)	0.560
Anesthesiology	4 (2.1)	6 (12.0)	0.006[†]
Other	21 (11.0)	9 (18.4)	0.223
How many years have you been practicing palliative care?			
5 years or less	48 (23.8)	11 (21.2)	0.879
6 – 10 years	40 (19.8)	12 (23.1)	
11-20 years	58 (28.7)	14 (25.0)	
More than 20 years	56 (27.7)	16 (38.8)	
Have you completed an accredited postgraduate training/YAC in Palliative Medicine?			
NO	151 (74.8)	40 (76.9)	0.747
YES	51 (25.2)	12 (23.1)	
Did you complete other training in palliative care?			
NO	98 (50.8)	21 (41.2)	0.371
YES – 3 months or less	51 (26.4)	14 (27.5)	
YES – 4 months or more	44 (22.8)	16 (31.4)	
Where did you receive your most recent palliative care training?			
In Canada	171 (91.9)	37 (77.1)	**0.004**
Outside Canada	15 (8.1)	11 (22.9)	

N=257	Late n=202 (79.5)	Early n=52 (20.5)	p-value
	n (%)		
In which province/territory do you currently practice?			
British Columbia (West)	36 (17.9)	8 (15.7)	0.631
AB, SK, MB (Prairies)	31 (15.4)	8 (15.7)	
Ontario	87 (43.3)	27 (52.9)	
Quebec	25 (12.4)	3 (5.9)	
NS, NB, PE, NL (Atlantic) AND NT, YT, NU	22 (10.9)	5 (9.8)	
Urban vs. Rural			
Urban	153 (95.0)	37 (90.2)	0.268[†]
Rural	8 (5.0)	4 (9.8)	
You are a:			
Full-time physician	174 (87.0)	47 (90.4)	0.508
Part-time physician	26 (13.0)	5 (9.6)	
What is your sex?			
Male	104 (51.7)	21 (40.4)	**0.114**
Female	97 (48.3)	31 (59.6)	
What is your age?			
20-39 years	43 (21.4)	9 (17.3)	**0.688**
40-59 years	117 (58.2)	30 (57.7)	
60+	41 (20.4)	13 (25.0)	
In a work-week, what proportion of clinical time spent practicing palliative care?			
10% or less	40 (19.8)	15 (28.8)	0.369
11-50%	66 (32.7)	15 (28.8)	
51% +	96 (47.5)	22 (42.3)	
Do you practice palliative care in an academic centre?			
NO	106 (52.7)	27 (52.9)	0.979
YES	95 (47.3)	24 (47.1)	
On average, how many unique palliative patients do you see per MONTH (including new and follow-up)?			
1-5 pts	34 (17.0)	13 (25.5)	0.295
6-20 pts	72 (36.0)	19 (37.3)	
21-50 pts	94 (47.0)	19 (37.3)	

N=257	Late n=202 (79.5)*	Early n=52 (20.5)*	p-value
	n (%)		
What type of palliative patients do you see?			
Adults greater than (=) 18 years old	198 (98.5)	42 (80.8)	**<0.001**†
Children less then18 years old	3 (1.5)	10 (19.2)	
Does your team provide a 24-hour on-call service for your palliative patients?			
NO	23 (11.5)	12 (23.1)	**0.032**
YES	177 (88.5)	40 (76.9)	
What proportion of the palliative care you provide is for CANCER patients?			
50% or less	23 (11.4)	17 (33.3)	**<0.001**
51-100%	179 (88.6)	34 (66.7)	
Number of palliative care settings you practice palliative care in?			
1 facility	31 (15.3)	9 (17.3)	0.303
2 facilities	39 (19.3)	7 (13.5)	
3 facilities	40 (19.8)	17 (32.7)	
4 facilities	53 (26.2)	10 (19.2)	
5+ facilities	39 (19.3)	9 (17.3)	
What type of setting do you practice palliative care in?			
Hospice	68 (33.7)	17 (32.7)	0.895
Private Office	60 (29.7)	19 (36.5)	0.342
Long-term care facility/nursing home	70 (34.7)	12 (23.1)	**0.111**
Palliative care unit	115 (56.9)	21 (40.4)	**0.033**
Inpatient palliative consultation in a hospital	130 (64.4)	31 (59.6)	0.527
Outpatient ambulatory palliative care clinic	62 (30.7)	21 (40.4)	**0.184**
Inpatient and/or Outpatient	137 (67.8)	33 (63.5)	0.551
Palliative home care	131 (64.9)	32 (61.5)	0.657
Other	21 (10.4)	9 (17.3)	**0.168**
Number of settings practiced palliative care in			
	Mean Rank (Mann-Whitney Test)		
	128.72	122.75	0.594

N=257	Late n=202 (79.5)	Early n=52 (20.5)	p-value
	n (%)		
Are you a part of a palliative care team?			
NO	33 (16.4)	12 (23.1)	0.263
YES	168 (83.6)	40 (76.9)	
	Mean Rank (Mann-Whitney Test)		
Number of palliative services available for referral to patients			
	124.94	130.18	0.641
Comprehensiveness of palliative care team			
	129.63	116.83	0.257

Note: Survey items that were not exclusive or were a subsample of specialized palliative care physicians were not eligible for univariable analysis; Column proportions are shown; Items that were significant on a p≤0.2 level (green) were considered for entrance into the multivariable model; Bolded items were selected for the multivariable model and entered using a backwards likelihood ratio method.

Table A3.2 Comparison of attitudes and opinions between specialized palliative care physicians who receive early vs. late referrals for their palliative care.

N=257	Late n=202 (79.5)	Early n=52 (20.5)	p-value
	Mean Rank (Mann-Whitney Test)		
I have sufficient resources in my palliative practice to provide high-quality palliative care 6-24 months prior to the end of life			
	125.15	136.63	0.299
Palliative care teams should only be involved in the last few weeks of life			
For Cancer	126.63	114.15	**0.152**
For Non-cancer	128.07	115.72	**0.202**
It is the responsibility of the referring physician to manage complications related to the treatment of a shared patient's primary disease			
For Cancer	125.32	116.55	0.419
For Non-cancer	128.20	114.98	**0.230**
Involvement of palliative care teams 6-24 months prior to the end of life has a survival benefit			
For Cancer	123.81	124.72	0.931
For Non-cancer	125.06	124.78	0.979
Involvement of palliative care teams 6-24 months prior to the end of life improves patients' quality of life			
For Cancer	122.49	129.66	0.384
For Non-cancer	124.23	135.23	**0.228**
The specialty of palliative care should be renamed supportive care			
For Cancer	122.54	29.49	0.519
For Non-cancer	125.16	131.67	0.553

N=257	Late n=202 (79.5)	Early n=52 (20.5)	p-value
	Mean Rank (Mann-Whitney Test)		
Patients should have stopped all chemotherapy before referral to palliative care			
	135.45	94.33	**<0.001**
Hematology patients should have stopped all transfusions before referral to palliative care			
	133.13	103.32	**0.004**
Patients would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care			
	125.51	132.74	0.509
Patients have a negative perception of the term palliative care			
	124.49	136.71	0.249
Referring physicians would feel more comfortable with referral to palliative care 6-24 months prior to the end of life if it were renamed supportive care			
	125.75	131.85	0.576
Patients without symptoms do not need palliative care			
	129.54	117.18	**0.237**
I am comfortable caring for patients who are full resuscitation			
	120.94	145.36	**0.025**
Once I am following a patients for palliative care, the referring physician stops seeing the patient			
	129.65	112.05	**0.100**
Referring physicians tend to refer late to my palliative practice			
	125.39	123.53	0.862
I prefer a model of care in which I completely take over palliative care from the referring physician			
	125.32	123.79	0.887

Note: Column proportions are shown; Items that were significant on a p≤0.2 level (green) were considered for entrance into the multivariable model; Bolded items were selected for the multivariable model and entered using a backwards likelihood ratio method. Specialized palliative care physicians responded on a five point Likert scale from strongly disagree to strongly agree.

A4: Surveys

1. Pilot Survey
2. English Early Palliative Care Survey Introductory Letter
3. English Early Palliative Care Survey

Early Palliative Care Survey

A Survey of Canadian Palliative Care Physicians

Instructions

Please only complete this survey once and if you practice any palliative medicine.

Alternatively, please check the appropriate box below and return the survey **UNCOMPLETED.** By returning the survey, you will be contributing to survey validity by helping to ensure accurate response rates. Thank you.

☐ I am completely retired
☐ I do not practice palliative care

Please return the completed survey in the enclosed stamped, addressed envelope to:

Early Palliative Care Survey
c/o Dr. Camilla Zimmermann
Toronto General Hospital
9 Eaton North, 200 Elizabeth Street
Toronto, Ontario M5G 2C4

Please contact the study coordinator -Anna.Sorensen@uhnresearch.ca -
for any questions or comments regarding this survey.

Demographics & Practice Characteristics

1. For which of these professional associations or societies are you a current member?
Check all that apply

☐ College of Family Physicians of Canada
☐ Royal College of Physicians and Surgeons
☐ Canadian Society of Palliative Care Physicians
☐ Canadian Hospice Palliative Care Association
☐ Provincial Hospice Palliative Care Association
☐ Provincial section of Palliative Care/Medicine
☐ Other (please specify):____________________

2. How long has it been since you completed your residency or fellowship (whichever is most recent)?

☐ ≤5 years
☐ 6 - 10 years
☐ 11 - 20 years
☐ >20 years

3. Have you completed any postgraduate training?
Check all that apply

☐ M.Sc.
☐ MBA
☐ M.Ed.
☐ PhD
☐ None
☐ Other (please specify):_________________

4. How many years have you been practicing palliative care?

☐ ≤5 years
☐ 6 - 10 years
☐ 11 - 20 years
☐ >20 years

5.a What specialties are you certified in?
Check all that apply

☐ Family Medicine
☐ Oncology
☐ Internal Medicine
☐ Pediatrics
☐ Psychiatry
☐ Surgery
☐ Other (please specify):_______________

5.b Where did you receive the above medical training?

☐ Canada
☐ Australia/New Zealand
☐ USA
☐ UK
☐ Ireland
☐ Other (please specify):________________

Demographics & Practice Characteristics Cont.

6. **Have you completed an accredited postgraduate training in Palliative Medicine?**

☐ YES
☐ NO

7.a **Did you complete other training in palliative care (e.g. workshops, seminars)?**

☐ YES
☐ NO

7.b **How long was this other training (whichever is longest)?**

☐ ≤3 months
☐ 4 - 6 months
☐ 7 - 11 months
☐ 12 - 24 months
☐ >24 months

8. **Have you completed any evaluations in palliative care?**

☐ YES
☐ NO

9. **Which province do you work in?**

☐ British Columbia
☐ Alberta
☐ Saskatchewan
☐ Manitoba
☐ Ontario
☐ Quebec
☐ Nova Scotia
☐ New Brunswick
☐ Prince Edward Island
☐ Newfoundland and Labrador
☐ Northwest Territories or Nunavut

10. **What are the first three digits of your *palliative care practice* postal code?**

___ ___ ___

11. **Please choose the ONE statement that best describes you.**

☐ Full-time physician
☐ Part-time physician

12. **What is your sex?**

☐ Male
☐ Female

13. **What is your age?**

☐ 20 - 29 years
☐ 30 - 39 years
☐ 40 - 49 years
☐ 50 - 59 years
☐ 60 - 69 years
☐ ≥70

14. **In a work week, what proportion of your clinical time is spent practicing palliative care?**

(0-100%):____________

15. **Do you practice palliative care in an academic centre?**

☐ YES
☐ NO

16. **On average, how many NEW palliative patients do you see per MONTH?**

☐ ≤1
☐ 2 - 5
☐ 6 - 10
☐ 11 - 20
☐ >20

17. **What type of palliative patients do you typically see?**

☐ Adults ≥18 years old
☐ Children <18 years old

18. **What proportion of your palliative referrals are for CANCER patients?**

(0-100%)_________

19. **What is the approximate average survival time of the patients referred to you for palliative care?**

☐ ≤2 weeks
☐ 3 weeks - 2 months
☐ 3 months - 6 months
☐ 7 months - 12 months
☐ >1 year

Palliative Care Resources

20.a What type of facility or facilities do you practice palliative care in? *Check all that apply*

- ☐ Hospice
- ☐ Private office/clinic
- ☐ Long-term care facility/nursing home
- ☐ Palliative care unit in a hospital
- ☐ Inpatient palliative consultation in a hospital
- ☐ Outpatient ambulatory palliative care clinic
- ☐ Palliative home care
- ☐ Other (please specify):_______________

20.b If you provide palliative care in a palliative care unit (PCU), the home, a palliative care clinic/consulation service, or a hospice, which types of patients are ACCEPTED ***(Check the box for yes)***

I do NOT provide palliative care in any of these environments ☐

I provide palliative care in a...	Palliative care unit (PCU)	Home palliative care	Palliative care clinic/ consultation service	Hospice
	☐	☐	☐	☐
I ACCEPT patients who...				
Are <65 years old	☐	☐	☐	☐
Have NOT signed a DNR	☐	☐	☐	☐
Are Non-Cancer patients	☐	☐	☐	☐
Have a prognosis between 6 -12 months	☐	☐	☐	☐
Have a prognosis > 1 year	☐	☐	☐	☐
Are receiving oral chemo/ hormone therapy	☐	☐	☐	☐
Are receiving blood transfusions	☐	☐	☐	☐
Are receiving dialysis	☐	☐	☐	☐
Are receiving IV chemotherapy	☐	☐	☐	☐
ALL OF THE ABOVE	☐	☐	☐	☐

Palliative Care Resources Cont.

21. Which of the following services are available for you to refer your patients to? *Check all that apply*

- ☐ Hospice
- ☐ Palliative care unit in a hospital
- ☐ Outpatient ambulatory palliative care clinic
- ☐ Pain clinic
- ☐ Palliative care home visits
- ☐ Palliative consultation service in a hospital
- ☐ Bereavement support
- ☐ Psychosocial support

22. Which of the following disciplines are available within your palliative practice? *Check all that apply*

- ☐ Palliative care nurse
- ☐ Psychiatrist/psychologist
- ☐ Social worker
- ☐ Spiritual counselor (e.g. chaplain)
- ☐ Bereavement counselor
- ☐ Occupational therapist/physical therapist
- ☐ Pharmacist
- ☐ Volunteers

23. How much do you agree or disagree with the following statements?

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
I have sufficient resources in my area to provide high-quality palliative care	☐	☐	☐	☐	☐
My area of practice has sufficient palliative care nurses	☐	☐	☐	☐	☐
My area of practice has enough palliative care physicians	☐	☐	☐	☐	☐

Attitudes & Opinions

24. In IDEAL circumstances, when is it appropriate for CANCER patients to be referred to palliative care?

- ☐ At diagnosis of cancer regardless of prognosis
- ☐ At diagnosis of incurable cancer
- ☐ >1 week of life
- ☐ >1 month of life
- ☐ 1-2 months of life
- ☐ 3-6 months of life
- ☐ 6 months - 1 year of life
- ☐ >1 year of life

25. In IDEAL circumstances, when is it appropriate for NON-CANCER patients to be referred to palliative care?

- ☐ At diagnosis of life-limiting illness (e.g. CHF)
- ☐ At diagnosis of advanced life-limiting illness (e.g. CHF with symptoms at rest)
- ☐ >1 week of life
- ☐ >1 month of life
- ☐ 1-2 months of life
- ☐ 3-6 months of life
- ☐ 6 months - 1 year of life
- ☐ >1 year of life

Attitudes & Opinions Cont.

26. In your opinion, for CANCER patients, when is referral to palliative care too late to provide high-quality care?

- ☐ ≤2 weeks
- ☐ 3 weeks - 2 months
- ☐ 3 months - 6 months
- ☐ 7 months - 12 months
- ☐ >1 year

27. In your opinion, for NON-CANCER patients, when is referral to palliative care too late to provide high quality care?

- ☐ ≤2 weeks
- ☐ 3 weeks - 2 months
- ☐ 3 months - 6 months
- ☐ 7 months - 12 months
- ☐ >1 year

28. How much do you agree or disagree with the following statements regarding *Professional Relationships:*

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
I enjoy providing collaborative care with referring physicians	☐	☐	☐	☐	☐
I enjoy working with *primary care* providers to provide palliative care	☐	☐	☐	☐	☐
I enjoy being the most responsible physician for my patients' care	☐	☐	☐	☐	☐
Other specialties have an adequate understanding of palliative care	☐	☐	☐	☐	☐
I have a good relationship with *referring physicians*	☐	☐	☐	☐	☐
I have a good relationship with other *palliative care physicians* that I collaborate with	☐	☐	☐	☐	☐
I have a good relationship with the other palliative care *team members* that I collaborate with (e.g. nurses, social workers)	☐	☐	☐	☐	☐

Attitudes & Opinions Cont.

29. In your opinion, how much do you agree or disagree with the following statements for CANCER and NON-CANCER patients? ***Please complete both columns***

Strongly Disagree ① ② ③ ④ ⑤ **Strongly Agree**

Neutral

FOR CANCER PATIENTS		**FOR NON-CANCER PATIENTS**
1 2 3 4 5	Palliative care should only be involved in the last few weeks of life	1 2 3 4 5
1 2 3 4 5	Palliative care 6 - 24 months prior to the end of life is not currently feasible	1 2 3 4 5
1 2 3 4 5	Palliative care 6 - 24 months prior to the end of life is a goal of my pallative practice	1 2 3 4 5
1 2 3 4 5	Palliative care is applicable for patients with a prognosis 6 - 24 months	1 2 3 4 5
1 2 3 4 5	There is not enough research to support the effectiveness of palliative care referral 6 - 24 months before the end of life	1 2 3 4 5
1 2 3 4 5	Palliative care begins where curative medicine ends	1 2 3 4 5
1 2 3 4 5	Palliative care 6-24 months prior to the end of life entails a burdensome number of extra visits for patients	1 2 3 4 5

Attitudes & Opinions Cont.

30. How much do you agree or disagree with the following statements regarding *Your Palliative Patients*:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My patients should have stopped all chemotherapy before referral to palliative care	☐	☐	☐	☐	☐
My hematology patients should have stopped all transfusions before referral to palliative care	☐	☐	☐	☐	☐
My patients have a negative perception of the term palliative care	☐	☐	☐	☐	☐
My patients would feel more comfortable with referral to pallative care 6 - 24 months prior to the end of life if it were renamed supportive care	☐	☐	☐	☐	☐
I am comfortable managing my patients clinical complications (e.g. nausea from chemotherapy) related to the direct treatment of their cancer	☐	☐	☐	☐	☐

Attitudes & Opinions Cont.

31. How much do you agree or disagree with the following statements regarding the *Scope of Palliative Care*:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I am comfortable caring for patients who are full resuscitation	☐	☐	☐	☐	☐
Patients without symptoms do not need palliative care before the last few weeks of life	☐	☐	☐	☐	☐
Palliative care should be available in conjunction with other therapies (e.g. holistic, alternative)	☐	☐	☐	☐	☐
Palliative care referral 6 - 24 months prior to the end of life has a survival benefit	☐	☐	☐	☐	☐
Palliative care 6-24 months prior to the end of life reduces healthcare cost burdens	☐	☐	☐	☐	☐

Completion of the Survey. Thank you!

Thank you for participating and completing our PILOT survey!

In an effort to improve our survey, please answer a few questions.

1. **How long did it take you to complete the survey?** ________________ (minutes)

2. **How did you find the length of the survey?**
   - ☐ Too Long
   - ☐ Appropriate length
   - ☐ Too Short

3. **Do you feel we missed any important questions? If so, please comment.**

4. **Do you feel any of the questions in the survey were redundant? If so, please comment.**

5. **Any additional feedback is greatly appreciated, feel free to do so in the space below.**

UHN
Toronto General
Toronto Western
Princess Margaret
Toronto Rehab

Dear Participant,

You are being asked to take part in a research study because you are a physician who expressed an interest in palliative care in the Canadian Society of Palliative Care Physicians (CSPCP) National Palliative Care Survey. The purpose of this study is to identify physicians' attitudes and opinions about early palliative care. We request that you complete this survey regardless of your access to or opinion of specialized palliative care services. It will take approximately 10 minutes to complete the survey.

Your participation in this study is completely voluntary. There are no foreseeable risks associated with this project. However, if you feel uncomfortable answering any questions, you can withdraw from the survey at any point without any consequences. If you decide to participate, please complete all questions to the best of your ability. It is very important for us to learn your opinions. As an appreciation for your time, you will receive a $5.00 Tim Horton's Gift Card.

All information obtained during the study will be held in strict confidence. Representatives of the University Health Network (UHN) Research Ethics Board may look at the study records to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines. You will not be named in any reports, publication or presentations that may come from this study. Responses will be stored in a locked cabinet in the Department of Supportive Care at UHN and no identifying information will be on the survey.

The completed survey can be returned using the stamped, self-addressed envelope included in the package mailed to you, online at http://fluidsurveys.com/s/EPCsurvey/, or fax to (416) 340-4739.

Questions about the study

If you have any questions, concerns or would like to speak to the study team for any reason, please write to Dr. Camilla Zimmermann at Camilla.Zimmermann@uhn.ca or Anna Sorensen, the study coordinator, at Anna.Sorensen@uhnresearch.ca. If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

By completing the survey, you are providing consent to participate in this study. We thank you for your time and participation.

Anna Sorensen MSc (Candidate)

Kirsten Wentlandt MD PhD

Camilla Zimmermann MD PhD

*We would like to thank the Canadian Society of Palliative Care Physicians for their assistance with distribution of this survey.

Version 1.0-eng1 - 1 JUN 2015

Early Palliative Care Survey

Instructions: **Please only complete this survey <u>once</u> and if you practice <u>any</u> palliative care. The survey will take approximately 10 minutes to complete.**

Alternatively, please check the appropriate box below and return the survey uncompleted. By returning the survey, you will be contributing to survey validity by helping to ensure accurate response rates. Thank you.

☐ I am completely retired
☐ I do not practice any palliative care

Please return the completed survey in the enclosed stamped, addressed envelope to:
Or fax back to: 416-340-4739

Early Palliative Care Survey
c/o Dr. Camilla Zimmermann
Toronto General Hospital
9EN Rm 220 , 200 Elizabeth St.
Toronto, Ontario M5G 2C4

Please contact the study coordinator - Anna.Sorensen@uhnresearch.ca - for any questions or comments regarding this survey.

Demographics & Practice Characteristics

1. **Do you practice palliative care by one or more of the following (*please complete entire survey regardless of response*): *Check all that apply***

   ☐ **Providing palliative care consultations & direct follow-up visits**
   ☐ **Acting as a palliative care resource to other care providers**
   ☐ **Providing indirect care as a part of a local/regional palliative care service**
   ☐ **Providing primary palliative care to my own patients**
   ☐ **Other (please specify):______________________________**

2. **For which professional associations are you a current member? *Check all that apply***

   ☐ College of Family Physicians of Canada
   ☐ Royal College of Physicians and Surgeons
   ☐ College des Médecins du Quebéc

3. **For which professional societies are you a current member? *Check all that apply***

   ☐ Canadian Society of Palliative Care Physicians
   ☐ Canadian Hospice Palliative Care Association
   ☐ Provincial Hospice Palliative Care Association
   ☐ Provincial Section of Palliative Care/Medicine
   ☐ Other (please specify):____________________

4. **Have you completed any postgraduate education? *Check all that apply***

   ☐ Master’s
   ☐ PhD
   ☐ None
   ☐ Other (please specify):__________________

5.a **What best describes your primary practice?**

   ☐ Family Medicine with a focused practice
   ☐ Family Medicine without a focused practice
   ☐ Specialist/Subspecialist
   ☐ Other (please specify):__________________

5.b **In what area is your focused practice?**

   ☐ Palliative Care
   ☐ Emergency Medicine
   ☐ Care for the Elderly
   ☐ General Practitioner in Oncology
   ☐ Hospitalist
   ☐ Other (please specify):__________________

5.c **What specialties/subspecialties are you certified in? *Check all that apply***

   ☐ Family Medicine
   ☐ Oncology
   ☐ Internal Medicine
   ☐ Pediatrics
   ☐ Psychiatry
   ☐ Palliative Medicine
   ☐ Anesthesiology
   ☐ Other (please specify):__________________

Demographics & Practice Characteristics

6. **How many years have you been practicing palliative care?**

☐ 5 years or less
☐ 6 - 10 years
☐ 11 - 20 years
☐ more than 20 years

7. **Have you completed an accredited postgraduate training/year of added competence in Palliative Medicine?**

☐ YES
☐ NO

8.a **Did you complete other training in palliative care?**

☐ YES
☐ NO (Skip to 9)

8.b **How long was this other training?**

☐ 3 months or less
☐ 4 - 6 months
☐ 7 - 11 months
☐ 12 - 24 months
☐ more than 24 months

8.c **Did this training include any exams in palliative care?**

☐ YES
☐ NO

9. **Where did you receive your most recent palliative care training?**

☐ Canada
☐ USA
☐ UK
☐ Ireland
☐ Australia/New Zealand
☐ Other (please specify):________________

10. **In which province/territory do you currently practice?**

☐ British Columbia
☐ Alberta
☐ Saskatchewan
☐ Manitoba
☐ Ontario
☐ Quebec
☐ Nova Scotia
☐ New Brunswick
☐ Prince Edward Island
☐ Newfoundland and Labrador
☐ Northwest Territories or Nunavut

11. **What are the first three digits of your *palliative care practice* postal code?**

___ ___ ___

12. **You are a:**

☐ Full-time physician
☐ Part-time physician

13. **What is your sex?**

☐ Male
☐ Female

14. **What is your age?**

☐ 20 - 29 years
☐ 30 - 39 years
☐ 40 - 49 years
☐ 50 - 59 years
☐ 60 - 69 years
☐ 70+ years

15. **In a work week, what proportion of your clinical time is spent practicing palliative care?**

☐ 10% or less
☐ 11 - 20%
☐ 21 - 50%
☐ 51 - 75%
☐ 76 - 100%

16. **Do you practice palliative care in an academic centre?**

☐ YES
☐ NO

17. **On average, how many unique palliative patients do you see per MONTH (including new and follow-up)?**

☐ 1 - 5
☐ 6 - 10
☐ 11 - 20
☐ 21 - 40
☐ 41 - 50
☐ more than 50

18. **What type of palliative patients do you primarily see?**

☐ Adults ≥18 years old
☐ Children <18 years old

19. **Does your team provide a 24-hour on-call service for your palliative patients?**

☐ YES
☐ NO

Demographics & Practice Characteristics

20. What proportion of the palliative care you provide is for CANCER patients?

☐ 25% or less
☐ 26 - 50%
☐ 51 - 75%
☐ 76 - 100%

21. What is the approximate average survival time of the patients for whom you provide palliative care?

☐ 2 weeks or less
☐ 3 weeks - 2 months
☐ 3 months - 6 months
☐ 7 months - 12 months
☐ more than 1 year

Palliative Care Resources

22.a What type of facility or facilities do you practice palliative care in? *Check all that apply*

☐ Hospice
☐ Private office
☐ Long-term care facility/nursing home
☐ Palliative care unit in a hospital
☐ Inpatient palliative consultation in a hospital
☐ Outpatient ambulatory palliative care clinic
☐ Palliative home care
☐ Other (please specify):______________

22.b If you provide palliative care in a palliative care unit (PCU), the home, or a palliative care clinic/consultation service, which types of patients are ACCEPTED there *(Check the box for yes)*

I do NOT provide palliative care in any of these environments ☐

I provide palliative care in a...	Palliative care unit (PCU)	Home palliative care	Palliative care clinic/ consultation service
	☐	☐	☐
My service ACCEPTS patients who...			
Are younger than 65 years old	☐	☐	☐
Have NOT signed a DNR	☐	☐	☐
Are Non-Cancer patients	☐	☐	☐
Have a prognosis greater than 1 year	☐	☐	☐
Have a prognosis between 6 -12 months	☐	☐	☐
Are receiving oral chemo/hormone therapy	☐	☐	☐
Are receiving blood transfusions	☐	☐	☐
Are receiving IV chemotherapy	☐	☐	☐

Palliative Care Resources

23. Which of the following services are available for you to refer your patients to? *Check all that apply*

☐ Hospice
☐ Palliative care unit in a hospital
☐ Outpatient ambulatory palliative care clinic
☐ Pain clinic
☐ Palliative care home visits
☐ Palliative consultation service in a hospital
☐ Bereavement support
☐ Psychosocial support
☐ Other (please specify):_______________

24.a Are you part of a palliative care team?

☐ YES
☐ NO

24.b If YES, which disciplines work within your palliative care team? *Check all that apply*

☐ Registered nurse
☐ Other palliative care physician(s)
☐ Psychiatrist/psychologist
☐ Social worker
☐ Spiritual counselor (e.g. chaplain)
☐ Bereavement counselor
☐ Occupational therapist/physical therapist
☐ Pharmacist
☐ Volunteers

25. In your community or area, palliative care is typically provided by:
Check all that apply

☐ Specialized palliative care team
☐ Patient's family physician
☐ Patient's oncologist or other specialist
☐ Advanced practice nurse
☐ Other (please specify):_______________

26. How much do you agree or disagree with the following statement:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I have sufficient resources in my palliative practice to provide high-quality palliative care 6 - 24 months prior to the end of life	☐	☐	☐	☐	☐

Attitudes & Opinions

27. In IDEAL circumstances, when is it appropriate for CANCER patients to be first referred to palliative care?

- ☐ At diagnosis of cancer regardless of prognosis
- ☐ At diagnosis of incurable cancer
- ☐ less than 1 week prognosis
- ☐ 1 week - 1 month prognosis
- ☐ 1-2 months prognosis
- ☐ 3-6 months prognosis
- ☐ 6 months - 1 year prognosis
- ☐ more than 1 year prognosis

28. In IDEAL circumstances, when is it appropriate for NON-CANCER patients to be first referred to palliative care?

- ☐ At diagnosis of life-limiting illness regardless of prognosis (e.g. CHF)
- ☐ less than 1 week prognosis
- ☐ 1 week - 1 month prognosis
- ☐ 1-2 months prognosis
- ☐ 3-6 months prognosis
- ☐ 6 months - 1 year prognosis
- ☐ more than 1 year prognosis

29. For CANCER patients, what do you consider to be a late referral to palliative care?

- ☐ At 2 weeks prognosis
- ☐ At 1 month prognosis
- ☐ At 3 months prognosis
- ☐ At 6 months prognosis

30. For NON-CANCER patients, what do you consider to be a late referral to palliative care?

- ☐ At 2 weeks prognosis
- ☐ At 1 month prognosis
- ☐ At 3 months prognosis
- ☐ At 6 months prognosis

31. How satisfied are you with the following *Professional Relationships:*

Please answer only if you are part of a team that receives referrals for palliative care.

If not, please check this box ☐

	Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied
Your relationship with referring physicians	☐	☐	☐	☐	☐
Your relationship with other palliative care physicans	☐	☐	☐	☐	☐
Your relationship with other palliative care team members	☐	☐	☐	☐	☐

Attitudes & Opinions

32. In your opinion, how much do you agree or disagree with the following statements for CANCER and NON-CANCER patients? ***Please complete both columns***

Strongly Disagree ① ② ③ ④ ⑤ **Strongly Agree**

Neutral

FOR CANCER PATIENTS		**FOR NON-CANCER PATIENTS**
1 2 3 4 5	Palliative care teams should only be involved in the last few weeks of life	1 2 3 4 5
1 2 3 4 5	It is the responsibility of the referring physician to manage complications related to the <u>treatment</u> of a shared patient's primary disease (e.g. nausea from chemotherapy, dehydration due to over-diuresis of CHF)	1 2 3 4 5
1 2 3 4 5	Involvement of palliative care teams 6 – 24 months prior to the end of life has a survival benefit	1 2 3 4 5
1 2 3 4 5	Involvement of palliative care teams 6 – 24 months prior to the end of life improves patients' quality of life	1 2 3 4 5
1 2 3 4 5	The specialty of palliative care should be renamed supportive care	1 2 3 4 5

Attitudes & Opinions

33. How much do you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Patients should have stopped all chemotherapy before referral to palliative care	☐	☐	☐	☐	☐
Hematology patients should have stopped all transfusions before referral to palliative care	☐	☐	☐	☐	☐
Patients would feel more comfortable with referral to palliative care 6 - 24 months prior to the end of life if it were renamed supportive care	☐	☐	☐	☐	☐
Patients have a negative perception of the term palliative care	☐	☐	☐	☐	☐
Referring physicians would feel more comfortable with referral to palliative care 6 - 24 months prior to the end of life if it were renamed supportive care	☐	☐	☐	☐	☐
Patients without symptoms do not need palliative care before the last few weeks of life	☐	☐	☐	☐	☐

Attitudes & Opinions

34. How much do you agree or disagree with the following statements:

Please answer only if you receive referrals for palliative care from other physicians.

If not, please check this box ☐

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I am comfortable caring for patients who are full resuscitation	☐	☐	☐	☐	☐
Once I am following a patient for palliative care, the referring physician stops seeing the patient	☐	☐	☐	☐	☐
Referring physicians tend to refer late to my palliative practice	☐	☐	☐	☐	☐
I prefer a model of care in which I completely take over palliative care from the referring physician	☐	☐	☐	☐	☐

Completion of the Survey. Thank you!

If you have any comments regarding any aspect of this survey, please feel free to add them here.